(47)

MENTAL HANDICAP

Mental handicap

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Introduction

Variations between people's personalities, skills and abilities are a usual and in many respects valuable aspect of life. But a few individuals' mental capacities in areas like simple calculation or the co-ordination of complex movements fall far short of average standards. Such people may as a result be in some ways disadvantaged as compared with their contemporaries and so considered to be mentally handicapped.

A more precise definition of mental handicap would be difficult to establish. It has many causes and its manifestations cover a considerable range of levels of capability. A minority of retarded individuals are totally unable to care for themselves. But others on the arbitrary border line between normality and subnormality may only experience slight limitations in their day-to-day lives, some perhaps caused through their unfortunately being labelled as mentally handicapped during their school careers.

Yet despite the disparate specific degrees and types of disabilities suffered most mentally handicapped people share certain underlying problems and needs, such as those related to finding a suitable occupation. For these to be adequately understood it is first necessary that the distinction between mental handicap and mental illness should be clearly understood. The latter is a usually temporary state of distressing, abnormal consciousness experienced by people who generally have average mental abilities. The term mental handicap refers to the normal level of functioning (which may or may not be subject to modifications through learning) of individuals with certain limited mental capacities. Given the right opportunities in life they need not experience any special distress or disturbance.

Since the 1920s it has been customary to make a division between the severely mentally handicapped, who may be conveniently described as having IQs of below 50,[1] and the mildly handicapped who have IQs in the 50–70 range. Table 1 shows how these terms relate to others commonly used. Individuals in the mildly affected group are often free of any detectable sign of damage or defect in their nervous systems whereas amongst the severely handicapped there is nearly always some evidence of physical abnormality.

This categorisation of the mentally handicapped into mild and severe groups is useful and it is used in this paper. But modern research indicates that it has some drawbacks. For example, it may

1 Standard IQ tests are so constructed that the average score is 100 and the standard deviation 15 points.

Table 1 *Terms used in mental deficiency*

General Terms	*Categories*	*IQ equivalent*
Mildly mentally handicapped	High grade Subnormal Feeble-minded Mentally handicapped Moron Debile Mildly retarded Educationally subnormal	50–70
Mentally handicapped Mentally retarded Mentally defective Mentally subnormal		
Severely mentally handicapped	Medium grade Retarded Imbecile Trainable	25–49
	Low grade Profoundly retarded Idiot Untrainable	0–24

Source After Kirman 1968

lead to the creation of an undesirably rigid bi-polar model of physically caused 'true' subnormality as opposed to environmentally derived 'pseudo' subnormality. In fact in most cases both physical and social factors are probably of some degree of significance.

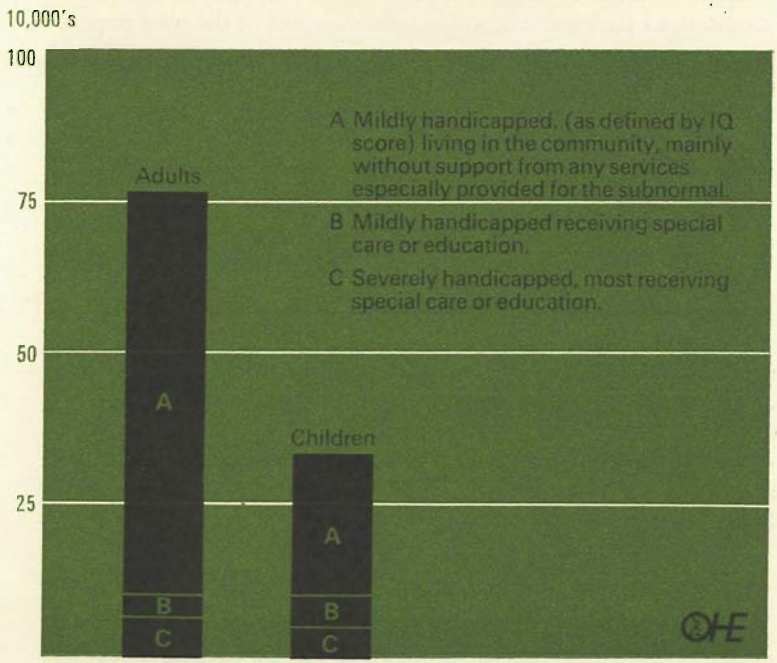
The use of IQ scores to assess overall mental performance also has a number of disadvantages, particularly in that IQ tests measure only a single facet of a matrix of abilities. However, at present they are one of the most useful indicators of mental development available. It may be said very approximately that a child with an IQ of 50 at the age of ten would have the ability of a child of five, although in certain areas he or she may be noticeably advanced or retarded relative to his or her general ability. As age increases an individual with a stable IQ of 50 would fall further behind his or her contemporaries in academic and general ability, although with suitable education the intelligence quotients of mentally retarded people usually rise throughout their childhood and also in a substantial part of young adult life – often long after average members of the population's abilities have become relatively fixed.

As defined by IQ (50–70) the mildly mentally handicapped in the United Kingdom number around one million. The majority of this group live independently in the community without the aid of

special services. There are approximately 140,000 severely handicapped people, 60,000 of whom are children of school age or below. Most of these receive special help such as residential care or adult training as do some of the less able mildly handicapped (see Figure 1 for England and Wales).

Current work on mental handicap centres both on ways of preventing its occurrence and on ways of meeting the social and educational needs of those affected. This paper examines and relates aspects of these two subjects, paying particular attention to the possibilities of preventing the more severe forms of mental retardation, after first looking at the abilities of the handicapped and the causes of their condition.

Figure 1 *Mild and severe mental subnormality in England and Wales*



Note Estimated figures providing only an approximate guide

Mental handicap

Townsend (1969) has pointed out that mental handicap has, in our society, three major components. These are subnormal intelligence, personal (social) incapacities and deviant behaviour. Although subnormal intelligence, as revealed by the rather imprecise methods available, is the most important factor, and is usually related to the other two, this is not always so. A proportion of the 60,000 adults and children in subnormality hospitals in England and Wales have recently been shown to have comparatively normal intelligence quotients (Castell and Mittler 1965, Mittler and Woodward 1966). Some of these individuals are in hospital because of social and behavioural problems which led others with authority to believe they were in need of a particular type of care and control.[1] But others are there merely because there is no suitable provision for them elsewhere in the community.

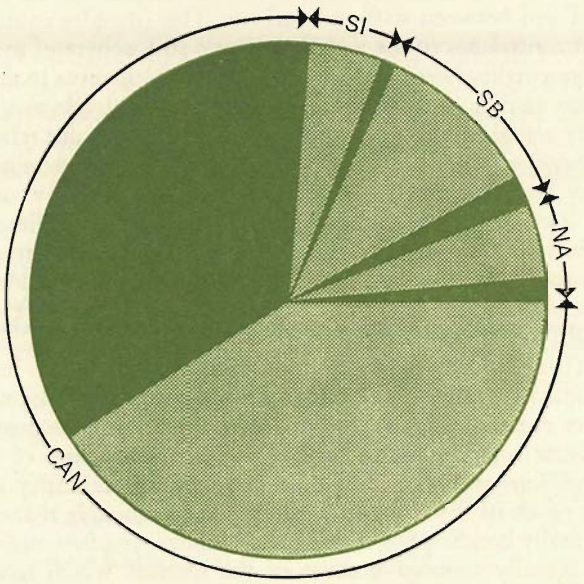
About two-thirds of today's subnormality hospital patients can, in matters such as feeding or dressing, look after themselves quite adequately (Bone *et al* 1972, Morris 1969). Nine out of ten mildly handicapped patients, who constitute one-third of the total population of subnormal people in hospital, fall into this category. About three-quarters of all subnormality hospital in-patients can speak, at least in short sentences, whilst one-quarter can read and understand simple magazines and newspapers. Figure 2, derived from a survey in the Wessex area (Kushlick 1964) shows that amongst the total population of adults classified as severely handicapped (both at home and in institutions) three-quarters were continent, ambulent and had no severe behavioural problems.

The number of individuals who are so badly handicapped that they are virtually helpless is small. Even when combined with those whose behavioural disorders are such that they require near constant supervision, the total is unlikely to be in excess of 15,000 persons in England and Wales. And recent research (Leck *et al* 1967) indicates that only a few per cent of these require the skilled medical attention which may only be provided in a hospital setting.

Regarding the behaviour of the mentally handicapped Kushlick (1972) has commented that evidence is accumulating that the

1 Castell *et al* (1963) showed that the average IQ of severely handicapped subnormality hospital patients was over 60, whilst the mean for those classified as mildly handicapped was over 70. One explanation of the high ability of the former group is that Section 33 of the 1959 Mental Health Act made it easier to detain compulsorily in hospital adults thought to be severely rather than mildly handicapped. This may sometimes lead the abilities of individuals thought to be in need of hospital care and control to be underestimated.

Figure 2 *The abilities of adults officially ascertained as being severely mentally handicapped. (From the Wessex survey 1964)*



Key

SI	Severely incontinent
SB	Severe behavioural disorders, often with incontinence.
NA	Non ambulant
CAN	Continent, ambulant with no severe behavioural disorders

Living in institutions

Living outside institutions (at home)

Source Kushlick (1970)

occasionally bizarre behaviour of mentally subnormal people may have been acquired from routines of child rearing at home or in under-staffed institutions which have acted as unplanned but effective reinforcement schedules for such behaviour. Tizard, King and Raynes (1966) have also pointed out that institutional life may affect behaviour. The block treatment of individuals as part of a batch rather than as persons in their own right coupled with regimentation and deprivation of those private experiences and

belongings necessary to maintain a sense of personal identity can all induce personality disorders. The administrative structure of many institutions induces 'social distance' between the various ranks of the staff and between staff and patients. This impedes communication and contributes to the anti-therapeutic atmosphere of many mental subnormality hospitals as does the split which exists in the minds of many staff, such as nurses, between their ideal role as a healer and their actual role of residential caring. Another point relating to the behaviour of the mentally handicapped is that personality disorders may be induced in any individual, however 'healthy' or 'normal', by long periods of under-activity. Bone and her colleagues (1972) estimated that of medium and high grade subnormal hospital patients (about 80 per cent of the total) one-third of those under 16 received no education or training and that about six out of ten adults in hospital had no occupation of any kind.

