MENTAL HANDICAP

ways forward

OHE PUBLICATIONS

Studies of Current Health Problems

ISSN 0473 8837

37 Prospects in Health 35p
38 Epilepsy in Society 35p
39 Hypertension 35p
40 Family Planning in Britain 35p
41 Migraine 35p
42 Hospital Purchasing 35p
43 Medicine and Society 35p
44 Medical Care in Developing Countries 35p
45 Rheumatism and Arthritis in Britain 35p
46 Skin Disorders 35p
51 Parkinson's Disease 35p
52 Multiple Sclerosis 35p
53 The Health Care Dilemma 35p
54 Medicines which Affect the Mind 35p
55 Anaesthesia 35p
56 Rabies 35p
57 Asthma 35p
58 The Reorganised NHS 70p
59 Preventing Bronchitis 35p
60 Physical Impairment: Social Handicap 70p

Reports on OHE Symposia

Innovation and the Balance of Payments:
the experience in the Pharmaceutical Industry £1.50
Human Relations in General Practice 75p
Economics and Innovation in the Pharmaceutical Industry £1.50
Evaluation in the Health Services 75p
The Pharmaceutical Industry and Society:
its changing environment and economics £1.50
Benefits and Risks in Medical Care £1.50

OHE Briefings

Venereal Diseases 20p
Accidental Deaths 20p
Infant and Child Health 20p
Violent Deaths 20p
Viral Hepatitis 20p

Pharmaceutical Monographs

Medicines in the 1990s 75p
The Canberra Hypothesis:
The economics of the Pharmaceutical Industry £1.50
Brand names in prescribing 50p
Sources of Information for prescribing doctors in Britain £1·00

About OHE *free*

Details of other OHE publications are available on request.

MENTAL HANDICAP: ways forward

Office of Health Economics
162 Regent Street London W1R 6DD

No 61 in a series of papers on current health problems published by
the Office of Health Economics. Copies are available at 35p.
For previous papers see inside front cover.

Printed in England by White Crescent Press Ltd, Luton

ISSN 0473 8837 61

OFFICE OF HEALTH ECONOMICS

The Office of Health Economics was founded in 1962 by the Association of the British Pharmaceutical Industry. Its terms of reference are:

To undertake research on the economic aspects of medical care.
To investigate other health and social problems.
To collect data from other countries.
To publish results, data and conclusions relevant to the above.

The Office of Health Economics welcomes financial support and discussions on research problems with any persons or bodies interested in its work.

INTRODUCTION

Variations between people's mental skills and abilities are a universal and in many respects desirable aspect of life. But some individuals' capacities in areas like speech, numeracy or the coordination and control of bodily movements fall very far short of average standards. As a result of such limitations they may be unable to live in a manner which would be considered entirely satisfactory or 'normal' by their contemporaries and they can thus be said to be mentally handicapped.

Impaired mental ability can have many causes and can express itself across a wide spectrum of different activities. A very small minority of mentally handicapped people are so seriously affected that they are totally unable to care for themselves. Others on the arbitrary border-line between handicap and normality may only have slight difficulties in coping with day to day life. Whether or not they are regarded as 'subnormal' will be determined by the thresholds of community tolerance and the presence or otherwise of other forms of disadvantage such as poverty or the problems commonly encountered by members of immigrant minorities.

Yet despite the disparate 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 necessary that the distinction between mental handicap and mental illness should be appreciated. The latter is a state of unpleasant, abnormal consciousness experienced by people who generally have average mental abilities. With modern psychotropic medicines and psychiatric care and support mental illness may usually be controlled or cured. 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 an appropriate environment and the right opportunities most mentally handicapped people do not experience the distress associated with psychiatric illness.

Since the 1920s it has been customary to make a division between severely mentally handicapped people, who may be defined as having IQs of below 50, and mildly handicapped persons who have IQs in the 50–70 range. Table 1 shows how these terms relate to others commonly used in the past.

The majority of mildly handicapped individuals are free of clinical indications of nervous system damage or defect whereas severely handicapped individuals nearly always suffer some clearly demonstrable form of impairment. In a significant number of cases this gives rise to physical as well as mental disabilities.

Table 1 *Terms used in relation to mental handicap*

General Terms	*Categories*	*IQ Equivalent*
Mild mental handicap	High grade Subnormal Feeble-minded Mentally handicapped Moron Mildly retarded Educationally subnormal	50–69
Mental handicap Mental retardation Mental defectiveness Mental subnormality		
Severe mental handicap	Medium grade Retarded Imbecile Trainable	20-49
	Low grade Profoundly retarded Idiot Untrainable	0–19

The most common of these include epilepsy and spasticity, blindness and hearing defects. Overall about one severely mentally handicapped person in three has a sensory or motor disability (Bone *et al* 1972).

As measured by IQ tests there are over one million people in the United Kingdom with intellectual abilities low enough to put them 'at risk' of being considered mildly mentally handicapped. However, most of these individuals live independently in the community without any special assistance. The administrative prevalence of mild mental handicap, that is to say the number of people who have at some stage in their lives come to the notice of service providing authorities as being handicapped or educationally subnormal, is much lower; probably in the order of 400,000 (DHSS 1976a).

In addition there are approximately 160,000 severely mentally handicapped people in the United Kingdom, 60,000 of whom are children. Four out of five of the latter live at home with their parents whilst of the adults about two out of every five live with their families. The remainder are mainly either in hospital or local authority residential care.

This paper analyses the occurrence and causes of reduced mental ability and its handicapping consequences with the objective of highlighting those areas where there is most opportunity for either preventing its incidence or alleviating the distress it generates. And it describes efforts made to improve services for the comparatively small number of more severely handicapped individuals since the publication of the 1971 White Paper *Better Services for the Mentally Handicapped* (HMSO 1971). In discussing the inter-related pattern of NHS and local authority care which has emerged it also considers the likely impact of economic restraints and new thinking on the social and educational needs of mentally handicapped people on official targets for service development up to the early 1990s.

MENTAL HANDICAP

Traditionally terms like mental retardation and mental subnormality have been used to refer collectively to three quite distinct phenomena: subnormal intelligence, reduced social and physical skills and deviant behavioural patterns. These components are themselves complex, at least as far as their causation is concerned. Subnormal intelligence, for example, may on the one hand be related to identifiable physiological impariments and, on the other, to poor development opportunities perhaps linked to cultural bias in intelligence testing procedures.

The employment of such imprecise terminology has often made it conceptually as well as practically difficult to distinguish between individuals' inherent mental limitations and the social handicaps they experience because of the effects of their impairments and functional disabilities on their way of life. This barrier to understanding has been a significant element in the creation of undue public and professional pessimism regarding the problems of mentally handicapped people. Because severe mental limitations are normally related to medically incurable defects stemming from before or around the time of birth it was widely assumed in the past that the behavioural disabilities and abnormalities observed in mentally handicapped people were similarly not amenable to 'treatment'.

The strength of the prejudice which even today exists against people who become labelled as mentally defective or subnormal began to be fully realised in the 1950s and 1960s when surveys demonstrated that many of the people 'put away' in subnormality hospitals were in fact of normal or near normal intelligence and ability (Morris 1969). Individuals who may have entered hospital simply because of a lack of alternative, more appropriate services to help them over a temporary crisis sometimes spent the rest of their lives in institutions. Studies suggest that the conditions frequently encountered in traditionally organised subnormality hospitals (such as depersonalising 'block' treatment and denial of any access to personal belongings, lack of employment and educative stimulation and the 'social distance' between staff in authority and the people under their control) often served to create or reinforce bizarre behaviour which was then taken as evidence of the inmates' abnormality and unsuitability for release into the community.

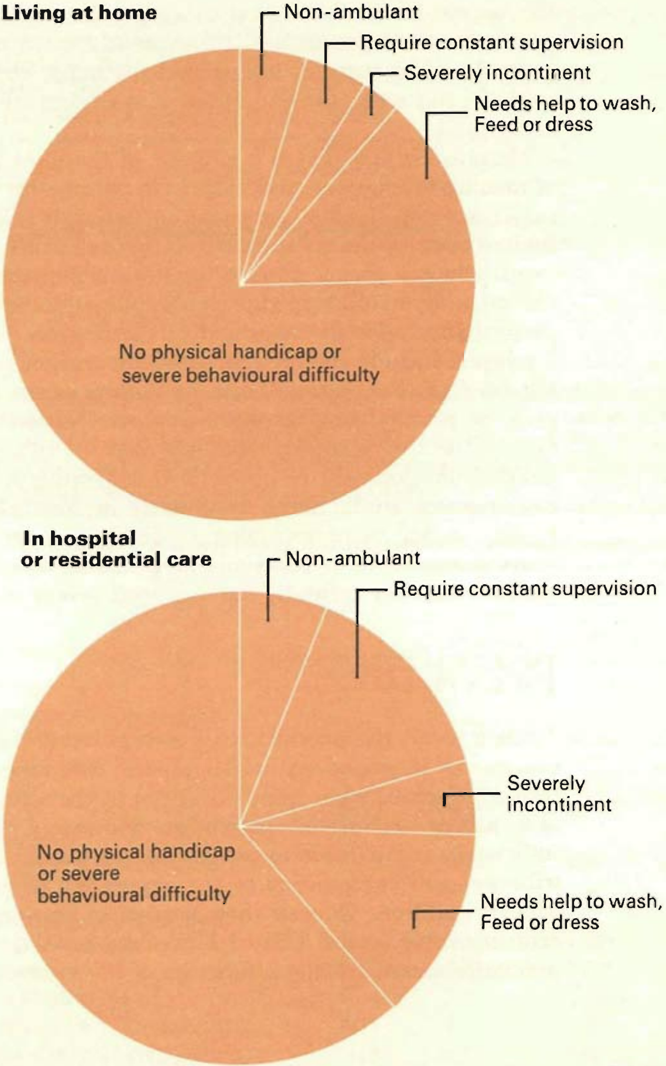
Figure 1 illustrates data collected in the 1960s. It indicates that two thirds of the roughly 60,000 people then in mental handicap hospitals in England were ambulant, continent and had no severe behavioural difficulties. The collection and publication of figures such as these was a significant element underlying the decision expressed in *Better Services for the Mentally Handicapped* to cut the hospital population by about 50 per cent by 1991. Today even this goal may be thought cautious in that probably only a few thousand mentally handicapped people require the type of medical care only available in a hospital context (Leck *et al* 1967).

However, many of the individuals who were in mental handicap hospitals in the 1960s are still in such institutions. Although the total hospital population has fallen to around 50,000, the most significant factor in this drop has been changes in admissions policy (particularly in relation to children and young people) rather than rehabilitation of existing patients. There is still significant concern about the 4–5 thousand mentally handicapped children in longer term care in hospitals (Oswin 1977) and investigations conducted at Normansfield Hospital have raised doubts in the minds of some people as to the conditions in and management of some others.

Yet these observations should not disguise either the fact that improvements have been made in the quality of life experienced by residents in many hospitals during the course of the past decade or that a real change in attitudes towards mentally handicapped people has started to take place in recent years. Campaign for the Mentally Handicapped has, for instance, noted a trend towards the provision of a village-like setting with shops and other service facilities in some formerly traditionally organised institutions (CMH 1977).

Measures of this type relate to an increased concentration on the behavioural rather than the underlying medical aspects of mental handicap. This has been closely linked with a shift in emphasis away from custodial and protective care towards therapeutically oriented educative and allied approaches. It may also be seen as behind current attempts of planners and caring

Figure 1 *The abilities and incapacities of mentally handicapped people aged over 15*



Source Cmnd 4683

Note These figures relate to the early 1960s. Since the abilities of mentally handicapped people are partially dependent on the services available they may underestimate the overall capacities of mentally handicapped people today.

staff alike to restructure existing services and provide new forms of support as well as to review critically past assumptions about the problems and characteristics of mentally handicapped people.

A key example of the latter trend has taken place in the area of the assessment methods used to assign the mentally disabled to particular care groups and subsequently to monitor their progress. Until recently IQ testing was the main 'tool' used for this purpose. But today the limitations of IQ scoring are more generally recognised.

Despite the fact that it is still one of the most useful measures of mental development available[1] (IQ parameters are used in this paper for classification purposes) IQ testing is relevant only to a limited area of the total matrix of human skills and if used incautiously can give a misleading and inadequate picture of any one mentally handicapped person's abilities and disabilities. Thus performance-related investigative techniques are emerging. Examples include the mental handicap register provided by the Health Care Evaluation Team at Wessex or the more extensive progress profile being formulated by the National Development Group for the Mentally Handicapped (NDG 1977a). And the parallel development of powerful investigative methods like the case register study being conducted in Sheffield (Martindale 1976a, 1976b) is encouraging evidence of moves towards the construction of the intellectual and practical foundations of more effective care for mentally handicapped people in Britain.

