

MENTAL HANDICAP

PARTNERSHIP IN THE COMMUNITY?



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Mental Health
Foundation**



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Since the start of the 1970s the pattern of care available to more severely 'mentally handicapped' people in Britain has undergone major changes. The passing of the 1971 Education Act and the publication of *Better Services for the Mentally Handicapped* (HMSO 1971) opened the way to a process of transition away from large institution based, medically orientated services towards a more disseminated, flexible and locally available system of educational and social provision.

One significant indicator of change is the 30 per cent fall in the total NHS mental handicap hospital/unit in-patient population in England which has taken place since 1970. This is illustrated in Figure 1. In the case of children aged under 16, the number in NHS mental handicap hospitals and units fell by some 80 per cent in the same period, to little more than 1,000 in England. Meanwhile short term mental handicap hospital admissions have more than tripled (from under 10,000 to around 30,000 per annum) whilst local authority provisions in residential units and adult training centres have approximately doubled. By 1984 the number of places available in such units and centres stood at 14,000 and 47,000 respectively (England).

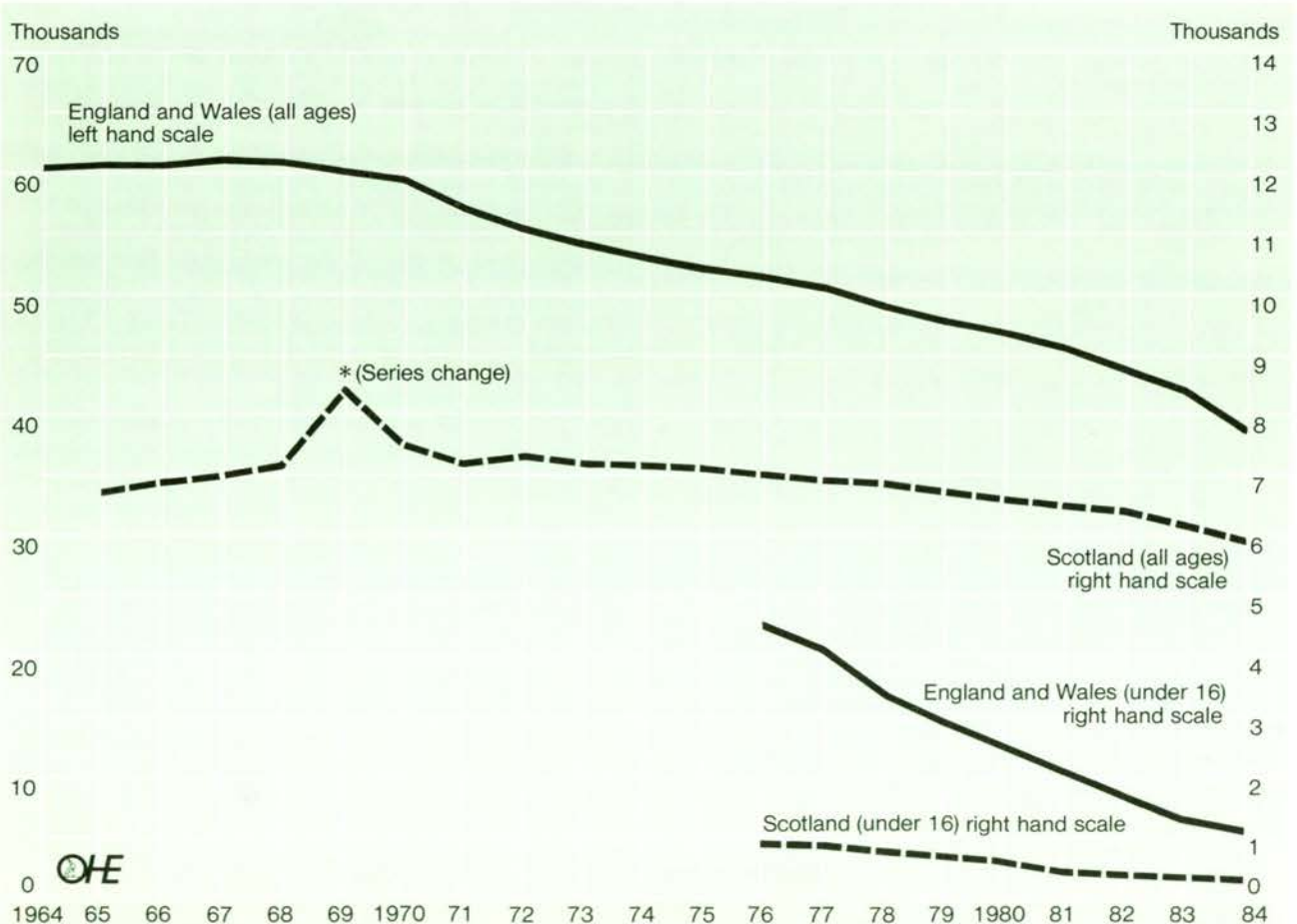
Against the background of the relative isolation and neglect of mentally handicapped people which existed in the United Kingdom before the 1970s such evidence of progress is clearly welcome. However, there is still significant

cause for concern about care for mentally handicapped persons in this country. For example, the National Development Team for Mentally Handicapped People recently suggested that a further 50 per cent of mental handicap hospital residents could be discharged to more suitable home or hostel accommodation either immediately or after a short period for training, if only sufficient resources were available (DHSS 1986).