There is thus evidence indicating that mentally handicapped people have been 'put away' in hospitals, often because of irrational fears regarding their behaviour, where they subsequently adopt deviant activities and forms of expression because of their poor conditions and social isolation. A significant minority are sedated for much of the time. It is reasonable to conclude that even today mentally handicapped individuals' abilities are often underestimated or actually reduced because of the services which have evolved to care for them. Awareness of this coupled with new research into the educability of the mentally retarded has led to a widespread desire for reform to ensure that they may have as happy and fulfilled a life as is possible.

Marked mental subnormality is often associated with physical disabilities other than a simple lack of manipulative skills. For example, in the Wessex survey it was found that one in three severely mentally handicapped children in hospital suffered from epilepsy, one in five had defects in vision or hearing and one in twenty was blind (HMSO 1971). Bone *et al* (1972) found that over one-third of all subnormal hospital patients had some form of motor or sensory handicap. These findings are of considerable significance in that physical disability often increases the difficulty of providing a mentally handicapped person with an acceptable way of life. The problem of the multiple-handicap has led some researchers to investigate the causes and effects of mental handicap in the context of other more specific handicaps and abnormalities such as epilepsy or spasticity. This shows signs of being a rewarding approach which may have the useful effect of reducing an unnecessary duplication of effort in these areas.

Prevalence

Table 2 shows the prevalences of mental handicap found by a number of surveys. Differences between their results may be largely explained by variations in the definitions and tests used. The lower occurrence amongst younger children indicates that as age increases the differences between mildly handicapped and normal children

Table 2 *The prevalence of mental handicap amongst children as reported by various studies*

a) Overall rates (per 1,000 population)

Study	*Age group*	*Prevalence/1,000*
England and Wales (urban) 1925–27 (Lewis 1929)	7–14	20·9
London 1960 (Goodman and Tizard 1962)	5–9	36·0
	10–14	45·3
Middlesex 1960 (Goodman and Tizard 1962)	5–9	30·1
	10–14	36·1
Salford 1961 (Susser and Kushlick 1961)	5–9	19·8
	10–14	28·4
Aberdeen 1962 (Birch *et al* 1970)	8–10	27·4
Britain 1965–69 (NCDS 1972)	7	7·7
	11	21·2

Note Although the rates quoted above are roughly comparable there are significant variations between them. This is mainly due to variations in the ascertainment of mental subnormality from 'cases brought to the notice of local health authorities' as in the Middlesex and Salford surveys to the more complex assessment methods used by Lewis and the NCDS study.

b) Rates of severe mental handicap (IQ under 50)
(per 1,000 population)

Study	*Age group*	*Prevalence/1,000*
England and Wales (urban) 1925–27 (Lewis 1929)	7–14	3·71
Middlesex 1960 (Goodman and Tizard 1962)	7–14	3·45
	10–14	3·61
Salford 1961 (Susser and Kushlick 1961)	15–19	3·64
Wessex 1964 (Kushlick 1964) County Boroughs	15–19	3·54
Counties	15–19	3·84
Aberdeen 1962 (Birch *et al* 1970)	8–10	3·7
Britain 1965, 1969 (NCDS 1972)	7	2·4
	11	3·7

Source After Birch *et al* 1970

become more marked and that identification by the relevant authorities becomes more thorough.

Regarding the severely handicapped the available figures indicate a fairly uniform prevalence of around 3.7 per 1,000 in the population of school age. However, it is reliably estimated that there are overall about 120,000 severely handicapped individuals in England and Wales (HMSO 1971). This suggests a lower prevalence between two and three per 1,000 of the overall population due to the higher mortality rate among the handicapped. Recent evidence indicates that the difference between the life expectancies of the severely handicapped and the rest of the population is decreasing and hence the overall proportion of the handicapped will rise slightly.

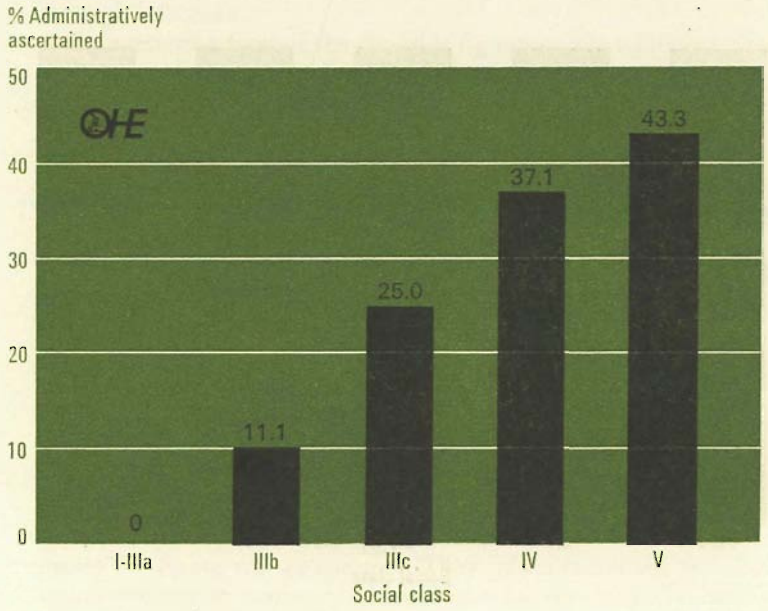
The prevalence figures for mild mental handicap are less clear cut. For example, the variation between the numbers recognised by agencies within the community (for example, the education authorities) as being mildly handicapped and the numbers of those scoring between 50–70 on IQ tests may be considerable. The differences in the strains experienced by, say, an agricultural labourer and an urban industrial worker are great enough to mean that an individual who is capable of meeting the requirements of the former life may be inadequate in the latter situation, and so the numbers of those recorded as mildly handicapped may vary with changes in society. Some children appear subnormal within the particular environment of a school but in adult life can cope well with jobs requiring non-academic intelligence. Others may develop normally in most areas but prove retarded in just one, such as reading. And biases in the age, sex or class structures of a sample may distort survey findings.

Despite these factors a general estimate of the prevalence of mild mental handicap may be derived. If an IQ of between 50–70 is taken as the definition then about 1,250,000 people in the United Kingdom fall into the category. On the basis of assessment of children by teachers and other professional workers, as used in the current National Child Development Study, a rather lower figure of just under 1 million is implied for the whole population. But the degree to which findings which relate principally to the specific situation of children of school age may be considered applicable to other age groups is doubtful.

Social class and mental handicap

In their survey of mental handicap in Aberdeen Birch *et al* (1970) found that by far the greatest proportion of mildly mentally handicapped children come from the poorer socio-economic groups. The recorded prevalence of such handicap amongst the children of unskilled urban manual workers was roughly nine times greater

Figure 3 *The relation of social class to the frequency with which mild mental subnormality is administratively ascertained*



Source Birch *et al* 1970

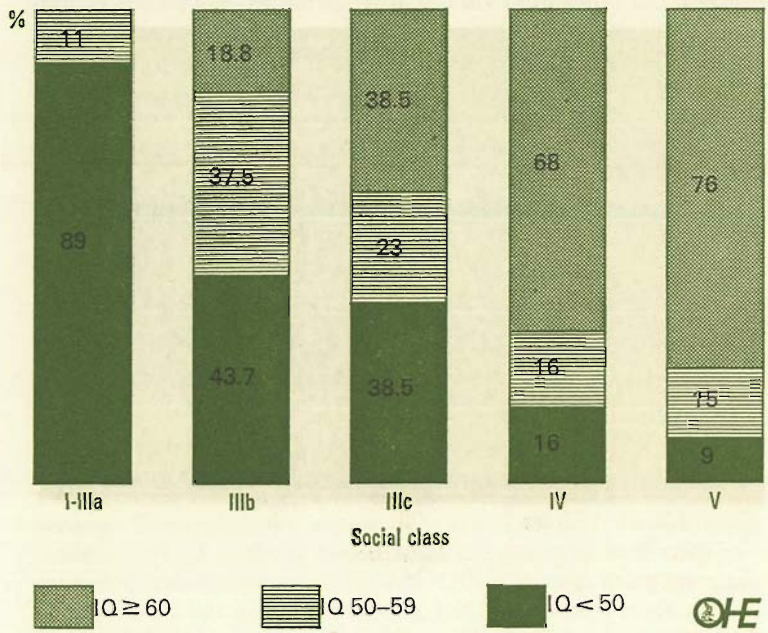
than it was amongst the children of those in non-manual occupations. They also found that mildly handicapped children from the middle classes nearly always showed clinical evidence of associated damage to the nervous system, even though the great majority of all children in this group showed no such damage. Figures 3 and 4 illustrate this research.

However, the incidence of severe mental handicap, which is usually accompanied by clinical evidence of nervous system damage, was found to be evenly distributed across the social classes. These findings have important aetiological implications which are discussed in the following section of this paper.

Trends in prevalence

Debate over whether mental handicap is increasing in prevalence began in Britain in the 1920s with the publication of the Lewis survey (Lewis 1929) for the Mental Deficiency Committee. His findings suggest that the incidence of mental handicap had doubled since the report of a Royal Commission some twenty years before. Although a variety of explanations for this trend were offered by

Figure 4 *The percentage of children having various degrees of severity of mental subnormality in each social class*



Source Birch *et al* 1970

commentators it has now been shown that this discrepancy between the two surveys arose from variations in the methods and thoroughness of the investigations.

But since the 1920s the numbers of some types of mentally handicapped people have genuinely increased. For example, the prevalence of mongolism has, due to improved chances of survival, risen considerably, especially in the younger age groups. Yet Goodman and Tizard (1962) in comparing their Middlesex survey findings with those of Lewis have pointed out that despite such an increase in the prevalence of mongolism the overall prevalence of severe mental handicap (which includes practically all mongoloid people) has fallen. For example, in the 7–14 years age group the drop was from 3.88 to 3.45 per 1,000. This, they calculated, indicated a decrease of about 30 per cent in forms of severe mental

handicap other than mongolism. Factors which may account for such a change include improved obstetric services and the development of medicines effective in reducing pre and post natal damage through infections.