PREVALENCE

Table 2 shows the prevalence of mental handicap as found by a number of independent investigations. Differences between the results presented stem from variations in the assessment methods and survey techniques employed. However, the figures are sufficiently comparable to provide an adequate guide to the distribution and composition of the population of mentally handicapped children. Overall they show that between 2 and 3 per cent of people in the United Kingdom have IQs below 70, the precise proportion being a function of the IQ test used.

---

[1] Roughly a child aged 10 with an IQ of 50 will have the ability of a normal 5 year old. This may be expressed $\text{IQ} = \frac{\text{mental age}}{\text{chronological age}} \times 100$, although this relationship should not be thought to have any sort of rigid application. IQ tests are normally designed so that an average person scores 100 and one standard deviation from the mean is equivalent to 15 points.

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 differences between them. These are mainly due to variations in the ascertaining of mental handicap 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*	*Down's Syndrome/ 1,000 (Mongolism)*
England and Wales (urban) 1925–27 (Lewis 1929)	7–14	3·71	0·34
Middlesex 1960 (Goodman and Tizard 1962)	7–14	3·45	1·14
	10–14	3·61	
Salford 1960 (Susser and Kushlick 1961)	15–19	3·62	0·90
Aberdeen 1962 (Birch *et al*)	8–10	3·7	0·60
Wessex 1963 (Kushlick 1963)			
County Boroughs	15–19	3·54	1·15*
Counties	15–19	3·84	1·18*
Isle of Wight 1964	5–14	3·1	1 approx
Edinburgh 1964 (Drillien 1966)	7–14	5·0	1·85
Camberwell 1967 (Wing 1971)	7–13	3·57	0·62
Britain 1965–69 (NCDS 1972)	7	2·4	0·8
	11	3·7	

*The Wessex survey suggested that 10 per cent of those with Down's syndrome have IQ scores of more than 50.

Of this total of about one and a quarter million individuals, just over one in ten is severely affected, that is has an IQ under 50. However, in the figures on administrative prevalence severe handicap often assumes a greater significance in that many people with IQs in the order of 70 live relatively independently. This is either because they are fortunate enough to have circumstances where they can cope satisfactorily with their problems, and are thus not mentally handicapped in social terms, or because services either do not exist to help them or do not analyse and record their problems as being linked to mental handicap. The latter factors account for sharp falls in the administrative prevalence of mild mental handicap after school age although on the positive side it has been noted that many mildly handicapped people continue to make IQ increments well after most 'normal' peoples' IQ growth has stabilised.

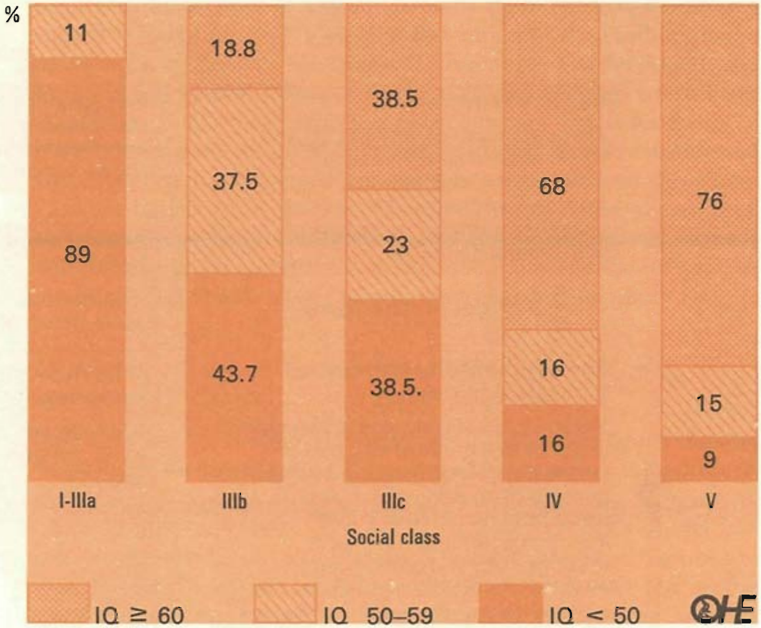
The reverse of this trend is found in mildly mentally handicapped people of school age and below (amongst whom age and prevalence are positively correlated). This is related to the fact that, as chronological age increases, developmental deficits become more apparent at school. Similar factors are not so significant in the context of severe handicap which is normally observed very early in life although it has been pointed out (Abramowiz and Richardson 1975) that lags may exist in administrative records. The true prevalence of severe handicap at age 7 is about 4 per 1,000 although were it not for differentials in infant mortality which adversely affect impaired babies it would probably be in the order of 6 per 1,000 (Kirman 1976a).

Social class and mental handicap

The report of the Committee on Child Health Services (HMSO 1976) emphasised that, whilst the figures available to it did not show significant social class related variations in the incidence and prevalence of severe mental handicap, there are major differences in the pattern of mild mental handicap between socio-economic groups. The latter was well illustrated by the research conducted in Aberdeen by Birch *et al* (1970). He and his colleagues found the prevalence of mild handicap to be roughly nine times greater amongst the children of unskilled manual workers than amongst those of people in non-manual occupations. They also reported that mildly handicapped children from middle class families were very much more likely to show clinical evidence of nervous system damage than were their class IV and V peers.

These findings, which have important aetiological implications, are illustrated in Figure 2. The severity of the skew in distribution which they show is strongly indicative of selective environmental influences on the incidence of mental handicap in the IQ 60–70

Figure 2 *The percentages of children having various degrees of reduced mental ability (by IQ) in each social class*



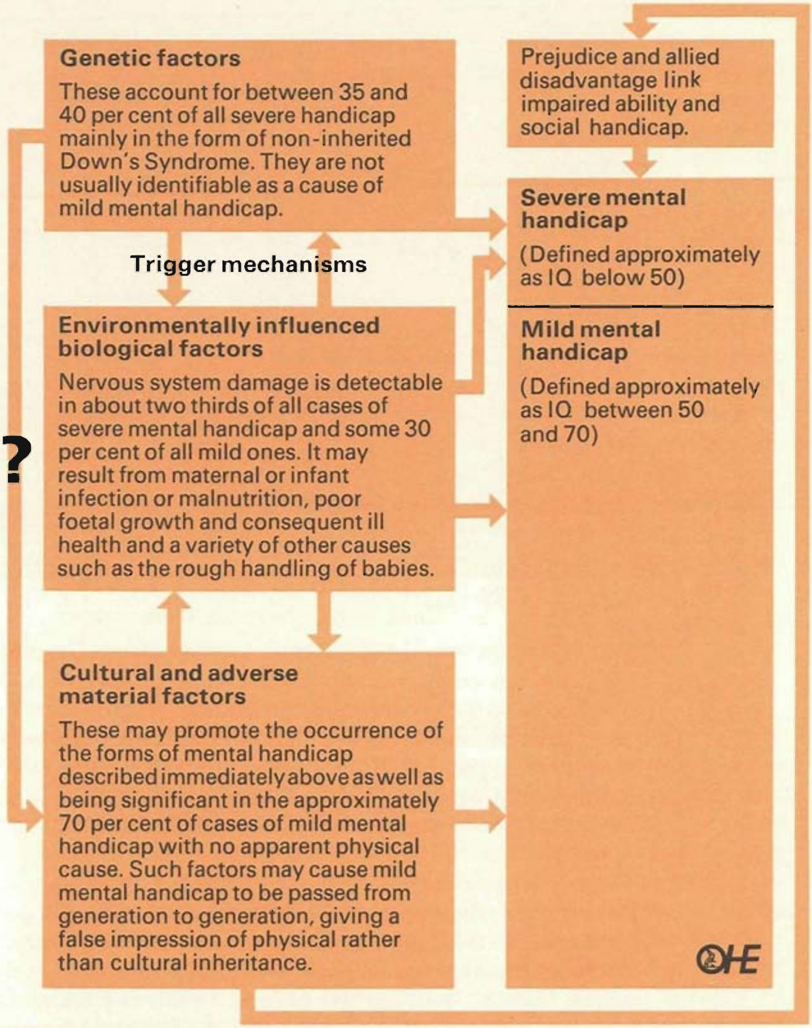
Source Birch *et al* 1970

band. Such factors are apparently less significant in severe handcap although comparatively recent work by Bayley in Sheffield (Bayley 1973) raises the possibility that class shifts in its incidence could exist in some localities. Although this may not be generally so at present, possible future trends such as a further shift towards a differential uptake of sophisticated prenatal care or screening services may eventually create such a situation.

Trends in prevalence

Debate over whether mental handicap is increasing in prevalence began in Britain during the late nineteenth century. It was stimulated further in the 1920s with the publication of the Lewis survey (Lewis 1929) for the Mental Deficiency Committee. His findings suggested that the incidence of mental handicap had doubled since the report of a Royal Commission (the Radnor Commission) some twenty years before. Although a variety of explanations for this trend were offered by commentators it has now been shown that this discrepancy between the two surveys arose mainly from variations in the methods and thoroughness of the investigators.

Figure 3 *The causes of mental impairment and handicap*



Genetic factors

These account for between 35 and 40 per cent of all severe handicap mainly in the form of non-inherited Down's Syndrome. They are not usually identifiable as a cause of mild mental handicap.

Environmentally influenced biological factors

Nervous system damage is detectable in about two thirds of all cases of severe mental handicap and some 30 per cent of all mild ones. It may result from maternal or infant infection or malnutrition, poor foetal growth and consequent ill health and a variety of other causes such as the rough handling of babies.

Cultural and adverse material factors

These may promote the occurrence of the forms of mental handicap described immediately above as well as being significant in the approximately 70 per cent of cases of mild mental handicap with no apparent physical cause. Such factors may cause mild mental handicap to be passed from generation to generation, giving a false impression of physical rather than cultural inheritance.

Prejudice and allied disadvantage link impaired ability and social handicap.

Severe mental handicap

(Defined approximately as IQ below 50)

Mild mental handicap

(Defined approximately as IQ between 50 and 70)

However, Lewis' work gave full data for children aged 7–14 with IQs below 50. Comparisons of these with subsequent research results such as those of Goodman and Tizard's 1960 Middlesex survey (Goodman and Tizard 1962) indicate that although the prevalence of Down's syndrome (mongolism) has increased due to improved survival that of severe mental handicap overall has not. This observation implies major reductions in some forms of handicapping event such as pre or postnatal damage associated with infection in the period between the mid 1920s and the 1960s. Current figures indicate that Down's syndrome prevalence may still be increasing (a trend related to the ageing of the Down's population) although there is little evidence of significant growth in the overall numbers of severely handicapped people.[2]

CAUSES OF IMPAIRED MENTAL ABILITY

Past failures to distinguish between inborn biological factors responsible for mental limitation, the environmental influences on physical and mental development and the social determinants of disadvantage have frequently helped to generate unbalanced and misleading views about the causes of mental handicap and hence the opportunities open for its prevention. For example, an undue emphasis on the genetic mechanisms underlying some cases of subnormal intelligence may have partially obscured the importance of high standards of prenatal and obstetric care. It has also distorted debate on performance variations between social groups.

Modern commentators thus stress the discreteness of these separate causal elements whilst accepting that they inter-relate, a point illustrated in Figure 3. In fact mental handicap is so much an amalgam of physiological and developmental factors that the term is not usually taken to refer to people who become mentally impaired in later life through, for instance, road accidents,[3] strokes or premature dementia. The social implications of undergoing primary habilitation with reduced mental ability are central to the concept mental handicap.

Overall it is estimated that in the order of 40 per cent of all severe lifelong mental handicap is associated with the types of specific genetic or chromosomal abnormality described in Table 3. Of the remainder the most significant proportion is related to

---

[2] In the 1920s only about one Down's syndrome baby in ten survived to the age of 5. By the late 1950s the equivalent proportion was 4 in 10. Today it is over 7 in 10.

[3] Road accidents cause an estimated 1,000 cases of serious, permanent mental impairment each year which are in most instances associated with physical disability.

damage or defect amongst babies of low birth weight. Relevant factors include maternal ill health and malnutrition, obstetric complications which may be exacerbated by an inadequate access to, or poor take up of, medical care and illness in the new born child. The risk of the latter is highest amongst people living in crowded conditions and with poor nutritional standards.

In the context of these points it is perhaps surprising that epidemiological investigations have not usually shown class shifts in the prevalence of severe handicap. Yet it may be that better survival rates amongst weak children with 'higher' class backgrounds act as a balancing factor. It is also possible that variations in rates of spontaneous abortion could act in a similar manner. Birch *et al* (1970) reported that very short women were significantly under-represented in the population of mothers of severely handicapped children in Aberdeen, a finding which could imply such an explanation.[4] This field remains, however, relatively poorly researched.