A central objective of this paper, therefore, is to review the development and coordination of NHS and local authority residential, social and educational support for mentally handicapped individuals. It updates and extends earlier OHE publications on this topic (OHE 1973, 1978). The study relates mainly to the situation in England, although some reference is also made to the levels of provision in other parts of Britain. In addition, questions about the occurrence, causes and opportunities open for the prevention of intellectual impairment are discussed in the opening sections of the paper. The intention is to provide a general overview of the field.

However, before turning to a consideration of these areas three final introductory points are important. The first relates to the definition of, and terminology used to describe, 'mental handicap'. Although today there is probably less confusion than in the past between mental illness and states related to intellectual impairment, the situation described in Box 1 is not satisfactory. In line with common

Figure 1 Residents in NHS mental handicap hospitals and units



Source: DHSS, WO, SHHD

usage, this study employs the term 'mental handicap' generally to describe the condition experienced by people with unusually limited intellectual and linked social skills. But readers should be aware of the advantages of the more precise schema outlined in Box 1.

Second, the UK's intellectually less able population includes not only the 160,000 plus more severely impaired people from whom those needing special residential care either in NHS, local authority (LA) or other facilities are predominantly drawn; it also numbers up to a million individuals who, although generally capable of normally independent life, may benefit from special help in some areas. The information available about and attention paid to 'the mildly mentally handicapped'¹ is in many respects very limited as compared to that concerning the more severely affected population. As increasing efforts are made to provide satisfactory services for those most in need, the social, educational and occupational problems of people with less immediately obvious, but nevertheless potentially serious, disabilities should be more clearly addressed.

Finally some professional workers involved in the area of mental handicap may in the past have paid too little attention to the critically important role that parents, other relatives and members of the public in general have to play in enriching the lives of intellectually impaired children and adults. To a significant degree effective help for 'mentally handicapped' people must involve support for their families. And if 'community care' is to be an efficient, successful reality then it must bring together professional skills and voluntarily and informally contributed resources and energies. The latter should complement and enhance, but in no sense replace or supersede, the activities of publicly funded care providers.

BOX 1

The definition and terminology of 'mental handicap'

'Mental handicap' is in some respects a confusing and unsatisfactory term used to describe the condition experienced by people with life-long intellectual impairments and consequent every-day disabilities in areas like speech or reading. A more precise schema, using the WHO distinction between physical impairments, functional disabilities and social handicaps could be applied as follows:

Intellectual impairment	Disability	Social handicap
Example: brain damage resulting from pre-natal or post-natal trauma or infection.	The lack of ability to perform normal activities such as reading or the computation necessary to handle money.	Disadvantage arising from disability (or disfiguring impairment) such that the subject cannot have a satisfactory life. Contexts of handicap include occupation, marriage and leisure.

Because 'mental handicap' is so widely used as a general term it is so employed in this paper. But readers should be aware of the following cautions:

1. To some people the use of the word 'mental' is seen as perjorative, and threatens to confuse needlessly the behavioural and social sequelae of intellectual impairment with the problems of psychiatric illness.
2. Many individuals suffer intellectual impairments acquired later in life as a result of accidents, strokes and conditions like senile dementia. They are not, however, considered to be 'mentally handicapped' in the sense used in this paper.
3. In the past terms such as 'idiot' and 'imbecile' were used to describe more severely intellectually disabled people, whilst words like 'moron' and 'defective' were reserved for those with lesser difficulties. This terminology is now redundant. Broadly, people with IQs under 50 are now referred to as severely 'mentally handicapped' or as having severe learning difficulties, whilst those with intelligence test scores in the 50-70 range are termed mildly 'mentally handicapped', or as having moderate learning difficulties. The rigid application of IQ scores to any of these labels is, however, to be avoided. (See main text).