An interesting facet of the available figures on the administrative prevalence of mental handicap (i.e. the numbers of mentally handicapped people known to various authorities) relates to the population of the subnormality hospitals over the last twenty years. The 1970 Census of Mentally Handicapped patients in England and Wales (HMSO 1972) reports that the total numbers in hospital fell slightly from 58,119 in 1954 to 57, 771 in 1970. The sex composition also changed only slightly from 53 per cent males in 1954 to 55 per cent in 1970. On the other hand the age composition changed substantially. For example the number of males aged 25–34 fell by 22 per cent but the numbers aged over 55 increased by 210 per cent. Whereas patients of both sexes aged 55 and over represented 9 per cent of the total in 1954 they stood at 24 per cent in 1970. These changes cannot be entirely explained by the improved survival of the elderly handicapped, particularly as the proportion of individuals who were mildly handicapped rose markedly with age. For example, in 1970 6 per cent of hospital patients aged 5–9 years were mildly handicapped whereas amongst the over 55 age group the figure was 44 per cent. They reflect rather the fact that improvements in community provisions for the mentally handicapped have mainly benefited the younger sections of the population. But it is of note in this context that Kusklick (1972) in comparing Lewis's (1929) figures and the Wessex survey has shown that overall the numbers of both adults and children in institutional care appear to have fallen. He also found that 80 per cent of severely handicapped children and 40 per cent of all such adults lived at home with their families, a higher proportion than did so fifty years ago.

Causes of mental handicap

An individual's mental ability is a product of the interaction of three main factors. These are, first, the inherited constitution of his or her nervous system, second, modifications or injuries to this caused by pre or post natal injury or disease and third the conditioning and training of the intellect. Workers in different fields have in the past focused relatively exclusively on one or other of these factors or have concentrated on particular subtypes of mental subnormality

and presented these as representative of the whole group of disorders which cause such handicap. More modern approaches emphasise simultaneously the inter-relationship between the three main groups of causal factors together with heterogeneity of mental handicaps. A diagrammatic expression of the causes of mental handicap is presented in Figure 5.

The problem of how to account for the prevalence of mental subnormality without clinical signs of brain damage in children born in lower working class environments is more complex than it may at first appear. The question of directly inheritable 'low intelligence' is discussed later in this section but most authorities feel that such handicap more usually stems from undetected physical defects or abnormalities combined with poor nutrition for both children and their mothers, inadequate education and stimulation both at home and in school,[1] particular cultural values and other possible factors.

Table 3 lists some material and social variables which surveys have indicated are related to the genesis of mental subnormality. These are the abnormal elements in the life of an otherwise normal individual which may restrict his or her learning ability. Table 4 shows the main types of genetic abnormality involved in the aetiology of mental handicap. Of these mongolism is by far the most prevalent condition, causing about one-third of all severe mental handicap. Lastly, Table 5 lists biological factors causing handicap which are themselves environmentally influenced, such as brain damage resulting from pre or post natal infection, or malnutrition. About half of all severe and one-quarter of all mild handicap is thought to be the result of physical damage sustained from causes such as these.

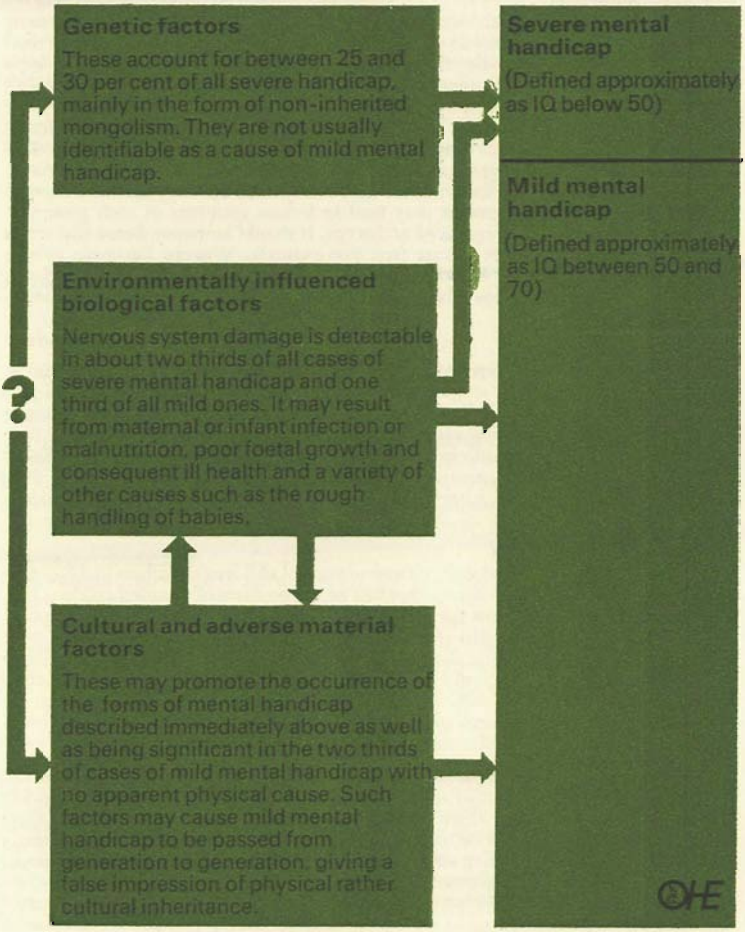
Ability and inheritance

In severe mental handicap the role of inheritable factors is limited but where they are significant it is quite clear cut in that there are observable genetic or chromosomal abnormalities which may be traced back to the parents concerned, although the case of mongolism the chromosome defects involved usually occur by chance and thus cannot be properly described as inherited.

It is in discussions on mental handicap where it borders on the low edge of normal mental ability and where there is no clear evidence of genetic abnormality that confusion occurs. This usually stems from dogmatic statements regarding the relative parts played by genetic and environmental factors. Most of these are, in the present state of both the social and biological sciences, conjectural.

1 In cases of autism the case may sometimes be reversed. It is possible that over-stimulation of certain children causes them to withdraw. This could account for the unexpectedly high proportion of autistic children from middle class families.

Figure 5 *The causes of mental handicap*



A number of researchers have attempted to clarify the role of inheritance in the incidence of mild mental handicap amongst individuals who do not manifest any clinical signs of damage to the nervous system. The Aberdeen, Salford and the Isle of Wight findings all indicated that the social class distribution of such handicapped children's grandparents did not differ significantly from that of those of random samples of normal children (Birch *et al* 1970,

Table 3 *Cultural and material factors related to mental handicap*

Cultural values
These may act on individuals' learning abilities in a number of ways. For instance, some groups may be observed to value present rather than future rewards more than others which emphasise the worth of delayed rewards. Members of the former type of group may well refuse to accept the deprivations and effort associated with learning more often than do members of the latter type. More specific factors such as the loose family structure of some negro cultures are probably of significance in affecting personality structure and hence learning ability. If the dominant culture of a society values the rejection or denigration of a sub-group within that society (e.g. blacks or women) this will not only directly affect their life chances but may also lead them to reject themselves. Social pressures may tend to induce members of such groups to behave according to some prejudiced archetype. It should be remembered that terms such as 'intelligence' are not culture free. For example, Western European culture values 'rational' convergent thinking more than emotive and/or divergent thinking. Individual members of groups which reject this approach may appear to be unintelligent in European eyes.

Education
The availability of educational resources varies with class for a number of reasons. There is a direct economic connection but also there are factors such as high staff turnover in poor areas. If one-third of the school staff leave every year, as happens in some London schools, this will adversely affect the pupils. It may be argued that little positive attempt is being made in most schools to give children from impoverished backgrounds the intensive assessments and training needed to help them with their particular problems and that schools are geared fundamentally to the needs of middle class education.

Family size and structure
Rutter *et al* (1970) found that only a third of control children's mothers had had four or more liveborn children whereas over half of the mothers of retarded children had. Similar findings emerge when the size of the household (number of dwellers) is considered. An indirect explanation of these figures may be that larger families tend to be associated with lower working class areas but it has been noticed that children of large families achieve less academically than those of small ones in separate studies of all social classes. Large families directly affect the amount of personal adult attention the child received and also, to some extent, the personalities of their members.

Family stability
In that this is sometimes a measure of other living conditions family stability relates to mental handicap. Also instability may cause psychiatric disturbance which may lead to retardation and even where there is no emotional disorder the personalities of those living in very loose family structures may be affected in such a way as to apparently reduce certain forms of learning ability. Rutter *et al* (1970) found that maternal absence from the home (periods of over ten days,) paternal unemployment and whether a child had ever lived in a foster home all correlated with the incidence of mild mental handicap.

Housing
Birch *et al* (1970) showed that poor housing and mild mental handicap were either directly or indirectly related. Rutter *et al* (1970) found a significant correlation between the person/room ratio of a household and handicap. Recent work in London has shown the isolating and retarding effects of tower housing blocks on children living in them.

Poverty
All the factors discussed above relate to poor material conditions. In Great Britain in 1971 the gross weekly pay (including overtime and bonus) for the 10 per cent lowest paid full-time male manual workers was under £20 a week (Social Trends 1972). Despite social security provisions the work of organisations such as the Child Poverty Action Group has shown that there is still a need for improved material conditions amongst that section of the population in which mild mental handicap is most prevalent.

Sex
Birch *et al* (1970) found that subnormal boys in the 8–10 age group outnumbered similar girls in the ratio of about 5:4. Although this might be partially explained by the generally greater physiological vulnerability of males it is of note that the number of boys ascertained as handicapped but who had IQs of over 70 was twice as great as that of similar girls. This means that it is probably behavioural factors which account for the variations in the sex specific rates of mental handicap at this age. Differences in the social roles of males and females (e.g. the degree to which expressed aggression is expected) are thought to be of significance particularly since, in the example quoted, the children were under the age of puberty when physical differences between the sexes would not be so great as in later life.