Mild handicap

By contrast much effort has been devoted to understanding the high prevalence of mild handicap amongst children born to social class IV and V families. Studies have revealed a consistent pattern of material deprivation, poor housing facilities and the sub-standard educational opportunities linked to other variables such as large family size and family instability amongst children 'born to fail' (Rutter *et al* 1970, Davie *et al* 1972, Wedge and Prosser 1973, Fogelman 1976). In addition it appears that subclinical physical defects (unlikely to affect survival in early life) and inadequate nutrition are particularly likely to adversely influence the physical and mental development of children in this group.

The possibility that inheritable factors may also be involved has been investigated in several surveys of mental handicap (Susser and Stein 1960, Rutter *et al* 1970, Birch *et al* 1970). The available data do not support the concept of an inbred, stable social class with an inferior genetic endowment. But there is some evidence indicating a tendency towards downward social drift amongst the parents of a proportion of mildly handicapped children. The reasons for this are uncertain although it is possible that declines in socio-economic status could themselves help to promote an adverse domestic environment.

It thus appears that to a considerable extent the uneven dis-

---

[4] Which in turn implies that, if living standards rise gradually but class based variations in standards of prenatal care and allied factors are maintained, a class shift in the prevalence of severe mental handicap may emerge.

Table 3 *Genetic factors in mental handicap*

Dominant conditions

Dominant inheritance is due to genes whose effects manifest themselves in the heterozygote, ie in the individual where only one allele (alternative form 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, ie in cases where both alleles are of the same type. If both parents are carriers there is thus a one in four chance of their children being affected. 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-phosphate-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 about 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 and possibly paternal 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, Klinefelter's syndrome (affecting 1 in 1,000 male live births) does so in some cases and males with an extra Y chromosome may sometimes be 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.

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 nor 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.

tribution of mental abilities between social sub-groups is a result rather than a cause of the existing social order. This observation in turn suggests that, despite the fact that there is always likely to be a substantial range of performance within the population as a whole, the numbers of people who are of ability below average to the extent that they have difficulty in coping independently with everyday problems could be very much reduced simply by improvements in the living standards of and the services available to those in most need.

PREVENTION

The conclusion that adverse social and environmental conditions are responsible for the poor mental performance of many children who, with more favourable surroundings, could develop abilities clearly within normal spectrum now appears to be generally accepted. As a result there is in future likely to be an increasing degree of 'positive discrimination' in the allocation of relevant health and social resources to localities with large proportions of disadvantaged families (Ennals 1978a). And although some of the ideas put forward by the Committee on Child Health Services (the Court Committee) regarding the development of new specialisms such as general practice paediatrics will probably not be translated into reality it is clear that its arguments in favour of improved integration and strengthening of the child health services have been positively received.

Consequent shifts in policy have already been reflected in the first official response to the Court report (DHSS 1978) and in joint DHSS/DES moves to coordinate health care and education for the under fives (DES/DHSS 1978). These encouraged the formation of closer links between schools, day nurseries, day centres, relevant NHS facilities and voluntary organisations and promised more support for play groups, mother and baby clubs and registered child minders. At present there is a severe shortage of pre-school facilities for mentally handicapped children, a factor related to low levels of recording of handicap in the under fives.

The implementation of such steps may require significant amounts of time and resource although there is no doubt that they offer the long term prospect of real progress in child health care. Impairment rates may be reduced both by the more effective treatment of illness contracted during early life and by secondary prevention of the handicapping effects of conditions caused either before or during birth. The prompt correction of or compensatory response to the latter may in many instances lead to the avoidance of developmental retardation.

Yet the great majority of the 3,000 babies born each year who today survive to become severely mentally handicapped children are physiologically damaged or abnormal before they draw their first breath. The same is true of at least a quarter of the 20,000 babies born who eventually become regarded as mildly mentally handicapped. In such cases primary prevention of impairment at the time of or before birth is the ideal goal.

Already some significant progress in this area has been achieved. Examples range from the use of anti-D-immunoglobulin to prevent heamolytic disease of the newborn to the control of maternal infections during pregnancy by antibiotics. The prevention of cretinism by appropriate diet supplements in iodine deficient areas was an early victory against 'congenital' subnormality which may be paralleled with recent developments such as universal rubella (german measles) immunisation for females before their child bearing years.

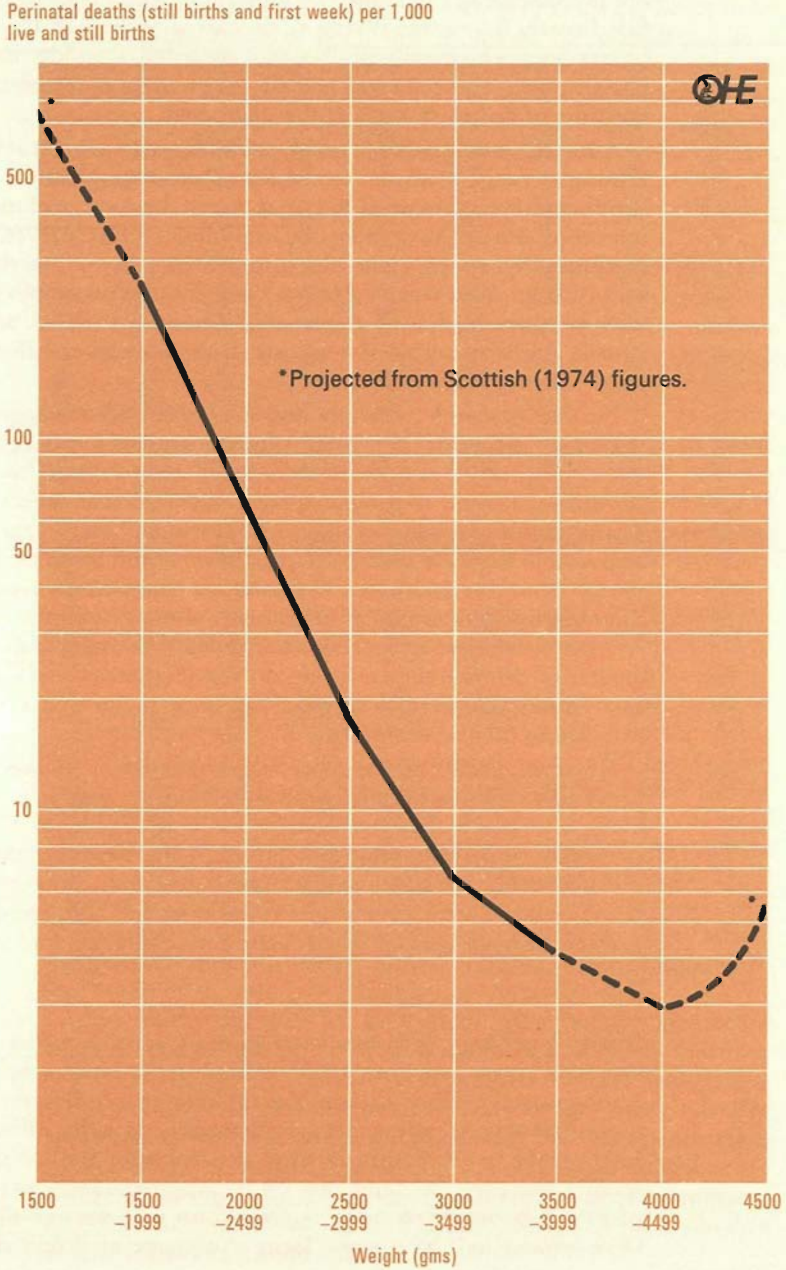
Further, research in Britain and the United States suggests that within a few years a proven vaccine against cytomegalovirus infection (CMV) may be available (Stern 1977). This is the commonest form of handicapping intra-uterine infection. It causes about 500 cases of severe subnormality each year and is responsible for several times that number of milder ones. Despite the fact that there may be still significant problems to overcome – the experimental vaccine is being tested amongst renal transplant recipients, who are at special risk from CMV, in order to gauge the danger of the virus reactivating during pregnancy – research on CMV immunisation thus appears to be a major route towards preventing mental handicap.

However, many of the more important issues in the field of prevention involve questions more difficult than those which are likely to relate to any decisions to use a new vaccine. Complex economic, organisational, and ethical considerations dominate the two fields discussed below. These are, first, antenatal care with special reference to low birth weight babies and, second, prevention through genetic counselling and diagnostic screening.

Low birth weight and mental handicap

Nearly 7 per cent of babies born in the United Kingdom weigh less than 2,500 grams (5.5 lbs). About 1 per cent weigh under 1,500 grams (3.3 lbs) (DHSS 1977a). As Figure 4 indicates, there is a very close relationship between mortality in early life and low birthweight, a relationship which also holds for the incidence of mental and physical handicap. Of the approximately 40 per cent of British babies born under 1,500 grams who survive their first year around half have some form of damage or defect resulting

Figure 4 *Birthweight and perinatal mortality in Britain (1970)*



from conditions like anoxia or hypoglycaemia (oxygen starvation and low blood sugar).

Although mortality and handicap rates amongst babies weighing more than 1,500 grams are less disturbing a number of commentators have linked Britain's poor international record in infant mortality to the relatively high numbers of light babies born. Studies such as that of Hagberg, Hagberg and Olow (1975) on cerebral palsy suggest that for similar reasons the incidence of some forms of severe handicap may be twice as high in this country as in Sweden. Figure 5 compares British and Swedish birth weight distribution data.

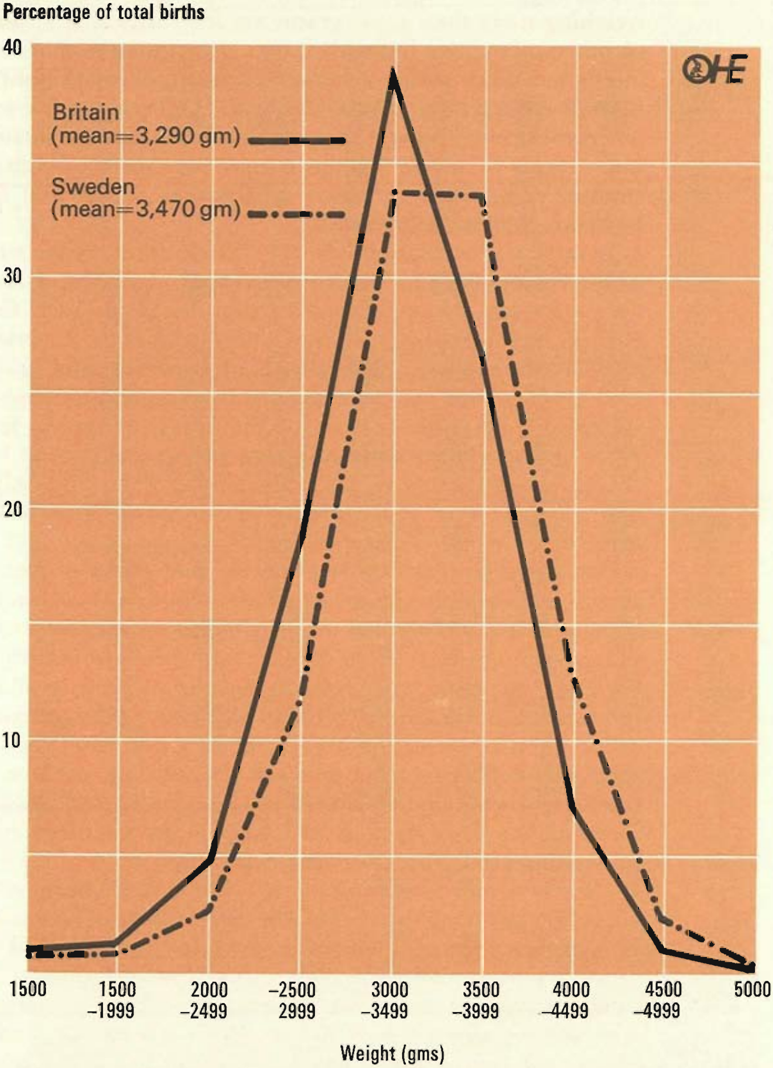
In response to this problem considerable effort has been devoted to improving the special care provisions available to low birth weight babies. Despite early fears that this would raise the number of handicapped survivors (Drillien 1967) experience in centres of excellence like the Hammersmith and University College Hospitals has gone some way to providing reassurance. Recent figures indicate that of the babies weighing less than 1,500 grams who survived and received special care at UCH less than a quarter had any detectable impairments and only about one in twenty were, at ten years of age, in special schools (Stewart *et al* 1977).

But although it is clearly desirable that effective special care should be available to very low birth weight babies (and in this context it should be noted that, although the current NHS priorities programme has led to reduction in general obstetric service funding, increased resources should have been available for intensive care facilities – Rothman 1978) such interventions alone are unlikely to lower the overall incidence of handicap. In that they may double or triple survival chances, for instance, falls in handicap rates may be largely cancelled out. And the achievements of the most sophisticated units in the country could be a misleading guide to nationwide experience.