Table 4 *Genetic factors in mental handicap*

Dominant conditions
Dominant inheritance is due to genes whose effects manifest themselves in the heterozygote, i.e. in the individual where only one allele (alternative forms of gene) is of the type forming the condition. Thus, there is a one in two chance of a child having the condition when an individual carrying the gene concerned mates with a normal spouse. Examples are in the group known as the phakomatoses which include epiloia, naevoid amentia and neurofibromatosis. They are very rare.

Recessive conditions
This form of inheritance is due to genes which promote manifest clinical effects only in the homozygote, i.e. in cases where both alleles are of the same type. Thus the affected person must receive the gene for the condition from both parents, there then being a one in four chance of him or her developing it. This is the largest group of single major gene defects causing mental handicap. It includes most of the inherited metabolic defects such as phenylketonuria, maple syrup urine disease and galactosaemia.

Sex linked (X-linked) inheritance
Sex chromosomes, like all others, carry genes affecting the structure and consequently the function of the individual. Sex linked conditions are carried by females who do not manifest the traits concerned but whose male children stand a one in two chance of being affected. Female children stand a one in two chance of being carriers. Examples which cause mental handicap are glucose-6-dehydrogenase deficiency and sex linked hydrocephalus.

Conditions resulting from chromosome abnormalities
Chromosome abnormalities are of two fundamental types, those where the defect is of number and those where there is a loss of or a re-arrangement of, chromosomal material. The most widely occurring of these conditions is Down's syndrome (mongolism) which accounts for between 25 per cent and 30 per cent of all severe mental handicap in children of school age. Normally this condition is due to the presence of an extra chromosome identical to the members of the normal pair 21 (resulting in trisomy 21). Its frequency is related to maternal age and the risk of recurrence is normally small. Occasional cases are due to a translocation (an extra 21 chromosome attached to another chromosome). This can be the result of inheritable factors.

Sex chromosome abnormalities may cause a degree of mental subnormality. For example, Klinefelters syndrome (affecting 1 in 1,000 male live births) does so in some cases and males with an extra Y chromosome are sometimes intellectually dull. The psychological effects of these conditions are a matter of some debate. Overall it appears unlikely that any particular deviant behaviour is directly related to genetic factors although individuals may be socially disadvantaged, and thus tend towards some forms of deviance, because of factors such as mild intellectual subnormality.

Table 4 continued

Conditions with partial and complex inheritance
There are still many conditions whose aetiology is not clearly understood but which may involve several mechanisms including some genetic variations. The methods available for analysing the causes of diseases thought to be of multifactorial origin are still very crude and too much importance should not be attached to the information currently available (particularly as it relates to mental illness). For example, familial incidence rates for certain diseases indicate neither one way not the other whether genetic or environmental causes are implicated. Both would be expected to affect certain families more than others. Conditions which fall into this category include spina bifida and anencephaly.

Table 5 *Environmentally influenced biological factors relating to mental handicap*

Maternal health
Indications of general maternal physical health show correlation with the incidence of subnormality. Maternal height is one most widely used. Thomson (1956) has pointed out that most short women (in a given population) are not genetically small but have been made so by conditions experienced during growth. Birch *et al* (1970) found that in Aberdeen the mothers of mildly subnormal children without clinical evidence of brain damage were twice as likely to be under 5 feet tall as were mothers of normal children in the same social class. Conversely short women were strongly under-represented amongst the mothers of severely handicapped children (possibly because of a greater tendency to abort any damaged foetus?) A strong correlation between mother's height and the condition of all children at birth was also found. Infections suffered by mothers during pregnancy may affect their children either directly, causing congenital abnormalities, or indirectly. An example in this latter category could be foetal damage caused by maternal hyperthermia occurring during an acute infection.

Obstetric complications
These may be broken down into three main areas. First, difficulties during pregnancy, such as preeclampsia or antepartum haemorrhage. Second, complications during labour and third, problems regarding the new born infant such as slowness to begin respiration. These factors relate to general physical problems which show a correlation with social class and should not be regarded in isolation. Birch *et al* (1970) estimate that clinically recognisable obstetric factors were principally responsible for subnormality in over 10 per cent of their Aberdeen sample.

The condition of the child
Low birth weight is considered in the text as a causal factor in mental handicap. Other environmentally influenced biological factors in this category include vulnerability to and risk of infection in early life and abnormal development or retardation resulting from malnutrition either before birth or in the first few weeks of life. (Such malnutrition should not necessarily be thought of as simply too little food but as of its nefficient utilisation as well.)

Susser and Stein 1960, Rutter *et al* 1970). This evidence contradicts any idea of an inbred, stable social class with an inferior genetic endowment. But there was shown to be a tendency towards downward social movement apparent amongst the parents of mildly handicapped children. The reasons for this are uncertain although such downward movement in itself could have an adverse effect on the children.

Some aspects of mental ability, such as scoring well in most intelligence tests, are distributed unevenly amongst the socio-economic classes. But whilst such variations in ability may affect the nature of the contributions any given individual may make to society, and hence his or her likely status, it is becoming increasingly understood that they are to a considerable extent a result rather than the cause of our present day social structure. The picture of mental abilities as being necessarily normally distributed amongst the population because of inherited factors, with the lowest 3 per cent inevitably being mentally handicapped and substantially more people being of well below average ability is now subject to considerable doubt. New knowledge of the problems involved implies that much mild mental handicap may be prevented simply by positively helping those in special need. In the past this was not appreciated and such mental handicap was regarded as inborn and accepted too passively.

Prevention

Every year in Britain between 3,500 and 4,000 children are born who, because of physical abnormalities or damage received at some time in their early life, will become severely mentally handicapped. Similar factors are known to play a role in at least one-quarter of the roughly 20,000 annual births of individuals who will become mildly handicapped. In the past decade several methods which may be used to prevent or reduce the incidence of such handicap have been developed. For example the detection and alleviation of birth asphyxia by modern obstetric skills can prevent brain damage. The use of anti-D-immunoglobulin to prevent haemolytic disease of the newborn infant is another important advance as is the development of a rubella vaccine. This infection has been known to cause serious damage to children *in utero* for over thirty years. Future advances in immunology and/or chemotherapy could lead to the prevention of several other congenital virus infections. Research is currently being conducted at St George's Hospital on the preparation of a vaccine against a virus which is believed

to cause between 400 and 500 cases of severe abnormality (eg microcephaly) each year amongst the children of women infected during pregnancy.

Developments could also take place as a result of the growing awareness of nutritional factors. For example, evidence from laboratory animals suggests that the mother's nutrition at the time of the greatest rate of nervous system development in the foetus (around the fifteenth week in humans) is a critical factor. Also epidemological research has indicated that the dietary variables may be related to the incidence of some mentally and physically handicapping congenital abnormalities, such as spina bifida. Renwick (1972) has pointed to the possible significance of potato blight in causing this condition. Naturally occurring steroids on green potatoes may also have damaging effects. Other writers, notably Knox (1972) have pointed to the importance of factors such as added nitrates and nitrites in the incidence of anencephalus.

Currently key areas in the medical prevention of mental handicap relate to the care of low birth-weight babies, genetic counselling and the pre-birth detection of genetic abnormalities, and the general extension of medical care for pre-school children designed to identify early any physical defects and to initiate corrective action. Some forms of social care may also have a significant role to play in preventing mild mental handicap.[1]

Low birth-weight babies and mental handicap

Over one in sixteen of all live births in the United Kingdom weigh less than 2,500 gms. In 1971 they numbered about 50,000. In about two-thirds of those cases birth was premature whilst in the remainder there was slow foetal growth caused by a variety of factors (DHSS 1972). Very low weight births, under 1,500 gms, number about 5,000 or 0.6 per cent of all live births. These latter babies are known to be at particular risk of becoming handicapped, often both physically and mentally, because of conditions such as hypoxia (oxygen lack) and hypoglycaemia (very low blood sugar). Although nearly 60 per cent of such infants currently die within twenty-eight days of their birth the majority of the remainder survive to adulthood. Perhaps half of them will be handicapped to some degree.

The development of modern medicines and medical techniques has allowed the survival of many individuals who in the past would have died at or near the time of their birth. There are fears that attempts to reduce the infant mortality rates which are now used as rather prestigious international indicators of social development

1 One potentially preventable source of mental handicap which has increased in importance in recent decades is road accidents. These cause around a 1,000 cases of disabling brain damage every year, many of them involving severe handicap.

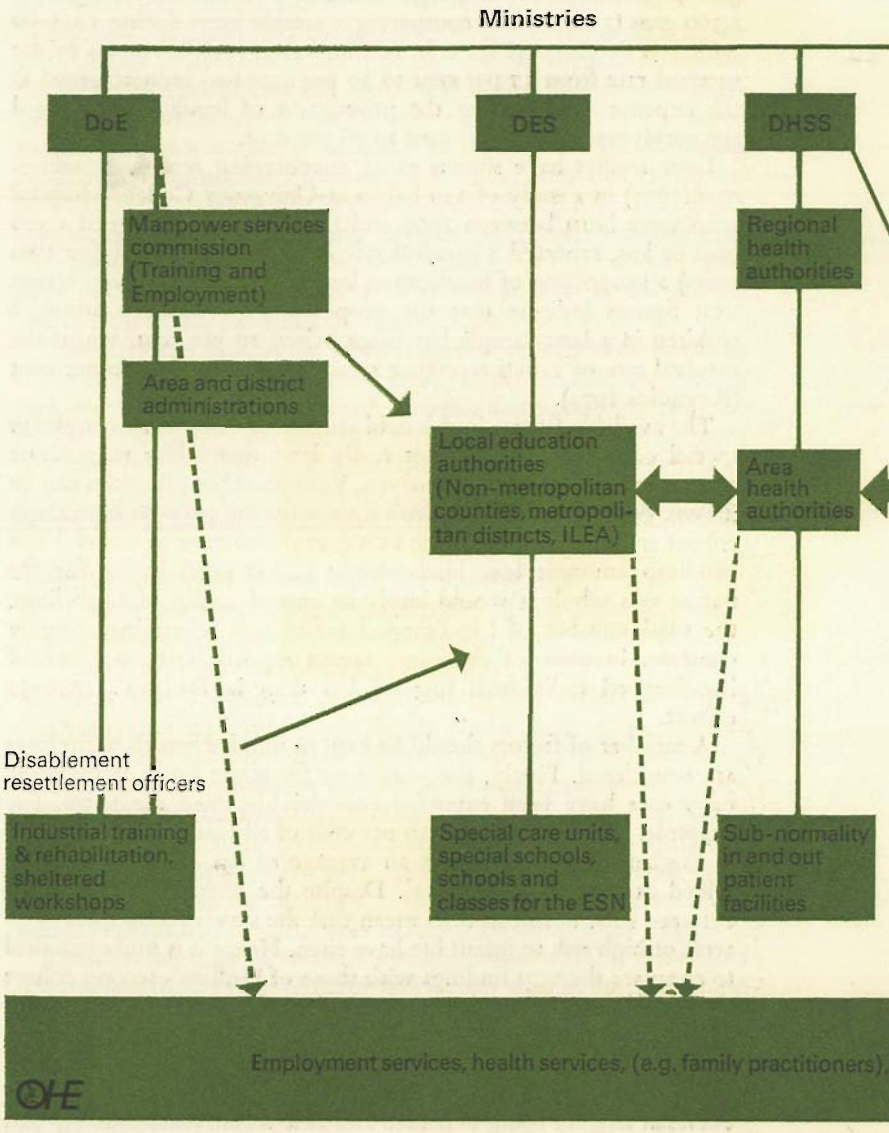
are increasing the prevalence of those with major handicaps. This is true, for instance, in some cases of spina bifida. Improvements in the general standards of care of low birth-weight babies have had discouraging effects in their early stages. For example, Drillien (1967) studied 112 Edinburgh children with a birth-weight of 1,360 gms (3 lb) or less, comparing a sample born during 1955–60 with one of the 1948–52 cohort. She found improvements in the survival rate from 17 per cent to 30 per cent had been achieved at the expense of increasing the proportion of handicapped school age survivors from 32 per cent to 56 per cent.

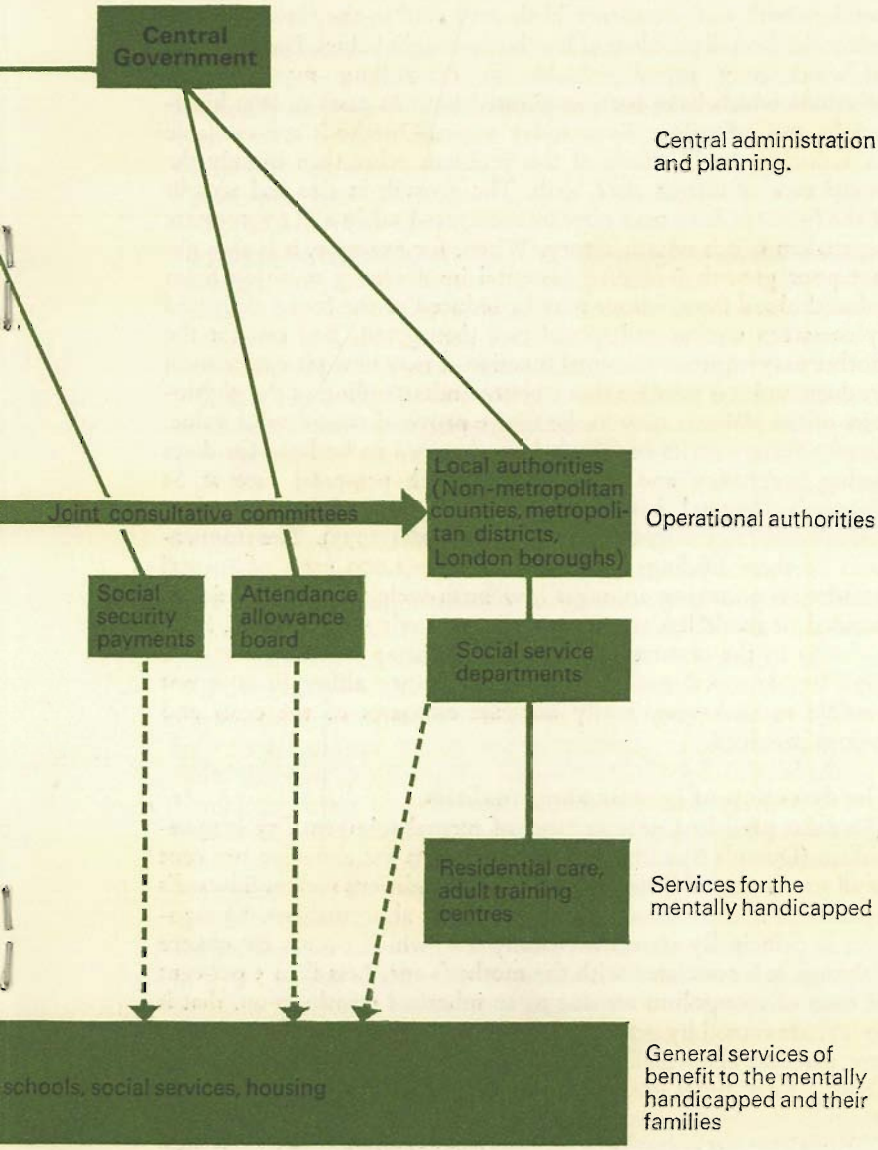
Later studies have shown more encouraging results. Rawlings *et al* (1971) in a study of 149 babies at University College Hospital who were born between 1966 and 1969 and who weighed 1,500 gms or less, reported a survival rate of 50 per cent and (after two years) a proportion of handicap as low as 13 per cent. More recent UCH figures indicate that the proportion of handicap amongst children in a later sample has fallen below 10 per cent, whilst the survival rate of babies receiving special care is nearing 70 per cent (Reynolds 1973).

The available figures in this field are drawn from small samples in special conditions and do not really lend themselves to accurate economic or demographic analysis. Yet general implications can be drawn. For example, if Drillien's figures for the 1955–60 Edinburgh cohort are compared with the UCH (1973) estimates of survival and handicap amongst low birth-weight (1,500 gms) babies for the nation as a whole it would imply an annual saving of 2,000 lives, the total number of handicapped individuals remaining roughly constant. In none of the more recent reports is the number of handicapped individuals implied less than in Drillien's 1948–52 cohort.

A number of factors should be kept in mind when these findings are considered. Firstly, the provisions for some form of intensive baby care have been extended considerably since the 1950s. For example, in 1971 well over 10 per cent of all births (97,000 babies) in England and Wales spent an average of ten days in units described as giving 'special care'. Despite the considerable variation between such units this does mean that the survivorship rates in all areas of high risk to infant life have risen. Hence it is more practical to compare the UCH findings with those of Drillien's second cohort than with those of her first. Second, many low birth-weight babies are born of mothers who have had difficult pregnancies before but who persist in their efforts to have a child because of deep personal needs. For this and other reasons special care facilities for babies at risk are being extended and as it would seem unlikely that this trend will be reversed it appears reasonable to argue that they

Figure 6 *Services for the mentally handicapped in 1974 (England and Wales)*




Central Government
Central administration and planning.
Local authorities (Non-metropolitan counties, metropolitan districts, London boroughs)
Joint consultative committees
Operational authorities
Social security payments
Attendance allowance board
Social service departments
Residential care, adult training centres
Services for the mentally handicapped
schools, social services, housing
General services of benefit to the mentally handicapped and their families

must be of the highest possible standard. Otherwise they will increase the numbers of disabled babies who live.

Even a 10 per cent handicap rate amongst low birth-weight survivors is very high. However, research into the causes of slow foetal growth and premature birth may well in the future help to reduce the overall problem of low birth-weight babies. For example, medicines may prove valuable in controlling mycoplasmic[1] infections which have been implicated both in cases of low birth-weight and infertility. Even today various methods are available for reducing the ill effects of this problem other than merely the special care of infants after birth. The growth in size and weight of the foetus *in utero* may now be monitored safely and appropriate steps taken if it is unsatisfactory. When, for example, it is thought that poor growth is due to placental insufficiency resulting from reduced blood flow, labour may be induced or the foetus delivered by caesarean section and special care then given. Bed rest for the mother may improve placental function as may new pharmaceutical products and it is possible that a better understanding of the physiology of the placenta may in the future prove of considerable value. Results from a series of fifty babies observed to be light for dates during pregnancy and who received such pre-natal care at St Thomas's Hospital have indicated no mental deficiency when perhaps ten cases might be expected (Rhodes 1973). The implications of these findings are that well over 1,000 cases of mental retardation occurring amongst low birth-weight infants could be avoided or made less severe, assuming today's survival rates. Such a change in the occurrence of mental handicap could clearly have considerable social and economic significance although it is not possible to make any really accurate estimates of the costs and savings involved.

The detection of genetic abnormalities

The most prevalent genetic cause of mental subnormality is mongolism (Down's Syndrome) which accounts for about 30 per cent of all severe mental handicap. Like rarer conditions such as Edward's Syndrome it is the result of chromosomal abnormalities. Mongolism is principally standard trisomy 21[2] which occurs by chance although it is associated with the mother's age. Less than 5 per cent of cases of mongolism are due to an inherited translocation, that is to say, are caused by genetic transmission in the sense of their being any parental abnormality. A mother aged 40 years or more has about a forty times greater chance of having a mongol child than

1 Mycoplasma may be described as organisms mid-way between viruses and bacteria.

2 See Table 4.

does a mother of 15–19.

It has been suggested (Stein *et al* 1973) that a pre-natal screening programme could lead to a virtual elimination of mongolism if backed by the termination of abnormal pregnancies. The great majority of parents would be able to have completely normal children in place of the mongol children who would have been born. Although many mongols have attractive personalities they are nearly all severely handicapped and a case can be made for the view that it is more desirable to bring people without their difficulties into the world.

The early detection of mongolism depends on the aspiration of amniotic fluid from the uterine cavity at around the fifteenth week of pregnancy (amniocentesis). The cells so obtained may then be cultured and examined or the fluid tested for specific enzyme deficiencies. This procedure is useful not only in the case of Down's Syndrome but also for the detection of other conditions such as Tay-Sach's disease or sex related abnormalities.