Clearly a more desirable option would be, where possible, a reduction in the proportion of low weight births. This could only be achieved through changes in attitudes towards child bearing and the pattern of antenatal care available in Britain.

Debate in this area has received some official encouragement (see *Reducing the Risk*, DHSS 1977b). Yet a case can be made to the effect that central government in Britain has failed to provide sufficient guidance regarding antenatal services and that compared with European countries like France, UK policy has lacked positive drive. It is widely acknowledged that at least 20 per cent of women in Britain still fail to seek or be actively offered relevant care during the first trimester of pregnancy and the true figure for those receiving inadequate support subsequently could be con-

Figure 5 *Birthweight distribution in Sweden (1973) and Britain (1970)*



Source (Figures 4 and 5): Wynn and Wynn (1978)

siderably higher. A high proportion of perinatal casualties are amongst the babies of mothers whose potentially correctable obstetric complications are not observed until they reach an acute stage necessitating emergency delivery (Ferster 1976).

It also appears that in some fields, such as the use of medicines to prevent preterm birth,[5] medical practitioners in the UK may have been slow to investigate the efficacy of new techniques. Although it may be taken as a hopeful sign that a trial of myometrial depressants (which have been in widespread use in countries like East Germany since the start of the 1970s) has now been instigated following a report from the Working Party on Infant and Perinatal Mortality it is a matter of obvious concern that perhaps 1,000 surviving babies are born severely mentally impaired each year whose condition might have been prevented by the full application of modern knowledge.

In the light of observations such as these Wynn and Wynn (1977, 1978) have argued that there is a need for an inquiry into antenatal care comparable to recent investigations into child health services (see the Court report) abortion (the Lane report) midwifery and maternity bed needs (the Peel report) and neonatal mortality (the Sheldon and Oppe reports). They have pointed in particular to topics like the potential importance of extensions in community midwifery services designed to support and educate mothers early in pregnancy.

Counselling and screening

There are three distinct types of technique for the primary prevention of impairments due to genetic or chromosomal abnormalities. The first rests on genetic counselling through which potential parents found to be carriers of inheritable conditions are warned of the risks involved if they decide to have a child. The second is the prenatal diagnosis of abnormality, after which it may be decided whether or not to terminate the pregnancy.[6] And the third is postnatal screening which in some circumstances may open the way to the early treatment of otherwise handicapping complaints.

The most obvious example of this last is that of phenylketonuria (PKU) which if left to follow its natural course always leads to mental impairment. But it can be controlled if a special dietary regime is employed in the first three years of life. All babies born in Britain are screened for PKU which affects around 1 in 10,000 births, an incidence rate which may rise as more carriers survive to healthy maturity.

However, the great majority of conditions related to genetic or

---

[5] The value of vitamin supplements to maternal diet during pregnancy in populations with poor nutritional habits may be another topic worth further investigation.

[6] This may only accurately be termed primary prevention if the moment at which life commences is regarded as being at the time or after the time the foetus becomes capable of existing independently of maternal support.

allied factors are not treatable, whatever the stage they are diagnosed at. The main options open therefore relate to counselling and prenatal diagnosis, which in practice are closely linked. As Kirman (1976a) has noted genetic counselling has in the past proved unpopular, partly because it is frequently of little value simply to inform people who wish to have children of the risks of handicap without offering any means of ensuring that they will be able to have an unimpaired baby. The advent of prenatal diagnostic techniques which may be used to identify foetuses affected by conditions like the metabolic defect Tay Sachs disease has helped to remedy this problem, at least for people to whom the idea of terminating an abnormal pregnancy is morally acceptable.

However, in the most common single cause of severe mental impairment, Down's syndrome, genetic counselling has little predictive value. Well under 10 per cent of the total number of cases involve any form of inheritable factor. Hence even though advances in fields such as dermatoglyphics[7] backed by chromosome studies may be useful in identifying a small number of people at special risk of having a 'mongol' child (Loesch 1974) they will not affect the more than 90 per cent of cases which are standard trisomony 21.[8]

Here the main factor which may be used for general risk prediction is maternal age. Women aged 15–19 stand less than a one in 2,000 chance of giving birth to a Down's syndrome baby. For those over 40 the risk is around 1 in 100. For mothers over 45 it is 1 in 50.[9]

The early detection of Down's syndrome can only be achieved through amniocentesis, the aspiration of amniotic fluid from the uterine cavity. This may be tested for cells showing signs of chromosomal abnormality and for enzyme deficiencies or protein factors indicative of other abnormalities.

The development of such techniques during the 1960s led to hopes for extensive screening. Some authorities (for instance Stein *et al* 1973) have proposed universal programmes which could theoretically reduce to nearly zero the future Down's syndrome incidence rate. Yet such ideas have since been subjected to considerable criticism on economic, ethical and allied practical grounds. Of the objections put forward the economic ones are the weakest and the practical ones the strongest.

---

[7] In this instance the study of palm prints.

[8] See Table 3.

[9] Higher risk rates implied from studies based on populations who have undergone amniocentesis are misleading because they include a significant proportion of people already identified as especially liable to give birth to a child with a chromosome defect.

Hagard and Carter (1976) have argued that in strict economic terms the 'break even' maternal age above which people should be screened for Down's syndrome is currently around 35 years. If all women of 35 or over were offered amniocentesis then up to 30 per cent of 'mongol' births could be detected. (The equivalent figure for age 30 is around 50 per cent). But as Hagard and Carter themselves observed their calculations are of little use as a guide to policy formation. Not only do they make no allowance for future cost trends in the care sector[10] but, more importantly, they do not attempt to measure the social cost/risk/benefit balance. As a universal UK screening programme could very probably be maintained for less than £80 million (in 1977 prices) annually economic restraints alone would not seem to preclude such an alternative were its total benefits judged sufficient.

A more substantive barrier stems from the hazards that mass screening might engender (the subject of a recent MRC investigation) and the likelihood that routine amniocentesis perhaps followed by abortion might prove unacceptable to significant numbers of people. Although the available American and European data implies that safety risks can be made acceptable (*Lancet* 1977) a low service take up would obviously defeat its purpose.

Perhaps, therefore, the most realistic goal for the immediate future would be the establishment of more thorough screening for mothers at special risk. At present around one baby with a handicapping chromosomal abnormality in every six[11] is born to a mother aged over 40 yet this group comprises little more than 1 per cent of all mothers. It would therefore seem reasonable swiftly to increase from the current 20 per cent level (Forster 1977) the proportion of pregnant women over 40 who are being screened for chromosomal disorders.

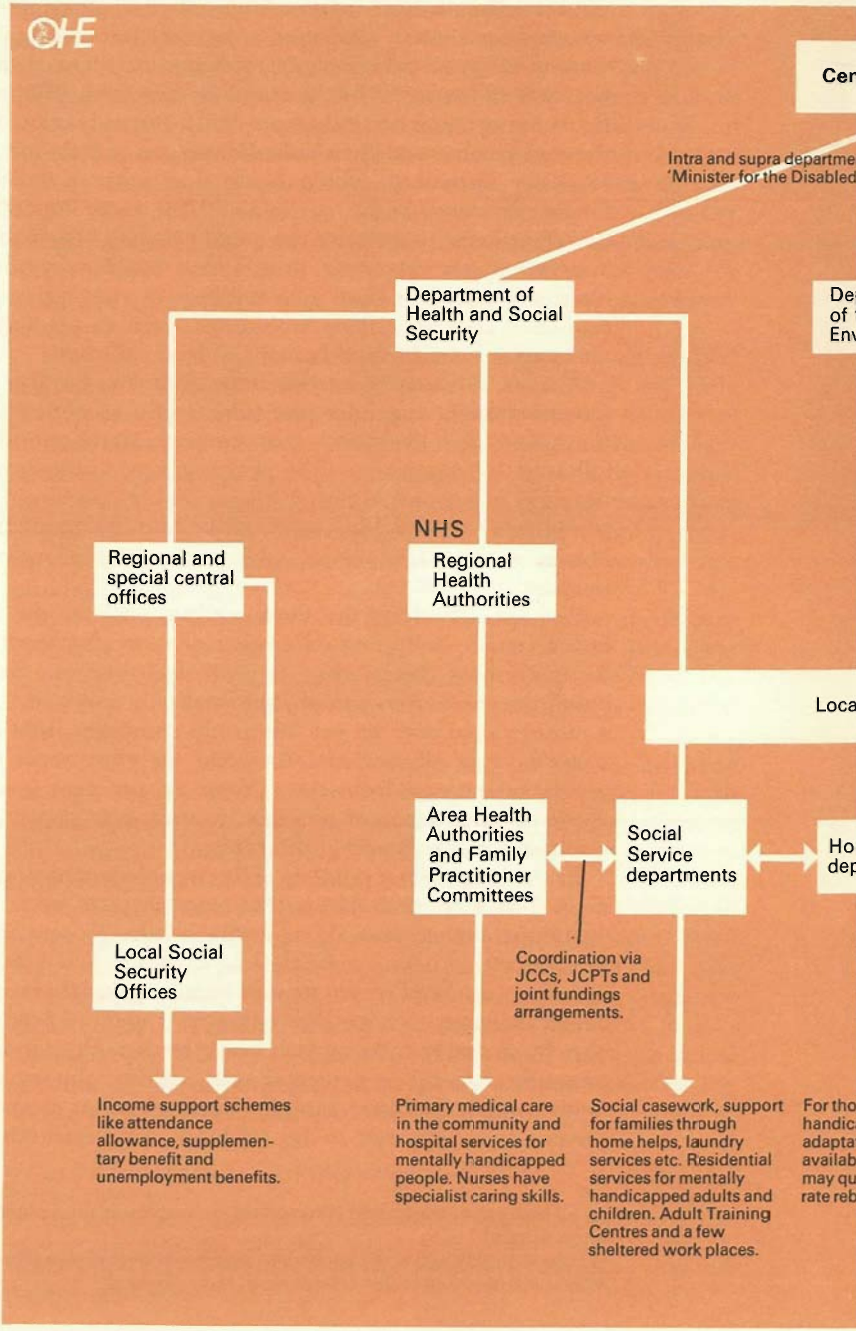
In the long term a number of foreseeable technical possibilities exist. The most desirable is that some form of initial screening technique analogous to the maternal serum test now available in the context of neural tube defects such as spina bifida (itself a significant cause of severe mental handicap) might be developed. There is reason to hope that equipment may be produced (perhaps by the early 1980s) which would be capable of indicating the presence of foetal or placental cells with an abnormal chromosome content in blood samples from pregnant women. Yet at present there appears to be no large scale research aimed at

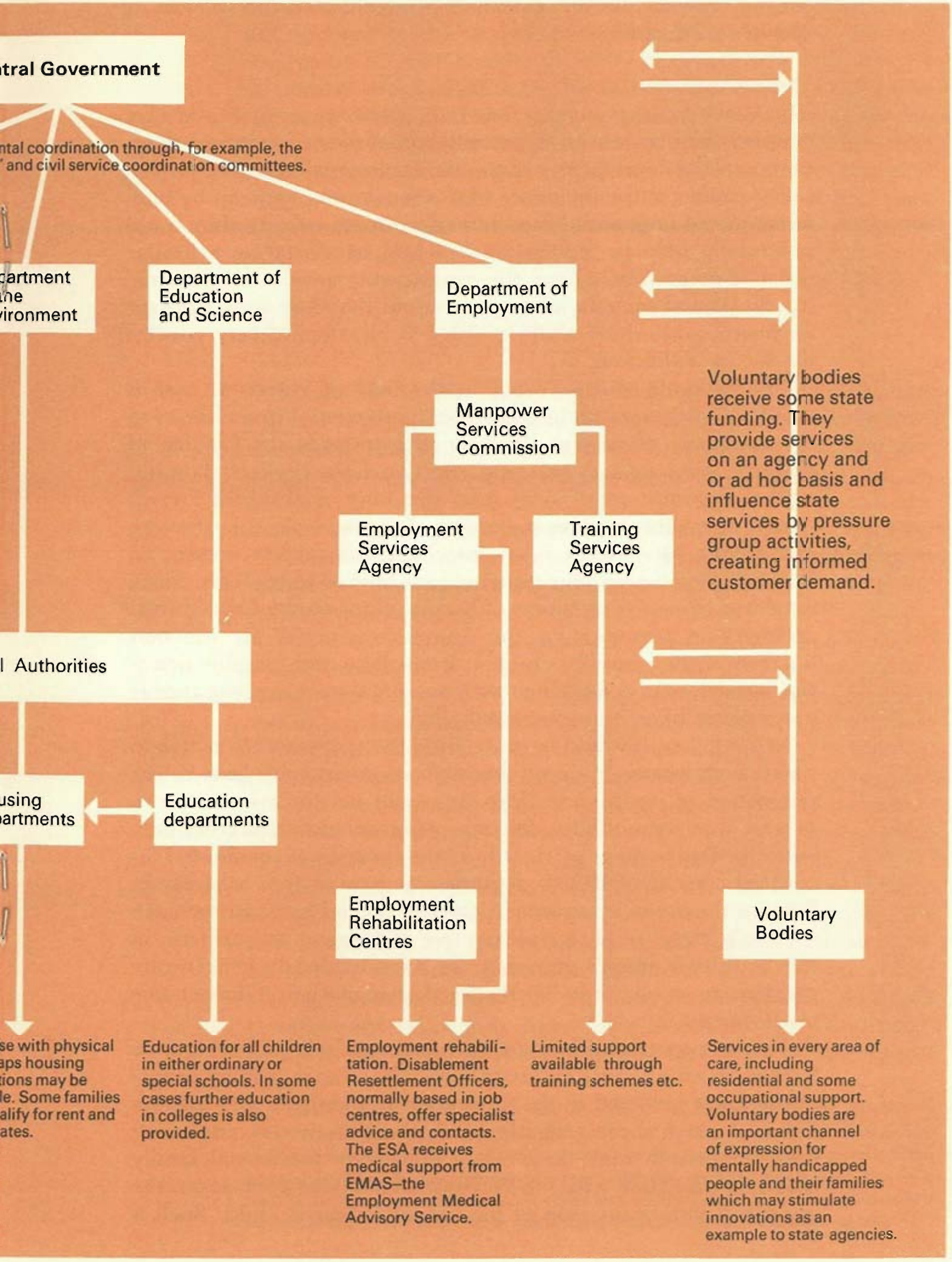
---

[10] Their use of traditional discounting techniques in this context might also be questioned.