But it has been found that there is a risk of induced abortion attached to amniocentesis and that the foetus may be damaged or even the mother's life threatened. There is clearly a need for caution and more research even though such risks are small. Until recently chromosome investigations took up to three weeks to complete but with present methods it is often possible to cut this to one or two days although the late time of diagnosis of an 'at risk' foetus may still present difficulties. However, it has been suggested that the use of prostaglandins to induce abortion in the mid tri-mester could soon obviate the need for operations (Rhodes 1973).

If every birth in the United Kingdom were screened in this way the annual expenditure would probably be in the region of £20–25 million per annum. It may appear tempting to compare the figure with the cost of caring for those handicapped individuals who would be born if preventive techniques such as these are not employed.[1] But attempts to do this are subject to severe computational and theoretical difficulties, as well as to the conceptual objections that the consumption of services by groups such as the mentally handicapped may be regarded as in some ways productive for society as a whole and that such services are of a fundamentally different nature from normal producer/consumer relationships. A social and medical rather than economic analysis of the costs and benefits involved should be the primary guide to the desirability of introducing such a screening service.

1 Currently the estimated annual cost of caring for mongol people is in the region of £60 million (private and public costs). At 1972 costs the lifetime consumption of goods and services by mongol people born in one year would be about £125 million (undiscounted sum).

Most authorities believe that it would be undesirable to expose all births to the small but finite risks of amniocentesis and that older women, who are at greater risk of producing a mongol child, may be psychologically better prepared to accept the screening process and its implications. If only women over 30 were screened this would cut the population being examined to about one-fifth of the total number of pregnancies. It may be calculated that a little over half of all cases of mongolism would be detected. If only women over 35 were screened this would reduce the number of births examined to less than one-tenth of the total but these may be expected to include well over a third of all cases of mongolism, although it cannot be assumed that all women would or should be prepared either to be examined by amniocentesis or agree to having an abnormal foetus aborted.

In some cases the detection of genetic abnormalities soon after birth is of value in preventive terms. For example, for inherited metabolic defects such as phenylketonurea (PKU) dietary treatments are now available. All babies are now screened for PKU, a condition which affects about fifty births a year in the UK.

Genetic counselling has in the past often been a rather negative activity not infrequently based on doubtful scientific grounds. For example, the relation of certain forms of illness or disabilities such as low intelligence to their familial incidence rates may be explained by environmental as well as inheritable factors. And it is often of little use to a couple to know that they may have, say, a one in twenty chance of having a handicapped child if the early detection of abnormality and removal of the foetus is not also offered. However, with the developments of the past decade and expectations of the future it does seem that now genetic counselling will have an increasingly important role to play in identifying risk situations and so reducing both the incidence and prevalence of mental handicap.

The medical care of young children

In many cases of mild mental handicap, which are often not detected until the child is well into its school career, there are contributory physical factors such as poor vision which are not observed during the first few years of life. A recent survey (Whitmore 1971) showed that about one-sixth of children entering school had conditions requiring treatment and that well over one-third had conditions requiring observation. At present most mothers do not bring their child to Child Welfare clinics after their first birthday and between the ages of 2 and 5 most children are not medically examined except when they fall victims of the usual acute childhood maladies.

It is likely that, if children did receive a thorough examination

during this period, some preventive or curative steps could be taken in certain cases and hence later problems could be avoided. For example, even minor handicap such as partial deafness may, if left undetected over a significant period and coupled with a poor background, lead a child to become labelled as educationally retarded and perhaps permanently impaired in terms of his or her career opportunities. The construction of developmental tests of auditory, visual, tactile and motor abilities and their cross co-ordination may provide valuable information about the genesis of mild mental handicap. In the future such tests, based on observed group norms, may replace rather unsatisfactory tools such as IQ tests as means for assessing children's physical and mental progress.

The need for a comprehensive child health service is most marked amongst the pre-school population although characteristic health care problems do occur throughout the first fifteen to twenty years of life and ideally the care of all young people of school age would be the objective of such a provision. The 1974 health service reorganisation will mean that the current schools' health service, run by local health services, will be merged into the general body of the NHS administration. The long term affects of this are as yet uncertain although whatever happens it seems certain that more doctors with working knowledge of the progress made over the past decade in fields such as the treatment of low birth-weight children and paediatrics in general will be needed. But one reason why specialist training in such areas may be limited is the fear that once it is received doctors may be encouraged to emigrate if they do not obtain a consultant post.

Preventive education and social care

It is widely believed by modern educationalists that the early education of the mentally handicapped, which is of course based on their early detection, is likely to be of value for both psychological and sociological reasons. Through it a mentally handicapped individual may avoid being labelled as hopeless and assuming a completely negative role in the family or school and may even gain a little kudos from the special attention given. The mentally handicapped have a better chance of being placed in learning situations if they can become established in an active role in the community around them and this needs to be achieved early before people reject them as sentient human beings.

Preventive special care hinges on the detection of potential problems. Cases of mild mental handicap are known to occur frequently amongst the children of 'problem' families and those of parents who have fallen in social class. The children of mothers who themselves have suffered deprivation in childhood, such as

separation from their mothers, may need special attention. The prevention of mild mental handicap is an area in which closer links between the schools' welfare services and the local authority social services could help to achieve the identification of children at risk and to provide for their special needs before their behaviour or development deviates from acceptable norms. Facilities such as organised holidays, out of school play groups and improved schooling may help deprived or disturbed individuals to avoid falling behind their contemporaries in mental development. However, research in America (the 'Headstart Project') has shown that it is most important to press for overall improvements in the normal environment of such people rather than to provide isolated special services.

Services for the mentally handicapped

Although there is every hope that medical advances and social changes will in the future substantially reduce the incidence and prevalence of mental handicap, this problem cannot be tackled by preventive measures alone. The forseeable techniques involved are unlikely to be 100 per cent efficient in that, for example, they may prove morally unacceptable to some members of the population. And the difficulties of today's mentally handicapped people will not be altered by the future evolution of preventive medical practices. Thus the question of the structure and extent of services designed to meet the everyday needs of the more markedly subnormal in areas such as education, occupation, housing and recreation remains one of central importance.

The foundations of our present services for the mentally handicapped were laid in the 1920s and 1930s during which period views on the provisions needed and the statutory responsibilities of the authorities concerned differed from those of today. It was thought desirable that residential care for the mentally handicapped should aim at their segregation from the general community so that shelter from the stresses of everyday life could be provided. This was achieved by placing the handicapped in geographically and socially isolated institutions which catered for individuals of all levels of ability from the profoundly retarded to those who were not of subnormal intelligence and who sometimes needed assistance because of social problems alone.

These institutions, together with the limited community services available, were controlled by the local authorities. In 1948, when the National Health Service was first established, they were transferred to the jurisdiction of the hospital authorities although services for those at home remained the responsibility of the local authorities. But the nature of the mental subnormality hospitals remained essentially unaltered from that of the inter-war establishments and they stayed largely separate from the other parts of the hospital service.

Between 1954 and 1957 a Royal Commission studied these arrangements. Its report recommended radical changes with a new emphasis on community care and the breaking down of segregation. In the light of studies on the medical needs and educability of the mentally handicapped it argued that as far as possible they should live outside hospitals and hospital-like institutions. More training and occupational opportunities were to be provided in order to enable mentally handicapped people to live more fulfilled lives.

As a result of this report change in the structure of services for the mentally subnormal took place in 1959. The local authorities were charged with providing a full range of community services including residential accommodation. This responsibility was one which they had been relieved of ten years earlier. During the past decade some progress has been made in meeting the aims described above, notably in the area of education for younger mentally handicapped people. The areas needing most reform today are residential care coupled with training and occupation opportunities for adult members of the handicapped population.

Several major events affecting the future of the service of the mentally handicapped have taken place in the past few years. One was the Seebohm reorganisation of the local authority social services. Another has been the publication of the White Paper *Better Services for the Mentally Handicapped.* And a third important advance has been a new Act relating to the education of mentally handicapped children, discussed below. Table 6 compares some elements of the existing provisions with government planning estimates of the services needed. It may be seen from this that the main area of intended expansion is in adult training and residential care in the community (increasing the latter provisions by six times over their present availability) whilst at the same time it is planned to halve the number of hospital beds available. Figure 6 (centre pages) shows the structure of the services designed to care for the mentally handicapped as they will exist after the 1974 re-organisation of the health services and the Department of Employment.

Table 6 *Planning figures for services for the mentally handicapped compared with existing provision*

Type of service	*Places for children (age 0–15)*		*Places for adults (age 16+)*	
	Required	*Provided*	*Required*	*Provided*
	Total England and Wales 1969	*Total England and Wales 1969*	*Total England and Wales 1969*	*Total England and Wales 1969*
Day care or education for children under five	3,900	500*	—	—
Education for children of school age:				
In the community:				
(i) for children with severe mental handicap living in the community	27,400	23,400	—	—
(ii) for children coming by day from hospital	2,900		—	—
In hospitals:				
(iii) for in-patients	3,400	4,600	—	—
(iv) for day patients	2,900	200	—	—
Occupation and training for adults:				
In the community:				
(i) for adults living in the community	—	—	63,700	24,500
(ii) for adults coming by day from hospital	—	—	9,800	100
In hospitals:				
(iii) for in-patients	—	—	17,200	30,000*‡
(iv) for day patients	—	—	4,900	200*
Residential care in the community (including short-stay):				
(i) Local authority, voluntary or privately owned residential homes:	4,900	1,800	29,400	4,300
(ii) foster homes, lodgings, etc.	1,000	100	7,400	550
Hospital treatment:				
(i) for in-patients	6,400	7,400†	27,000	52,100†
(ii) for day patients	2,900	200*	4,900	500*

* Estimated † NHS beds allocated to mental handicap *Source* Cmnd 4683
‡ The quality of many of these places may be poor at present

Note These figures represent government planning estimates at the start of the 1970s, and may be subject to revision in certain areas. For example, it has been suggested (CMH 1972) that the fostering rates for mentally handicapped children could be raised three times with beneficial results. Also the required number of hospital beds estimate may prove to have been set at too high a level.

Until the Spring of 1971 most severely mentally handicapped children were excluded from the general education system, services for them being administered by the local health departments or the hospital authorities. Now such children's education is the responsibility of the local education authorities. This change typifies the trend in recent years toward accepting many of the problems of mental handicap as essentially social and educational rather than medical.

A detailed discussion of the education of the mentally handicapped lies beyond the scope of this paper. However, a few general points can be made. For example, the number of children in special schools, (formerly junior training centres) in England and Wales doubled in the 1960s, there now being around 24,000 places. Adding on the numbers catered for by services such as special care units for particularly delicate or disturbed children it appears there are something over 28,000 places primarily for severely handicapped children in England and Wales whilst overall there exist about 80,000 places for the educationally subnormal. But even so this latter figure implies that over 100,000 children in England and Wales who may in some way be regarded as mildly mentally handicapped are not receiving special education. Findings such as this indicate that there is a considerable need for teachers with special knowledge of the problems of mental retardation in ordinary schools, a need which it can be argued would to some extent be met by a greater integration of present services for the mentally handicapped with the rest of the schools' system. Increased social contact between retarded and academically normal children may prove beneficial to both groups through, for example, preparing the way to a wider acceptance of the mentally handicapped by the general public.

One area in which advances have been made is in the evolution of special education techniques such as 'operant' conditioning, based on behaviourist theories. These are of particular use in helping more severely handicapped people. Fears have been expressed that such techniques 'dehumanise' both those who practise them and those they are practised on, but these stem mainly from a lack of knowledge of the psychological mechanisms and theories involved. For instance, if a handicapped child does not understand the nature of his parents' anger, perhaps mistaking it as reward in the form of strong attention, he or she may learn socially undesirable habits. Operant conditioning techniques may overcome such problems although it should be based on positive reward rather than on punishment. The latter may brutalise teachers and repress in the subject more than simply the undesired behaviour concerned. By the use of educational methods like these socially disabling behav-

iour such as incontinence may be dramatically relieved and subjects helped to a freer and more active life.[1]

The social care of the mentally handicapped and their families should aim at providing as great an element of choice as possible for people facing difficult and potentially very restricting problems. Thus as well as attempting to deal with immediate emergencies social services may be directed at long term goals such as breaking down the social isolation which may result from a family having a mentally handicapped member. In this organised holidays, clubs and play facilities outside school time for the handicapped are of considerable importance, especially as they may help the parents of an affected child to pursue normal career and leisure activities.

Current social service provisions are subject to a number of criticisms. Quantitatively they are widely regarded as being inadequate, with regional variations strongly accentuating the shortages of facilities revealed by the national average figures. Qualitatively there are several points. It may, for instance, be argued that there is a confusion in areas such as adult training as to what the services are trying to achieve. At the moment such provisions too often offer a form of sheltered care rather than the means of gaining new and occupationally useful skills. This applies to the services provided by the Department of Employment as well as to those of the local authorities although in the latter case there is the additional matter that it is difficult to see why training facilities should be under their control at all.

Another important factor is that social workers often have to try to help families and individuals to accept and adjust to poor conditions rather than offering any radical alternative. They may thus be retarding overall changes which could be generated if distressing conditions were not obscured by their work. It may also be suggested that the loss of specialist skills in mental health which resulted from the Seebohm re-organisation of the social services has reduced the value of the help given by social workers to the mentally handicapped. This criticism may be premature but it appears that the load of 'generic' work placed on each individual worker is at the moment restricting the growth of specialist skills in a manner that was not intended by the Seebohm report.

Education and social care are often closely linked. An example of this lies in the training of mothers to understand the problems they and their families are likely to encounter if they have a mentally

1 However caution regarding the value and efforts of certain forms of education should be maintained. For example in the case of the American Doman-Delacato method, which recently received considerable attention in the UK, the main value may possibly be in helping parents and their children overcome the stigma of being mentally handicapped, which is strong in the USA where high value is placed on competitive ability, rather than in any unique physiological effects of the therapies used.

handicapped child, an approach developed in the 'workshops' for mothers of the handicapped set up by Mittler in Manchester. Although people still often turn to doctors in such situations it is important to remember how little experience of problems such as mental handicap the average general practitioner has. For example, he will probably encounter only one case of mongolism in fifteen or twenty years of practice. Education for parents of the handicapped could give them enough understanding of the problems involved to allow them to be able to assume more personal responsibility for directing their families' future. Such knowledge may also diffuse from them into the surrounding community and so help to improve conditions for the handicapped.

Residential care

Despite some advances in the past decade there is still a marked shortage of suitable residential care for mentally handicapped adults and children outside the subnormality hospitals. For example, there are in England and Wales around 5,000 places for adults in local authority hostels for the mentally handicapped as opposed to over 50,000 hospital beds. Much evidence shows that the majority (or perhaps all) of the individuals currently in hospitals would benefit considerably from the more independent and active life which may be provided by facilities less isolated from the general community (Morris 1969, Bone *et al* 1972, CMH 1972). That such innovations in the residential care of the mentally handicapped are workable has been demonstrated in other countries and is also indicated by the very marked variations in the use of subnormality hospitals between the regions of England and Wales.

Currently considerable efforts to improve the hospital services are being made by both raising standards in existing institutions and by the selective provision of smaller new hospitals. But these have been criticised for a number of reasons. For example, it may be argued that estimates regarding future provision of hospital care are not based on sufficient research into the needs of the mentally handicapped and that when this area is closely examined the implications are that the need for hospital care is still being over-estimated. The danger here is that money is being allocated for improving hospital services for the handicapped at the expense of medical research into the causes and prevention of handicap and the extension of effective community services for the handicapped.

Morris (1973) has commented that revelations of bad conditions in mental subnormality hospitals in the past few years have in some ways proved counter-productive in that they have drawn attention away from the positive argument that improved services are most needed in the community. Thus 'Campaign for the Mentally

Handicapped' has called for the abandonment of investment into new hospitals and large cuts in old hospital 'improvement' schemes because that organisation believes that such developments will not meet the underlying needs of the mentally handicapped. Certainly it is true that although the long term capital costs of improving local authority services envisaged in *Better Services for the Mentally Handicapped* are about 25 per cent greater than those of improving hospital services (£150–160 million at 1970 prices) current capital expenditure in the two areas is roughly comparable despite the known greater shortage of resources in the local authority services. Yet it must be recognised that for the next fifteen to twenty years at least substantial numbers of reasonably able mentally handicapped people, particularly in the older age groups, will probably stay in hospital care despite its defects. The bettering of certain aspects of the service, such as the quality of the food,[1] would therefore seem a worthwhile end.

Alternatives to conventional hospital care may take a number of forms. For instance, Wessex Regional Hospital Board has in recent years developed small units catering for about twenty or twenty-five individuals. One of these may serve a neighbourhood of approximately 50,000 persons. Smaller units may allow the more effective use of staff than to large hospitals in terms of time in contact with those in care and permit the formation of more personal relationships. Also relatives may maintain better contact with locally placed facilities. Provisions established on this model are proving to be economically viable, the average cost per patient being in the order of £35 per week as opposed to about £25 per week per subnormality hospital bed.[2] Yet such units may in fact retain many of the undesirable aspects of hospitals although in less clearly identifiable ways. In particular, it may be argued that to improve in the staff/patients time of contact is less valuable that it would be to lose the conventional status of the staff as opposed to the 'inmates' and the behavioural expectations and effects which this separation promotes.

Another possibility for both adults and children is that present hospital buildings could be removed from the health services and

1 Despite the fact that improvement of the food in mental subnormality hospitals has been considered by the DHSS as the first priority since 1969 weekly catering expenditure still ranges from £11.60 per in-patient capita in a London Teaching Hospital to £3.15 for mental subnormality hospitals.

2 Overall per capita expenditure in 1971–72 was about £23 in subnormality hospitals as opposed to £76 in acute hospitals. But the use of crude average cost has been criticised (Primrose 1972) in that there are considerable variations with types of patients concerned. It would be desirable to see attempts made to estimate cost comparisons between hospital care and community care for particular sub groups of the mentally handicapped.

converted for use as housing for independent communities for the handicapped. Some such communities already exist (such as the Steiner homes) in Britain and abroad and appear to be successful. But they too may be subject to many of the general drawbacks of isolated care.

For children one way of avoiding these could be to increase the numbers cared for in foster homes or in ordinary children's homes. Whilst conditions in the latter may often be less than ideal and very severely handicapped children present special problems this is on the whole a workable plan and is being adopted by an increasing number of local authorities.

During the past two decades thinking about progress in residential services for mentally handicapped adults has increasingly centred on the development of small group homes scattered in the normal housing areas of the community. They may either be maintained by a small staff (housing up to a dozen residents) or may be provided with only a minimum of non-resident supervision. Through such facilities mentally handicapped people may be enabled to enjoy as full as possible a life whilst receiving any extra help they need to cope with their day-to-day problems.

The cost of providing such accommodation for all those mentally subnormal people currently in hospital would be unlikely to be as great as that of currently planned improvements in hospital services, provided that it made full use of normal domestic housing throughout the country (Teeling-Smith 1970). And experience with an existing system of this nature in Sweden has shown that it works well both for the handicapped and for the rest of the community. However, Sweden retains a hospital provision for the very severely handicapped. For this group Wessex type facilities may prove to be the best alternative. Also, the Swedish system provides considerable resources and direction for the leisure activities of those in small group homes both at weekends and in the evenings, a point which is not always made clear.

Social aspects of mental handicap

The segregation of groups such as the mentally subnormal in most industrialised communities has proved to have a number of ill effects. For example, the social isolation of services for this group may cause deficiencies in them to pass unobserved and may encourage 'normal' members of the staff to feel that the individuals over whom they hold power should not be regarded as having a

right to the standards of life and liberty enjoyed by the 'normal' population. In many cases the poor conditions within institutions such as subnormality hospitals affect individuals so profoundly that they may appear considerably less able than they potentially are.

It may be that now that such tendencies have been clearly recognised and the mechanisms underlying them understood effective controls designed to counteract the process could be developed. Today some model hospitals show how good such provisions can be. One point in favour of the mentally handicapped living alongside each other and to some extent removed from the rest of the community is that in this way they may avoid always being the least able in any social interaction and can, between themselves, enjoy a full range of experiences such as leading, planning and innovating. Whilst mentally handicapped people need a 'normal' life in the sense that their day-to-day life should be acceptable within their own conception of society's structure of norms, any pressure for normality in the sense of trying to make their life styles direct copies of those of more able individuals is probably misguided.