[11] In the early 1960s the equivalent figure was over one in five. The decline reflects changes in fertility behaviour in older women.

Figure 6 *Services for mentally handicapped people in England*





ntal coordination through, for example, the " and civil service coordination committees.

Voluntary bodies receive some state funding. They provide services on an agency and or ad hoc basis and influence state services by pressure group activities, creating informed customer demand.

se with physical aps housing tions may be le. Some families alify for rent and ates.

Education for all children in either ordinary or special schools. In some cases further education in colleges is also provided.

Employment rehabilitation. Disablement Resettlement Officers, normally based in job centres, offer specialist advice and contacts. The ESA receives medical support from EMAS–the Employment Medical Advisory Service.

Limited support available through training schemes etc.

Services in every area of care, including residential and some occupational support. Voluntary bodies are an important channel of expression for mentally handicapped people and their families which may stimulate innovations as an example to state agencies.

establishing the feasibility of this objective, a fact which is surprising in view of the gravity and world-wide prevalence of Down's syndrome.

Policy implications

The above findings suggest that improvements in antenatal care coupled with advances in current techniques of prenatal diagnosis and the development of a cytomegalovirus vaccine of proven safety could cut the incidence of severe mental handicap by half. If combined with social care and educational reforms they could potentially help to reduce mild mental handicap by a similar order of magnitude. Given the considerable social and economic significance of such an advance it would therefore seem prudent for health authorities in this country to investigate every possibility for its realisation.

The example set by France in the field of antenatal care is worth careful examination. It raises fundamental questions as to the adequacy of current British policy towards the funding of obstetric services and ensuring effective links between hospital and community provisions. And the long established French system of making certain maternity allowances payable through early clinic attendance is an interesting model. At present in Britain no such economic motivation is offered to mothers. Since some less educated members of the population may have special problems in planning for the future and identifying the best interests of their unborn children immediate and tangible financial incentives to compliance with antenatal care regimes appear particularly likely to prove worthwhile.

Nevertheless, it would be misleading to exaggerate the extent to which such relatively simply innovations could contribute to the prevention of mental handicap. It would be similarly wrong to suggest that responsibility for improving antenatal care lies only with the Department of Health or the professions involved. It is perhaps typical of British attitudes in general that whereas in Sweden the feminist movement has laid special emphasis on each woman's 'right' to have children free of physical impairment, in this country women's organisations have tended to concentrate much more on questions like the freedom of mothers to have home confinements.

Thus improvements in antenatal care standards will need to be backed by an educational programme aimed at informing people of the issues involved in the prevention of handicap and helping them to reach clear judgements. Viewed from this angle one future approach may be a closer linkage of traditional family planning education with the distribution of information about the small but significant risks of having an impaired child. Such a development could not only help to increase the uptake of antenatal services and encourage parents as well as professionals to feel responsible for the avoidance of handicap. It might also help to prepare the unfortunate minority of people who will, despite all possible precautions, suffer the ill chance of having a baby who has some form of abnormality. Currently most parents in this group have to consider the problems of handicap for the first time when actually confronted with them. In such circumstances it may be extremely difficult for a mother or father to accept that, despite impairments, their child will with adequate assistance probably be able to live happily.

THE EVOLUTION OF CARE

Although there is every hope medical advances and social changes will in the future substantially reduce the incidence of both mild and severe mental impairment there is as yet no possibility that preventive measures will prove totally effective. And the difficulties faced by today's handicapped people will not in any case be altered by future developments in that sphere. Thus the question of the structure and extent of caring services designed to meet special needs in fields such as education, occupation, housing and recreation remains one of central importance.

The origins of state backed care for mentally handicapped people in Britain stem back to the days of the Poor Law workhouses and hospitals.[12] Throughout the nineteenth century few special provisions were made in the public sector other than those generally available to those who were, through mental or physical sickness or other disadvantage, impoverished (Jones 1972). But towards the beginning of the twentieth century mental deficiency (as it was then referred to) emerged as a distinct problem, a trend initially reflected by the passing of the 1886 Idiots Act.

There were several reasons why late Victorian Britain came to recognise the problem of mental handicap. For example, the shift from an agricultural to an industrial economy and the introduction of universal education made impaired mental ability amongst some sections of the population more 'visible'. Also falls in infant mortality may have been associated with disproportionately increased survival rates amongst babies suffering ab-

---

[12] And to the evolution of the prison system. An important point relating to the reform of the 1959 Mental Health Act is the need to balance the desirability of discretionary powers designed to protect mentally handicapped people from unduly harsh treatment under the law with the danger that committal to a mental handicap hospital can in effect act as the imposition of an unlimited custodial sentence for a crime considered minor amongst 'normal' people.

normality. Such apparent increases in the incidence of mental handicap disturbed many individuals in authority who, acting within the constraints of the knowledge of the day, feared that the proportion of 'defectives' within the population might rise indefinitely.

It was against this background that the Mental Deficiency Act was passed in 1913. This was intended to establish a separate system of care for mentally handicapped people based both on community support and segregated colonies. The latter were seen as being especially appropriate for either severely handicapped persons or those with near normal intelligence who displayed behavioural deviance like drunkeness or, for females, moral incompetence (defined as bearing an illegitimate child whilst in receipt of poor relief).

The intention behind the Act was both to provide protective care for people with impaired mental ability and to control the future population of such persons. Since mental deficiency was in those days believed to be largely inherited, since contraception was not seen as an appropriate option and since there was imprecise theoretical distinction between low mental ability and social incompetence or deviance it seemed reasonable to some policy makers to attempt to limit by segregation and strict control the procreativity of people of subnormal ability.

In the interwar period the number of local authority administered places in institutions for the mentally handicapped expanded rapidly, from a little over 5,000 in 1918 to approaching 50,000 in 1939. This rise was facilitated both by new building and the transfer of Poor Law hospitals and other facilities to the local authorities. It was during this period that caring for mentally handicapped people became widely regarded as an activity appropriately conducted by doctors and nurses. This was partly because there was still much confusion between the concepts of mental handicap and mental illness. In retrospect it may also be seen that the 'take off' in curative medicine at the time was simultaneously shifting medical attitudes away from the caring approach appropriate in mental handicap more towards an emphasis on curing acute conditions.

The Second World War effectively ended the rapid growth in numbers of institutional places. It also led to a drastic reduction in the voluntary association backed community services like industrial centres for the mentally handicapped. Since local authority provisions in this field had not expanded very fast in the 1920s and 1930s there was in the postwar period, when the NHS was first established, a considerable imbalance between the hospital and community services available for mentally handicapped persons. The difficulties this led to were accentuated by the fact that the local authorities retained control of the latter whilst the residential services were under the separate hospital administration.

In the mid 1950s a Royal Commission studied the existing arrangements. In the light of a more modern understanding of genetics and the causes of reduced mental ability coupled with new knowledge regarding the educability of even profoundly retarded people it recommended a break down of segregation and stronger emphasis on community based care. However, despite the passing of new legislation in 1959 (which amongst other innovations charged local authorities with once again providing residential care) effective reforms appeared to many commentators to be disappointingly slow to follow.

This may have been in part because the report of the Royal Commission itself contributed to confusion relative to topics like psychopathic disorder and the distinction between mental illness manifested in aggressive behaviour as opposed to the distress and despair displayed by human beings of low mental ability who had been confined for their lifetimes in hospitals which usually provided minimal care and no recreation or occupation. The fact that the 1959 Mental Health Act tended to blur the clear distinction between mental illness and mental handicap is regarded as one of its main defects by present day reformers who wish to see either no special, or entirely separate, legislation for mentally handicapped people emerging from the current review of this topic (see DHSS 1976b).

Delays in the emergence of new forms and standards of care may also have been due to tardiness amongst some people with authority over mental handicap services (Crossman 1977). Not until the storm over conditions in Ely hospital finally broke in 1969 did a fundamentally more vigorous policy emerge. This was expressed in 1971 in the White Paper *Better Services for the Mentally Handicapped* the main recommendations of which are described in Table 4.

Innovation in the 1970s

During the current decade several factors have influenced the development of provisions for mentally handicapped people, the pattern of which is shown in Figure 6 (pages 23 and 24). For example, the Seebohm reorganisation in 1971 created independent local authority social services departments and strengthened social work as a profession, though in the short term it may have dissipated some specialist skills. The 1974 reorganisation of the health, local authority and employment services provided the possibility of a more integrated pattern of care for mentally handicapped people. And measures such as the formation of the

Table 4 *Planning figures for services for mentally handicapped people compared with provisions existing in 1969*

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

Source Cmnd 4683

*Estimated. †NHS beds allocated to mental handicap.

‡The quality of many of these places may have been poor.

See note on opposite page.

National Development Group (NDG) for the Mentally Handicapped (which is linked with the National Development Team) and the introduction of joint funding arrangements between the local authorities and the NHS in 1976 were also of major significance in as much as they may help to make possible the goals of *Better Services for the Mentally Handicapped.*

For instance; apart from overall economic restraints one of the main factors inhibiting the build up of local authority residential services was that the relevant authorities had little direct incentive to relieve the mental handicap workload of the NHS. And in any case they frequently lacked sufficient liaison with the health service to plan adequately the transition from hospital to community based services. The availability of joint funding money channelled via Area Health Authorities and with it the formation of Joint Care Planning Teams has reduced these barriers.

In some instances the work of the last few years has also helped to modify and/or clarify detailed aspects of the objectives of the White Paper. The NDG suggestion that there should be specialist community (ie sub-district) Mental Handicap teams[13] is an illustration of how the 1971 proposals have been so supplemented, as is its work on Adult Training Centres (ATCS).

With regard to the latter recent studies have suggested that the performance of these centres as far as rehabilitation is concerned is of limited value. Fewer than 4 per cent of the handicapped people attending them pass on annually to more open employment and researchers have found that the largely untrained staff tend to have unnecessarily low expectations of their clients' abilities (Whelan 1975, Whelan and Speake 1977). Jones (1975) found that 70 per cent of ATC trainees had been there for over five years and that only 30 per cent of staff had formal training. The

Note to Table 4 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 that the fostering rates for mentally handicapped children should be raised. Also the required number of hospital beds estimated may prove to have been set at too high a level, particularly as regards children.

It is difficult to compare precisely the latest available data with that in Table 4. Overall it appears that local authority services in England alone grew to the level of 37,000 ATC and 13,000 residential places in 1977. Child residential places stayed relatively static but provision in ESN(s) schools rose to 33,000 places. The hospital inpatient population in England in 1977 was around 43,000 adults and 4,500 children, with over 4,000 attending out-patient clinics.

---

[13] These should work in coordination with the District Handicap Teams suggested by Court (DHSS 1978). The construction of such teams should help to move the focus of care activity out of an institutional context. The NDG also stressed the value of the primary care team in providing full day to day health care to mentally handicapped people although this is an activity quite distinct from the specialist support available from the MHT.

NDG has attempted to define the role of ATCS more closely (NDG 1977d), pointing to their potential value in improving severely mentally handicapped individuals' social skills. This is reflected in its recommendation that ATCS should expand to include special units for those with particular difficulties and that they should be renamed Social Education Centres.

Yet perhaps the most important progress which has been achieved since 1971 does not relate to any single reform or policy review. Rather it is the gradual resolution of some of the problems inherent in formulating a general philosophy of care for mentally handicapped people. Nowhere has the need for a reduction in confusion and conflict been more apparent than in the field of residential care and planning for the future of existing mental handicap hospitals.

Hospital versus community?

In an atmosphere periodically charged with dismay and anger associated with public revelations of the poor conditions prevalent in long stay mental handicap hospitals during the 1960s a strong antagonism developed between the proponents of hospital care and those in favour of alternative 'community based' services. Even today there is an apparent divergence between groups who believe that hospital support and specialist nursing will always be necessary for many more severely handicapped people (see Royal College of Psychiatrists 1976) and those who urge early closure of such health service facilities (MIND 1977). Even new smaller health service provisions have been criticised as being in effect traditional hospitals (CMH 1976).

For outside observers it is often difficult to gain a balanced picture of the issues involved in this debate. Available statistics, for instance, can be used to support both the view that 'real advances' in the pattern of hospital care have been made during the last decade and the contention that in reality little has changed. On the one hand there was a 70 per cent fall in first admissions to mental handicap hospitals between 1964 and 1975 balanced by a near 100 per cent rise in stays of less than three months in the same period (DHSS 1977c). On the other, three quarters of all patients had been in residence for over five years in 1975, this proportion ranging from a low of 66 per cent in the Trent and Oxford Regions to a high of about 90 per cent in the North Western Region.[14] Fraser (1976) has estimated that in Scotland a 15 per cent fall in the total mental handicap popula-

---

[14] Another informative example of Regional variation is that the 1975 per capita mental handicap hospital population in South West Thames Region was more than twice that of Oxford and Wessex. This picture matches that of NHS mental handicap expenditure variations (DHSS 1977d).

tion will not be achieved until 1991 whilst the NDG (1977c) has shown that less than 10 per cent of hospital places are available for short term care.

But slowly a more coherent and sophisticated appreciation of mental handicap service development is emerging, one based on an understanding of statistical data in its full context and on the key principles underlying the reforms of the 1970s. Bayley (1973) has made the useful distinction between care 'in' the community and care 'by' the community. This brings out that although shifts in the location of residential facilities may allow mentally handicapped people to be physically near their relatives they will not necessarily be brought into closer contact with the values and opportunities of the 'normal world'. Thus although small local hospital units such as those pioneered by Kushlick and his colleagues at Wessex and similar local authority residential homes can have substantial advantages over traditionally organised hospitals they can, if managed in a negative manner, have many of their faults. By the same token older hospitals opened to the surrounding community and run on democratic and stimulating lines can have many desirable features although it then becomes questionable whether such facilities should be called hospitals.

Thus the real issues cannot be fully understood in terms of hospital *or* community care. Instead more important questions relate to the undesirability of isolating mentally handicapped persons from the rest of the community and to whether or not mental handicap should be seen as a medical condition or a social state. People on opposing sides of the hospital versus community care dispute often hold similar views in these crucial areas. Many accept that the behavioural and social determinants of mental handicap are of central significance and most reject the principles upon which strictly segregated services were built up in the 1920s and 1930s. The common goal of everyone working in the field should be to establish an integrated pattern of support allowing individuals to attain maximum levels of independence through a natural process of transition from a more protected to a less protected environment as quickly as possible, given the social, economic and manpower restraints which exist.

Seen in this light conflicts between different interest groups become more understandable. For example, those based in traditional hospitals are faced with an ageing patient population and one which may increasingly include only very severely handicapped younger persons. They fear the transfer of all more able clients to community care which often in its present rudimentary state offers few advantages over the hospitals, especially as many social service staff lack specialist knowledge of the problems of mentally handicapped people.

At the same time planners in the NHS and social services face major difficulties. In London, for instance, with its ring of outlying massive institutions serving complex catchment areas and the economic and allied barriers to building new facilities in the heavily built up inner areas, transition to a new pattern of care is a difficult objective. Factors like uncertainties and rivalries over professional status complicate the situation further.[15]

Solutions for the dilemmas at present confronting individuals in the mental handicap services would therefore appear to lie in two main areas. The first is a shift in attitudes which would encourage a pragmatic approach to the community versus hospital care conflict. Although in the long term larger establishments (and perhaps even those in the 100 to 200 bed range) will outlive their usefulness to society the immediate priority would appear to be to avoid regarding the two as radical alternatives but use both to achieve the main objective of giving mentally handicapped people a satisfactory place in society. One route to this target is through greater emphasis on the need for collaboration between and ultimately the potential unity of the professions involved in mental handicap support, an area touched on in the Briggs report (HMSO 1972) on nursing and subsequently relevant to the work of the Jay Committee on mental handicap nursing and care.

Second, concurrent with a shift away from medical attitudes based on curative practice towards an emphasis on the social and educative needs of people with impaired mental abilities, more effective management needs to be introduced. Kushlick and his colleagues (1977) have pointed out how improved managerial techniques and procedures might help to strengthen awareness of the successes of the mental handicap services as well as their failures and to maintain a clear picture of their objectives, so preventing any drift towards the authoritarian control and unsatisfactory conditions found in traditional 'total institutions'. Like the NDG they also stress that along with better management practices continous patient review should be introduced to ensure that individual achievements are clearly observed and that people can move without restriction up through the system of support towards independence.

FUTURE PROSPECTS

History suggests that it would be imprudent to become too optimistic regarding the future for mentally handicapped people

---

[15] The NDG is currently studying mental handicap hospitals with a view to preparing a report for the Secretary of State, a version of which will be published later. The NDT is simultaneously conducting studies on individual mental handicap hospitals.

in our society. As Jones (1975) has commented in this context ideals are frequently not translated into reality and there are some areas where it is in any case very hard to predict the course of coming events. In the field of occupation, for example, it could be that the mechanisation of both physical and mental work will by the end of this century have so progressed that many individuals will have to move away from traditional job expectations. Like everyone else mentally handicapped people can benefit greatly from the disciplines and interest of the cooperative activity involved in the production of goods and services. Yet unless government agencies under the Manpower Services Commission, employers and trade unions form clearer and more positive policies in this area opportunities for mentally handicapped people in terms of paid employment may decline from even today's low level.[16]

Another area where new problems are likely to arise is in the care of elderly mentally handicapped persons, the population of whom will grow in future years. To assume that they need either community services designed to meet the requirements of older persons of normal mental ability or 'psychogeriatric' hospital places would be misleading but there is as yet limited experience in this context. And it is not absolutely certain that governments will be able to meet their commitments in the field of mental handicap, despite the apparent desire of the major parties to provide at least the services outlined in the 1971 White Paper. In 1976–77 some elements of spending fell below targets planned in earlier years in both the community and hospital sectors.

Nevertheless, there are reasons for believing that in some ways the situation of people with significantly impaired mental abilities will improve during the 1980s and 1990s. One is that the disadvantages of segregated care, in which abuses of power by professionals over the people in their charge could pass unobserved, have been today fully perceived. A second is that in fields like education (see box on following page) techniques for helping even the profoundly retarded have been developed. A third is that commentators have become more precise in the application of terms like 'integration', the vague use of which in the past may

---

[16] One problem is that many people do not understand that although mentally handicapped persons may lack abilities in some areas they may be very skilled in others. Thus employers underestimate their capacity to learn and workers feel insulted if it is suggested that a mentally handicapped person could do a job similar to their own. Another is that the Manpower Services Commission apparently has not clearly developed a policy regarding employment services for mentally handicapped people as distinct from the disabled in general. A working party recently considered the rehabilitation of 'the mentally disabled', but its report is of little relevance to mental handicap.

EDUCATION AND MENTAL HANDICAP

Since April 1971, when the Education Act 1970 came into force, the schooling of all children became the responsibility of the local authority education departments. Hitherto those with severe handicap had been excluded from the general system. This change typifies not only the move away from past policies of total segregation but also the trend towards accepting that many of the problems of mentally handicapped people are essentially social and educational and should not be approached in a primarily medical environment.

The number of mildly handicapped children in England and Wales currently receiving education in designated ESN(M) (ie educationally subnormal – mild) schools is around 80,000. There are about 33,000 in places for severely handicapped children (DES 1977). The last figure is about three times the equivalent at the start of the 1960s and is about 50 per cent above the number of places available when the former junior training centres were handed over to the education departments. This encouraging growth reflects increased awareness of the educability of even profoundly handicapped children, whose skills in fields ranging from bowel control to linguistic expression can now be aided by the systematic application of modern techniques of teaching based on behaviourist theory.

Yet these improvements have not been achieved without some accompanying criticisms and 'side effects'. For example, there has been concern that in some instances vulnerable parents may have formed or been presented with distorted ideas about the methods necessary to help severely handicapped children, who in fact will respond like all others to sufficient levels of any form of stimulating attention. Also, it has been argued that too many children are in special schools and that many could be integrated into the 'normal' system. The subject has been studied recently by the Warnock Committee, the work of which is of particular importance in the light of the recommendation contained in the 1976 Education Act that, wherever practical, handicapped children should be educated in an ordinary school.

In some instances separate schooling as opposed to, say, help in special units in ordinary schools does appear undesirable. But it would be wrong to exaggerate the disadvantages of either ESN(S) or ESN(M) schools. The frailty and allied problems of many more severely handicapped individuals and the difficulties encountered by a proportion of children on the border-line of 'normal' IQ measured ability (who frequently start their educational careers in schools without specialist facilities) counsel caution regarding the break up of the existing pattern of special provision.

In this context it should be noted that a special school place costs around three times the amount of one in an 'ordinary' school. People wishing either to cut total education expenditure or to increase the funding available to non-special schools may believe that moving children with mild handicap out 'into the community' could reduce such resource distribution skews. But this would not necessarily advantage the children concerned. Indeed, such observations might suggest that more provision should be made for the approximately 100,000 children of school age with IQs in the 70-plus region who at present do not receive special education.

Following on from this point a number of authorities have advocated education for mentally handicapped people beyond normal school leaving age. The NDG, for instance, has stressed the need for a smooth transition between a severely mentally handicapped person's school life and his or her going on to an ATC (or Social Education Centre) which may in turn lead to further advances. A break between these two stages can be traumatic (NDG 1977b). This may still occur in some localities as national ATC availability is still only half the 1991 target level. MIND (1977) has argued in favour of formal education for mentally handicapped people up to the age of 21 whilst there is growing interest in the concept that Colleges of Further Education would be a suitable setting for the provision of such courses (King's Fund Centre 1975).

have resulted in some helpless or frail people being left without any form of adequate support. Another is that the increasing wealth, education and diversity of the community generally may help further to reduce prejudice against groups like the mentally handicapped by breaking down rigid preconceptions of 'normality'. And a fifth is the fact that the NHS and local government reorganisations and the allied reforms of the mid 1970s are now beginning to bear fruit in terms of tangibly improved health and social service communication, cooperation and planning.

Although the significance of any one of these (and the many similar) factors relevant to mental handicap care could easily be over-rated together they provide a stronger basis for continued reform of the treatment of mentally handicapped people than has existed at any time in the past. Recent consultations over the rights of mentally handicapped people to vote – an Interdepartmental Working Party is considering the topic following a recommendation of the Speaker's Conference on Electoral Law – is one symbolically important example of how people with limited mental ability are gradually gaining democratic rights in the British community.

Against this background the remainder of this section examines two areas which are of particular relevance to future patterns of care. The first is the relationship between mentally handicapped people, their families and outside care agencies. The second is the economic restraints affecting care provision.

Mental handicap in the family

Most children in Britain grow up with their natural families until they reach their late teens when they embark on the first stages of adult life. This is usually seen as a more independent form of existence than that in childhood, although it could also be thought of as a transition from one form of dependence on the outside world to another. The individual gains increased responsibility for his or her actions, broadens some specific aspects of the early child/parent link to form a more general relationship with the community as a whole and normally builds up strong emotional ties with a marriage partner and, ultimately, a new immediate family.

There is no reason why most mentally handicapped people should not experience and benefit from a similar pattern of growth towards adult maturity. This is not to say that the 'nuclear family' is the only 'right' environment in which to rear children. But in Britain today it is the normal one to do so in and whilst well run collective homes may in theory offer an acceptable alternative in practice this may be difficult to achieve, not least because some staff and managing bodies may not believe success to be possible. Certainly childrens' lives in hospital tend to have many unsatisfactory aspects (Oswin 1977), and David Ennals (1978b) has stated that *Better Services for the Mentally Handicapped* overestimated the need for child mental handicap hospital places.

Conversly a proportion of mentally handicapped people continue living with their parents, often very happily, until well after the age at which most people leave their families. In the past this was often seen as desirable as mentally handicapped persons were regarded as in many ways perpetual children. Yet despite the need for flexibility such arrangements can have disadvantages.