Yet although the above argument implies that handicapped individuals should live in the community in groups of equals rather than alone, it cannot be used to justify their total segregation. Even the suggestion that older patients, who have become fully adjusted to institutional life, would suffer by being returned to the community may be doubted. Morris (1973) has commented that attempts to reintroduce such individuals into the community often fail because they are badly organised and fail to give sufficient protective support.

One of the major factors regarding the improvement of community care for the mentally handicapped is the attitude of the general public who often fear and consequently reject this group. The reasons for this range from simple ignorance to existential problems raised by very marked mental variations amongst human beings. It appears that the most effective way to change this situation is through accelerating the integration of services such as education for both 'normal' and handicapped children. In this way greater understanding on the part of the population as a whole towards the mentally handicapped may be achieved. Also it can be argued that through bringing the disabled of all types more openly into the every-day activities of the community human values and duties which are sometimes obscured in complex industrial societies may become more clearly perceived, thus enriching the lives of many people. But a cautionary note must be sounded in that a price for these general benefits might have to be paid by some of the handicapped themselves. A minority are markedly frail and defenceless

and they may always require a degree of protection from the rigours of 'normal' life, a point which should not be obscured in discussions of general principles.

The families of the mentally handicapped

It is possible for most of the handicapped to lead a happy and contented life. It is usually amongst their families, in particular their parents, that some distress is always going to be likely. Disappointment is understandable. So even is guilt or shame, although these responses are not rational. And in material terms the cost of family life may be increased by a handicapped child or adult living at home, for instance through one parent being deprived of work opportunities. Yet if it is remembered that for the subnormal themselves there need be no sense of loss or failure then the way is opened to constructive action, both economically and socially. The two points considered below, the acceptability of residential care and the promotion of independence, are of particular interest in family terms.

It is known that the presence of a mentally handicapped child in a family may cause both economic and emotional stress. For example, siblings may be embarrassed to bring home friends and so may become socially isolated and the burden of constant (although sometimes unnecessary) care on a house-bound mother can become intolerable. Also the pressures and tensions existent in some families can themselves contribute to the occurrence of some forms of mental handicap whilst the presence of a so affected child in such families may promote further difficulties. For reasons like these it appears that there will always be a demand for the residential care of mentally handicapped children in foster homes or other facilities although good local services such as provisions for care outside normal school hours may reduce this. Unthinking attempts to make parents personally care for handicapped children are themselves sometimes irresponsible, although it is still common to hear professional workers stress the need for parents to accept a situation without trying to understand the needs of the individuals concerned. Because of approaches such as this some distress is caused by children being left in an undesirable family environment too long and it may be suggested that it is because the authorities controlling residential services for children do not try to create a radical alternative to the nuclear family but only a stop-gap emergency provision that services are inadequate.

In this context one argument against those who wish to make the life styles of mentally handicapped people as near 'normal' as it is possible is that they may be attaching too much importance to current values and opinions. It may be that some mentally handi-

capped children would benefit from a less isolated sense of identity than that which is formed by the family life of the twentieth century. Changes in the law designed to increase the long term stability of non-familial child caring groups may be an important innovation in this field. But despite speculations such as these it is clear that in present circumstances a great number of parents and their handicapped children desire and benefit from the conventional family structure. They should be enabled to exercise choice in this area knowing both that suitable residential care exists and that those who decide to care for their children at home will themselves be supported economically by the community so that they do not have to bear an unjust burden.

Regarding adults it appears that the chance of an independent life away from the family is generally desirable for all individuals. Parents often continue to treat the mentally handicapped as children long after they have in reality become retarded adults. For example, they often restrict their opportunities for sexual activity and so may force them into deviant expressions of sexuality or deprive them of the loving and supportive relationships which are often generated by initially sexual contacts.

The knowledge that their handicapped child will grow to an independent existence outside the family home or an unpleasant institution may help parents to accept him or her more naturally than has often happened in the past. For example, it may decrease any tendency to over-protect the child if it is known that he or she will in time be going to leave home. It may also relieve fears about what will become of the child when both parents die. Perhaps the cruellest event which may strike any mentally handicapped person is to be suddenly taken into a hospital for the subnormal after a lifetime of protected family care because their parents have died or become too old to manage. The only sure way to avoid this type of occurrence is to see that handicapped people embark on as independent a life as is possible, preferably supported by relationships such as marriage,[1] at the age when most children remove themselves from the parental home. Most people do not achieve independence without having to learn to resist their parents' control. It is largely up to mothers and fathers of mentally handicapped children, who often cannot oppose the will of the adults around them, to help their offspring to independence even if this involved their love passing to other people.

1 Marriage amongst the mentally handicapped is sometimes criticised on the grounds that similar children may result. Perhaps more intelligent arguments follow the reverse line that the normal child of handicapped parents may have profound problems. But such marriages may be of great value even if contraceptive measures are taken. The adoption of younger mentally handicapped children by similar, older couples is a possibility.

Conclusion

Until recently mental handicap was seen as a largely unpreventable and unalleviable state but today an improved understanding of both its causes and the potential abilities of the individuals categorised as mentally handicapped is changing such attitudes. There is now every hope that further research coupled with the application of present knowledge about its physical and social nature will provide the means to reduce both the incidence of and the distress surrounding this condition.

Although services for the mentally handicapped in Britain still suffer from inadequacies real improvements have been and are being made. Planned re-organisation and extension of them in the 1970s and 1980s is estimated to involve an overall capital expenditure of between £250 and £300 million at 1970 prices (HMSO 1971). This presents an encouraging prospect for the future. Yet some cautionary points should be made.

Firstly, currently intended innovations are thought to be going to take fifteen to twenty years to complete, with considerable variations between regions. Where the need for better services has been so clearly described this does appear to be rather too long a time, despite difficulties such as the time needed to train specialist staff. Advances in the prevention and alleviation of mental handicap may reduce the size of the problem (amongst children at least) by the time the new services are functioning as they should, whilst in the meantime sections of the handicapped population are suffering from a lack of resources. Possibly some interim measures such as increased direct grants to the handicapped living or capable of living in the community should be considered.

Secondly, it is to be hoped that the 1974 re-organisation of the health services will be successful in its aim of improving services to groups such as the mentally handicapped though providing a more integrated service. A key area here is that liaison between the health services and the local authority social services should prove efficient and that the latter's provision of facilities such as homes in the community for mentally handicapped people should not be affected by local political concerns or by lack of central government funds. It is also to be hoped that the extensive changes in the health system, the nursing profession and the social services which have recently occurred or are planned to occur soon will not draw attention away from the interests of the recipients of these services and concentrate it on the desires and ambitions of the professional groups involved.

A third point is that whilst about £100 million is spent in England and Wales each year on running services for the mentally handicapped only about a third of a million pounds is spent on state financed research into its causes, epidemiology, prevention and the needs of these affected by it. Even when private expenditure is taken into account the sum is little over half a million pounds although this does not include expenditure of indirect value by groups such as the pharmaceutical industry. It appears that more money could justifiably be allocated to this area, particularly towards investigating means of preventing mental handicap in its more severe forms and implementing existing knowledge of value in this context. Techniques already exist which, if applied on a nationwide scale, could probably cut by more than 50 per cent the annual incidence of severe mental handicap and relieve many other cases.

Finally, although services for the more markedly mentally handicapped are developing, many individuals of both school age and above with mental abilities on the borderline of what may be regarded as normal (i.e. with IQs in the 65–75 region) are receiving no special help. The particular problems of this group may in general be shown to be related to poor material conditions. More attention must be paid to improve factors such as the housing and educational facilities available to sections like the lowest paid workers and their families if the incidence of this form of handicap is to be lowered.

The existence of mental handicap in our society and the means we may possibly adopt to deal with this problem gives rise to a number of moral issues. One of these relates to the acceptability of aborting abnormal foetuses. The suggestion that it is desirable to terminate pregnancies where there is good evidence that the child to be born would be severely handicapped need not imply that the lives of individuals who have established a distinct personality, despite low intelligence or deviant behaviour, are less valuable than those of normal individuals. But where parents planning a family may in effect be able to choose between having a handicapped child or a perfectly healthy one abortion of abnormal foetuses does appear to be justified. It may be noted in this context that suggestions that people who are morally opposed to abortion, and who will not give an undertaking to have such an operation performed if it is found that they are to have an abnormal child, should not be given access to screening services may be questioned. It is possible that views based on abstract principles would change when individuals became confronted with real choices.

Perhaps a more difficult problem is presented by the ability of modern medical techniques to prolong considerably the survival of very badly damaged or grossly abnormal babies. Whether

deliberately allowing such cases to die should be regarded as euthanasia in the normal sense and if either is desirable is debatable. What is certain is that further advances in the life preserving skills of doctors will necessitate a clearer code of practice in this area than at present exists.

Regarding the long term future of the mentally handicapped it is to be remembered that the problem that they present has increased in significance due to a number of aspects of industrialisation. For example, these individuals now often survive where in the not too distant past many would have died very young from, say, infections or selective infanticide. Also the increasingly complex nature of life in modern societies may sometimes make more obvious some people's lack of general or academic education and/or ability. Although the evidence available indicates that the widely held belief that existence has become more difficult for groups such as the mentally handicapped during this century is not true, fears have been expressed that in the future the increasingly technological orientation of both work and domestic life will make it harder for individuals of low mental ability to find an acceptable social role.

But against this must be placed the development of a better understanding of the needs of this group which may be expected to emerge. And it may be argued (after Durkheim) that as social roles become more differentiated in complex societies tolerance of individual variations in behaviour and personality will increase and the value of overall norms decrease. Such a process could enable the mentally handicapped to become more widely accepted in modern pluralistic communities. Even today one of the most effective ways to help people who suffer from stigma caused by conditions such as mental handicap is not just to emphasise their 'normal' aspects but to show more clearly the wide variations in behaviour, values and abilities which exist within the 'normal' population.

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