Not only should the parents of handicapped children be able to look forward to a time when, like other fathers and mothers, they will be free of the responsibilities of child care. The effect of a person of low mental ability having to face the death of a much loved mother or father before they are psychologically prepared to do so is potentially highly destructive. This is particularly so as such an event is likely to precipitate the grieving and confused victim into residential care for the first time. One of the very few local authority surveys on the needs of mental handicapped people (Somerset County Council 1977) showed that, of mentally handicapped adults living in the community, 40 per cent are at hazard in this way because of parental ill health.

Current thinking on the care of children and adults who happen to have impaired mental abilities is thus focussing on two key areas. The first is the maintenance of most children in their homes or an as near home-like environment as possible. And the second is the provision of varied supporting services designed to act as an integrated system through which they might progress stage by stage to a satisfactory adult life. For a mildly handicapped person the latter might mean supplying just a little more help than is usually needed for someone to establish themselves in an ordinary job or house in the open community. For less able subjects targets might range from enabling them to live in a small group house with a few other people of similar attainments who together can cope with most daily problems to supplying much more positive recreational, occupation and environment support services.

Awareness of the desirability of helping mentally handicapped people to enjoy a normal family background followed by a normal shift towards adult independence has concentrated attention on the need to support families and help them with problems before they reach a crisis stage. At present this is often not achieved. It is obvious that parents may face unusual demands on their time and emotional stamina, and that domestic, social and work life may suffer as a result. The brothers and sisters of mentally handicapped children may thus be disturbed. Some parents and siblings may even be ashamed or embarrassed to bring friends home, a feeling which can only be dispelled by an accurate knowledge of the causes of mental impairment and the social phenomena which create handicap.

Experiments like the Honeylands project at Exeter (Brimblecombe 1974) have shown the value not only of providing short term residential care to relieve family stress (the high benefits and small cost of which has also been emphasised by the NDG – 1977c) but also of more intimately involving parents and families in the overall process of planning and delivering care. 'Parents' workshops' at the Hester Adrian Research Centre at Manchester have shown that many parents accept moves towards this end and welcome education in more specialised areas related to mental handicap. There is now a growing sense that parents and professionals should work together in achieving a satisfactory life for handicapped children (King's Fund Centre 1976). In the past some professional groups, perhaps because of insecurity over status, unjustifiably stressed parents' inabilities and even suggested that emotional factors might make parents unable to take a rational view of their children's difficulties. Resultant antagonisms occasionally hinder cooperation between state and voluntary agencies which is unfortunate in that the latter are an invaluable community resource as well as a source of innovation and example.

However, a few handicapped children cannot live with their families. In some instances parents have special difficulties which mean that even when their relationship is stable and intact it would be quite wrong for external professionals to try to force them to accept the 'right' solution of having a handicapped child at home, whatever resource restraints exist. Local authority residential provision for mentally handicapped children has shown little growth in the last ten years although with the introduction of joint funding arrangements a few more progressive local government bodies are beginning to remedy this situation. And some authorities have pioneered schemes involving foster parents who receive both special training and relatively high payments (about £50 per week – NDG 1977c). The Children's Act (1975) increased the long-term stability of non-familial caring groups, a valuable development.

A final topic to consider in the context of family life and mentally handicapped people is sexual behaviour and the question of marriage and child bearing. These are questions of importance not only because they involve tensions and uncertainties in the minds of many parents today but because they touch on the foundations of twentieth century attitudes towards mental handicap. The eugenic beliefs partly behind the 1913 Mental Deficiency Act are no longer widely held. It is understood that most severe mental handicap is not genetically transmitted and that in any case many people with conditions like Down's syndrome are infertile. But prejudices about the need to control mentally handicapped people still live in the minds of some people, a fact demonstrated in the sexual segregation sometimes still found in community as well as institutional provisions for their care.

Clearly severely mentally handicapped people are unlikely to make entirely adequate parents. The problems faced by the 'normal' child of such a parent or parents would be likely to be very distressing. But modern contraceptive technology and the natural infertility of many severely mentally impaired individuals mean that this is a relatively minor barrier to their enjoying a full emotional life which if they wish should involve normal sexual activity and, again where desired, marriage. In the field of mild mental handicap the possible existence of social deprivation passed from generation to generation may complicate the picture but it is not amongst this group that effective restrictions on sexual behaviour and the opportunity to form loving relationships are normally imposed.

If individuals who in some fields have the misfortune to have abnormally low mental abilities are to have as normal a biography and full a life as possible relationships involving physical and mental affection are likely to play an important role in the transition from childhood to adulthood. But a barrier to their formation exists not only in the occasional cases of active opposition from parents and professionals. There is also much more frequently a lack of active assistance.

Adolescents of normal mental ability can resist or overcome parental restrictions and seek new ways of self realisation. Indeed, a period of rejection of parental authority is usual during the difficult process of assuming an adult role. Amongst other things this may help to prepare individuals for the inevitable shock of losing their parents. But mentally handicapped people may lack the skills and confidence needed to achieve this separation. A powerful reason for involving parents closely with professionals in planning the education and future care of mentally handicapped children is that it is largely up to the mothers and fathers of such children to help their offspring towards independence in the sense of the day to day focus of their affection passing to people beyond the childhood family.

Care costs

Better Services for the Mentally Handicapped estimated that the capital expenditure necessary for the long term completion of the programme it described would be about £280 million at 1970 prices. In today's terms this is about £600 million. Over the twenty-year period of improvement a little under half of this money was allocated to NHS projects like upgrading existing hospitals and building new 100–200 bed units. Rather more, £154 million at 1970 prices, was believed to be needed for the construction of the 50,000 new Adult Training Centre and 25,000 adult and 3,000 child local authority residential places needed.

The White Paper projected that the running costs of hospitals for mentally handicapped people would stay roughly constant in real terms after the 1970s. This was because it was anticipated that the 50 per cent fall in hospital beds would be balanced by increased in-patient unit costs and extended out-patient services. By contrast, however, local authority constant price revenue costs would, on the government's figures, rise by more than three times in the period up to the early 1990s. However, the relatively low predicted cost of running community care facilities as compared to hospital revenue spending meant that the latter would still be about 30 per cent higher than the cost of local authority care at the end of the programme.[17]

During the early 1970s, spending on mental handicap services increased in line with the White Paper's calculations. But after 1974–75 the economic position of the country had so deteriorated that planners were forced to review policy in all fields of health and social care. It was against this 'crisis' background that the priority programme for the reorganised NHS was finally established in 1976. Its implications for England were described in *Priorities for Health and Personal Social Services for England* (HMSO 1976a).

As regards mental handicap the consultative document suggested that improvements in the quality of care available should still be regarded as a high priority. But it also stated that whilst the annual target for ATC places should be about 2,400 new places per year and for LA residential care 1,000 new places per year (the levels needed to attain White Paper goals by the early 1990s), hospital capital development should only proceed at about half the target levels.

Given that several commentators have argued that the need for investment in hospital care was overstressed in the 1971 publica-

---

[17] *The Way Forward* (HMSO 1977d) estimated an adult mental handicap hospital place to have a revenue cost of £3,340 in 1975–76 rising to £3,816 in 1979–80 (£ November 1975). By comparison a local authority adult residential care place equivalent cost was £1,240 in 1975–76 rising to £1,310 in 1979–80 and a similar day place required £720 in 1975–76 rising to £740 in 1979–80. However it should be stressed that in Sweden, where a pattern of a small hospital sector balanced by extensive community care is already in operation, significant additional funds are spent in areas like recreation. And extensions in community care could have hidden costs in areas like the use of primary care professionals' time.

tion, the emphasis in the 1976 priorities document seems to have some justification although it proposed no acceleration in community service development to match the cutback in hospital improvements. It also appears unfortunate that, as Figures 7a and 7b show, in the last year for which figures are available (1976–77) English local authority capital investment requiring loan sanction in new facilities for mentally handicapped people fell to the lowest level this decade. This presents a stark contrast to the hope of 2 per cent per annum real growth in capital spending throughout the later 1970s expressed in the White Paper.[18]

The significance of this fall should not be overstated. New local authority provisions in the period 1976–77 stood at almost 1,000 residential places and just 2,000 new training places (Moyle 1978). But even so the latter figure is some 15 per cent below target and it may also be that the full effects of unplanned local authority capital spending cuts in 1976–77 have yet to reveal themselves in terms of new facilities coming 'on stream'. It is perhaps significant that even the major DHSS backed project on mental handicap in Sheffield has been affected by short falls in non NHS residential provision which has made comparisons of different patterns of care difficult to conduct (Martindale 1978).

In future joint funding may encourage local authority compliance with national development plans although this is not as yet a certainty. For example, some authorities might still be reluctant to accept the full revenue consequences of new facilities for mentally handicapped people whilst in London more progressive boroughs could take up a disproportionate amount of the joint money available.

An indicator of the gross inter-authority variations which exist is that the NDG has noted that, in the mid 1970s, twenty-four authorities made no residential provision for mentally handicapped children whilst more successful ones had between three and four times the national average level of places available. Findings like these suggest that unless the joint funding scheme is in some way further strengthened or unless consumer bodies like Community Health Councils become more aware of local authority failings in NHS/LA service overlaps the targets of *Better Services for the Mentally Handicapped* may not be achieved in some parts of the country by the 1990s. In an area of care where there is such a widely acknowledged need even this date seems to some people unacceptably distant.

[18] Even in the 1976 priorities document projected total capital spending on local authority mental handicap residential and day care fell by 6 per cent as between the 1975–76 provisional figure and the 1979–80 estimate. Recent figures indicate that total mental handicap spending as a proportion of global HPSS costs did not increase between 1975–76 and 1976–77.

Figure 7a *English local authority PSS capital spending (requiring loan sanction) on mental handicap facilities 1971–72 to 1976–77 in £1970*

*In 1976–77 an additional £.111 million (1970) was spent on special care units.

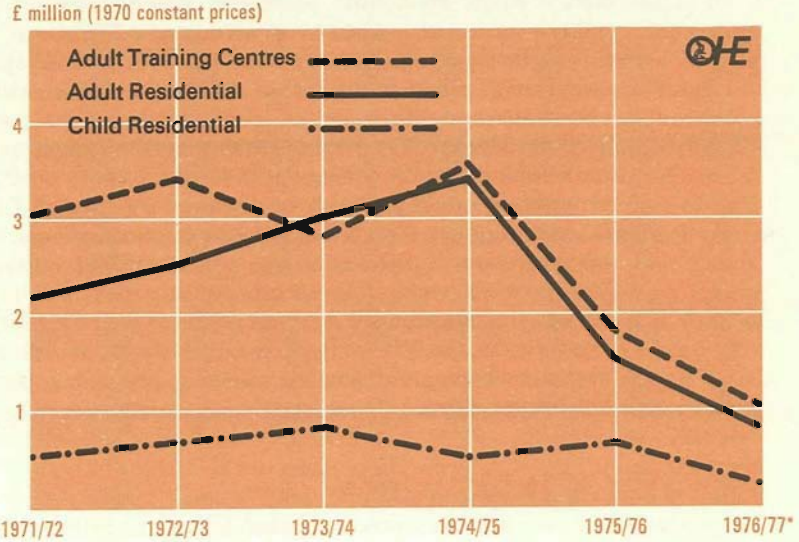
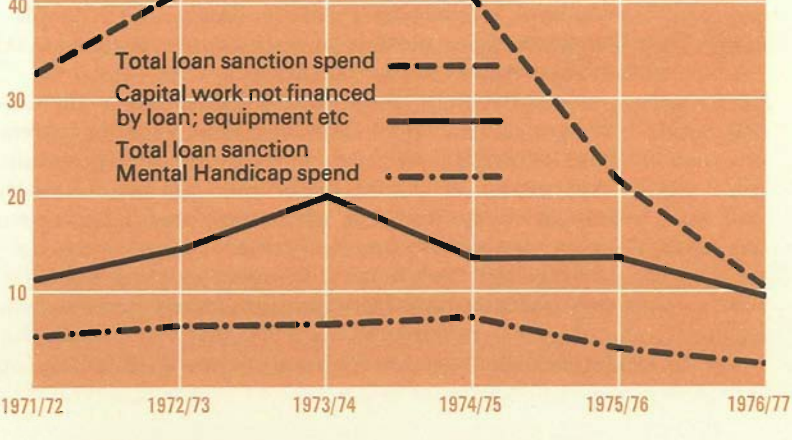


Figure 7b *Total English local authority PSS capital spending 1971–72 to 1976–77 in £1970*



These facts suggest that it may be useful for policy makers to consider ways in which the provision of local authority training and residential places could be further facilitated. One option which presents itself is that efforts could be made to reduce their capital costs – the figures in the 1976 priorities document show that a single residential place, for instance, would require in today's terms some £14,000 of investment. Wider use of existing houses (and perhaps NHS property) appropriately adapted should cost less (Teeling-Smith 1970) although people with physical handicaps and other special needs may require purpose-built accommodation. Yet even if existing cost estimates are accepted the remainder of the White Paper local authority capital building programme could probably be achieved for around £250 million in current prices. Given that revenue implications and manpower restraints are of significant but not overriding importance this sum does not seem to be so great that policy makers reviewing HPSS capital spending should not consider the possibility of bringing forward the White Paper's target dates for full community care achievement, much less allowing progress substantially to fall behind them.

CONCLUSION

Since the start of the twentieth century there have been in Britain radical developments in knowledge relating to the causes of impaired mental ability and consequent social handicap. Awareness has grown that the former may often be preventable and the latter alleviable by appropriate social support. As a result government policy has shifted away from its focus on segregated institutional care, which in the past was frequently characterised by abuses ranging from undue authoritarianism to the excessive use of sedative medicines. Instead there is more emphasis on helping mentally handicapped people to live as satisfactorily as possible in open contact with their families and other members of the community.

However, there are a number of barriers to the negotiation of this transition. These include economic restraints related to the long established working patterns and the legitimate fears and expectations of certain professional groups. The latter in part stem from the fact that when segregated institutional care was being established under medical control medicine itself was undergoing revolutionary changes stemming from the impact of new pharmaceutical products and allied curative techniques.

As 'cure' rather than 'care' became increasingly the dominant medical theme and as the nature of mental handicap became more clearly understood so it became apparent that social support, rather than health care, was the usual requirement of mentally handicapped people. The advent of modern local authority social service departments, coupled with the 1974 NHS reorganisation and measures like the establishment of NHS/LA joint funding for service developments, offered the structural possibility for a transition in the focus of mental handicap services. But groups such as mental handicap nurses, who have long worked in poor conditions and like social workers have often been the subject of misplaced criticisms, may naturally regard movements towards a social service oriented pattern of support with caution, especially in view of the 'teething problems' of post Seebohm social care. It will require restraint and careful judgement on the part of individuals within such groups if their ambitions and interests are to be fairly balanced against the long term interests of their clients.

It may also require careful and determined judgement on the part of politicians and policy makers to protect, in a time of resource shortage, development plans for mental handicap care against the economic demands of groups of people more able to express themselves. There have in recent years been disturbing, if possibly temporary, downturns in local authority initiated capital investment in community services, even though the 1976 priorities document (HMSO 1976a) projected a revenue spending growth in mental handicap services which was a third above the health and personal social service average and in line with the 1971 White Paper's projections. This indicates the DHSS policy has been genuinely to protect the mental handicap programme. But the question still remains as to whether the 1990s are not too distant a date to set for the achievement of more satisfactory facilities for the relatively small severely handicapped population and whether or not capital spending on provisions for this group should not be accelerated. The joint funding programme will be a critical factor affecting future progress in this aspect of care.

There are several other matters relative to mental handicap which may similarly raise significant concern. One is the position of people on the borderline of 'normality' and 'subnormality', that is those with IQs in the 65–75 region. There are well in excess of half a million such individuals of school age and above who live without any special assistance designed directly to compensate for their low mental ability. They probably comprise a disproportionate fraction of the population who suffer from problems like poor housing, low pay or long-term unemployment and unwittingly contribute through such difficulties to the ongoing problems of their children. The Court report represented a start towards more effective service planning and provision. Yet it has to be accepted that many of the fundamental aspects of where society draws the 'cut off' line between those considered so handicapped that they are entitled to special resources and those who are merely considered poor competitors within the normal spectrum remain unexamined. Employment is one field requiring closer analysis in this context.

Another important topic, which raises ethical as well as economic questions, is that of prevention. It is probable that the incidence rate of severe mental handicap could be reduced by approximately 50 per cent, given the development of a safe cytomegalovirus vaccine, more sophisticated techniques for the prenatal diagnosis of Down's syndrome and improved antenatal care. Although it would be wrong to minimise the practical difficulties inherent in the full attainment of such a long-term goal its importance in terms of the relief of human distress and the maximisation of human potential is such that its feasibility should carefully be examined. The current interest in this topic now being expressed by voluntary bodies and independent commentators in Britain thus appears justified, especially in the light of the French government's programme to reduce handicap.

A final issue to be considered with regard to mentally handicapped people in British society is that of public attitudes. One of the more unfortunate effects of segregated institutional care is that it encouraged 'ordinary' members of the population to think of 'the handicapped' as a race apart. Mentally handicapped individuals became strangers even within their own families. Thus it is not surprising that other people tended to underestimate their abilities and personal qualities.

This long term consequence of past policies inhibits development even today. For example, a decreasing number of persons still object to locally based provisions for mentally handicapped people because understandably their picture of the latter is bounded by the bizarre and frightening images often associated with traditional mental handicap hospitals. Some people in authority point to this as evidence that services must develop slowly. Yet such prejudice will fade as new patterns of care are established, bringing more mentally handicapped persons into open contact with the general public. It is to be hoped that as this happens the mass media will switch away from the valuable role of exposing the horrors of the past to the more challenging and difficult one of discussing mental handicap in the context of normal day to day life.

It is of course true that such a process may take many years to complete, especially if economic pressures raise further worries about employment and living standards. Even so, one of the more positive points to stress about modern plural societies like Britain is that there are already signs that traditional forms of intolerance against people disadvantaged by impaired mental ability are breaking down. This real progress cannot be reflected in conventional figures of economic activity, which are frequently taken as guides to a community's overall success in the world. But this may only mean that Britain's achievements in the 1970s need to be measured by more sensitive indicators than those which were developed at the time when this country pioneered world industrialisation.

REFERENCES

Abramowiz H K and Richardson S A (1975). *American Journal of Mental Deficiency*, 80, 18–39.

Bayley M (1973). Mental Handicap and Community Care. Routledge and Kegan Paul, London.

Bone M, Spain B and Martin F M (1972). Plans and Provisions for the Mentally Handicapped. George Allen and Unwin, London.

Birch H G, Richardson S A, Baird D, Horobin G and Illsley R (1970). Mental Subnormality in the Community. Williams and Wilkins, Baltimore.

Brimblecombe F (1974). *British Medical Journal*, 4, 706–09.

Campaign for the Mentally Handicapped (1976). Enquiry Paper No 4.

Campaign for the Mentally Handicapped (1977). Enquiry Paper No 5.

Crossman R (1977). The Diaries of a Cabinet Minister, vol 3. Hamish Hamilton and Jonathan Cape, London.

Davie R, Butler N R and Goldstein H (1972). From Birth to Seven. Longman and the NCB, London.

DES (1977). Annual Statistics of Education: Schools Vol 1. HMSO, London.

DES/DHSS (1978). LASSL (78)1, HN (78) 5.

DHSS (1976a). Priorities for Health and Social Services in England. HMSO, London.

DHSS (1976b). A Review of the Mental Health Act 1959. HMSO, London.

DHSS (1977a). On the State of the Public Health 1976. HMSO, London.

DHSS (1977b). Reducing the Risk. HMSO, London.

DHSS (1977c). Health and Personal Social Statistics for England. HMSO, London.

DHSS (1977d). Priorities in the Health and Social Services: The Way Forward. HMSO, London.

DHSS (1977e). *Joint Care Planning*, HC (77) 17.

Drillien C M (1958). *Archives of Disease in Childhood*, 33, 10–18.

Drillien C M (1967). *Hospital Medicine* 1, 937.

Ennals D (1978a). 1978 Eleanor Rathbone Memorial Lecture.

Ennals D (1978b). *Hansard*, 10/1/78, Col 694.

Ferster G and Jenkins D M (1976). *Lancet*, 2, p 727–29.

Forster D P (1977). *J men H defic res.*, 21, 263.

Fogelman K R (Ed) (1976). Britain's Sixteen Year Olds, NCB, London.

Fraser W (1976). *Social Work Today*, 7, 4, BASW.

Goodman N and Tizard J (1962). *British Medical Journal*, 1, 216–19.

Hagard S and Carter F A (1976). *British Medical Journal*, 1, 753.

Hagberg B, Hagberg G and Olow I (1975). *Acta Paediat Scand*, 64, 2, 187–92.

Heaton-Ward W A (1976). Mental Subnormality. Wright, Bristol.

HMSO (1957). Report of the Royal Commission on the Law relating to Mental Illness and Mental Deficiency. Cmnd 169.

HMSO (1971). Better Services for the Mentally Handicapped. Cmnd 4683.

HMSO (1972). Committee on Nursing Report (Briggs Report). Cmnd 5115.

HMSO (1976). Report of the Committee on Child Health Services (Court Report). Cmnd 6684.

Jones K (1972). A History of the Mental Health Services. Routledge and Kegan Paul, London.

Jones K (1975). Opening the Door. Routledge and Kegan Paul, London.

King's Fund Centre (1975). Mental Handicap paper 5. KFC, London.

King's Fund Centre (1976). Mental Handicap paper 9. KFC, London.

Kirman B H (1976a). The Mentally Handicapped Child. Association Scientific Publishers, Oxford.

Kirman B H (1976b). Mental Retardation – medical aspects. In Rutter M and Hersov L (Eds) Child Psychiatry – Modern Approaches. Blackwell, Oxford.

Kushlick A and Blunden R (1974). The Epidemiology of Mental Subnormality. In Clark A D B and Clarke A M (Eds) Mental Deficiency: The Changing Outlook. Methuen, London.

Kuslick A (1975). Some Ways of Setting, Monitoring and Attaining Objectives for Disabled People. Health Care Evaluation Research Team, Wessex RHA.

Kushlick A, Palmer J, Felce D and Smith J (1977). Research report 126. Health Care Evaluation Research Team, Wessex RHA.

Lancet (1977). i 986–87.

Leck I, Gordon W L and McKeowan T (1967). *Brit J of Prev and Soc Med*, 21.

Lewis E O (1929). Report of an Investigation into the Incidence of Mental Deficiency in Six Area, 1925–27. In the Report of the Mental Deficiency Committee, Part IV, HMSO.

Loesch D (1974). *J mentl defic res*, 18, 209.

Martindale A (1976a). Sheffield Case Register, Report 2.

Martindale A (1976b). Sheffield Case Register, Report 3.

Martindale A (1978). Personal Communication.

MIND (1977). Evidence to the Royal Commission on the National Health Service with regard to Services for the Mentally Handicapped People.

Morris P (1969). Put Away. Routledge and Kegan Paul, London.

Moyle R (1978). *Hansard*, 26/1/76, 716.

National Development Group for the Mentally Handicapped (1976). 1. Planning together.

National Development Group for the Mentally Handicapped (1977a). 2. Mentally Handicapped Children: A Plan for Action.

National Development Group for the Mentally Handicapped (1977b). 3. Helping Mentally Handicapped School Leavers.

National Development Group for the Mentally Handicapped (1977c).

4. Residential Short Term Care for Mentally Handicapped People: Suggestions for Action.

National Development Group for the Mentally Handicapped (1977d). 5. Day Services for Mentally Handicapped Adults.

Oswin M (1977). *Child: care, health and development* 3, 349–55.

Rothman D (1978). Personal communication.

Royal College of Psychiatrists (1976). Evidence to the Committee of Enquiry into Nursing and Care for the Mentally Handicapped.

Rutter M, Tizard J and Whitmore K (1970). Education, Health and Behaviour. Longmans, London.

Somerset County Council (1977). Report (stage 1) on the adult mentally handicapped living at home. County Hall, Taunton.

Stein Z, Susser M W and Guterman A (1973). *Lancet* 10/2/73.

Stern H (1977). Personal Communication.

Stewart A, Turcan D, Rawlings G and Gregory S (1977). Outcome of infants at high risk of major handicap. CIBA symposium on the cost of mental handicap. In press.

Susser M W and Kushlick A (Eds) (1961). Report on the Mental Health Services of the City of Salford for the year 1960. Salford Health Department, Salford.

Teeling-Smith G (1970). A Look to the Future (Address to the annual conference of the National Association of Mental Health).

Webster R C (1977). *Royal Society of Health Journal*, 2, 64–66.

Whelan E (1975). In King's Fund Centre Mental Handicap paper 8. KFC, London.

Whelan E and Speake B (1977). Adult training centres in England and Wales: Report of the first national survey. Hester Adrian Research Centre, University of Manchester, NAMH.

Wynn M and Wynn A (1975). Nutrition Counselling in the Prevention of Low Birth-Weight. Foundation for Education and Research in Child-Bearing, London

Wynn M and Wynn A (1976). Prevention of Handicap of Perinatal Origin. Foundation for Education and Research in Child-Bearing, London

Wynn M and Wynn A (1977). The Prevention of Pre-term Birth. Foundation for Education and Research in Child-Bearing, London.

Wynn M and Wynn A (1978). Personal communication.