¹ Traditionally severe mental handicap is said to exist when an individual's IQ score is below 50. Mild mental handicap exists in the 50-70 range. This division may still be generally useful, but readers should be aware of its arbitrary nature. It has been suggested that, roughly speaking, a child aged 10 with an IQ of 50 will have the ability of an average 5 year old. This may be expressed

$$IQ = \frac{\text{Mental Age}}{\text{Chronological Age}} \times 100.$$

However, this relationship should not be thought to have any rigid application and could prove misleading given the plurality of mental skills. IQ tests are normally designed so that an average person scores 100 and one standard deviation from the mean is equivalent to 15 points.

The results of a number of surveys of the occurrence of impaired mental ability in the United Kingdom are presented in Tables 1a and 1b. From these and other data (HMSO 1971, Welsh Office 1982, DHSS 1980) it may confidently be estimated that the overall prevalence of severe 'mental handicap' is slightly in excess of 3 per 1,000 population. This figure, which is about half to one third of the birth incidence of severe mental impairment (Kirman 1976, Stein and Susser 1984), implies a UK total of over 160,000 affected individuals. Of these some 60,000 are under 16. People with IQs of around 50 or below are found on an evenly distributed basis across the social classes.

In the school age population of individuals with severe learning difficulties around 30 per cent have Down's syndrome². This condition is often taken to typify 'severe mental handicap', although in reality such a view is questionable for two sets of reasons. First, the abilities and skills of many people with Down's syndrome, particularly those who have had the advantage of modern educational sup-

port, are at the higher end of the severe intellectual impairment spectrum. Indeed, a significant proportion – probably between 1 in 5 and 1 in 10 – have IQs of over 50.

Second, a half or more of all severely 'mentally handicapped' people do not suffer from genetically or chromosomally related conditions like those described in Box 2. Rather, damage to their nervous systems is usually the result of factors affecting intrauterine development or the process of birth. In such cases forms of physical or sensory disability often accompany impaired intellectual functioning.

2 The survival from birth to age 5 of children with Down's syndrome has risen from 10 per cent to around 80 per cent between the 1920s and the present day. However, their life expectancy past middle age is still limited. Factors such as this probably serve significantly to alter the age structure of the severely mentally handicapped population as against that of the community as a whole.

Table 1a The prevalence of mental handicap amongst children as reported by various studies
a) Overall rates (per 1,000 population)

<i>Study</i>	<i>Age Group</i>	<i>Prevalence/1,000</i>
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 <i>et al</i> 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.

Table 1b
b) Rates of severe mental handicap per 1,000 population

<i>Study</i>	<i>Age Group</i>	<i>Prevalence/1,000</i>
England and Wales (urban) 1925–27 (Lewis 1929)	7–14	3.71
Middlesex 1960 (Goodman and Tizard 1962)	7–14	3.45
	10–14	3.61
Aberdeen 1962 (Birch <i>et al</i>)	8–10	3.7
Wessex 1963 – urban (Kushlick 1963)	15–19	3.54
– rural	15–19	3.84
Isle of Wight 1964	5–14	3.1
Edinburgh 1965–69 (NCDS 1972)	7–14	5.0
Britain 1965–69 (NCDS 1972)	7	2.4
	11	3.7
Camberwell 1972 – urban (Wing and Fryers 1975)	5– 9	4.39
	10–14	4.17
Salford 1975 – urban/rural (Wing and Fryers 1975)	5– 9	5.73
	10–14	5.81
Sheffield 1975 – urban/rural (Martindale 1975)	5– 9	2.95
	10–14	4.65

Notes 1. The prevalence in the 10–14 and 15–19 is regarded as the most accurate since most individuals will have been identified by these ages.
2. Prevalence of Down's syndrome increases from 9 per cent of all severe mental handicap in the Lewis study to about a third in most of the later studies.

BOX 2

Genetic factors in mental handicap

Human cells contain 46 chromosomes, on each of which there are around a thousand genes. The chromosomes are arranged in 22 structurally identical pairs, together with a twenty third pair known as the sex chromosomes. In females the latter are also identical, in that there are two X (female) chromosomes. In males there is a single X chromosome paired with a shorter Y chromosome. Conditions associated with intellectual impairment may result from the inheritance (or mutation) of particular genes, or structural or numerical abnormalities of the chromosomes.

Single gene disorders

Most of these result from the inheritance of a pair of recessive genes, that is one from each parent. (Dominant gene conditions like epiloia are very rare). Examples include microencephalus and hypothyroidism (autosomal – that is situated on the non-sex chromosomes) and hydrocephalus (X-linked). The latter may also result from non-genetic causes, as when it occurs in cases of spina bifida.

Abnormal genes often cause enzyme deficiencies, and consequently metabolic disorders. Relevant instances here include Tay-Sachs disease, phenylketonuria (PKU) and galactosaemia. Brain damage resulting from the latter two can be prevented by special diets, provided that early screening identifies those with the disease and that, in the case of PKU, females with the relevant gene pair resume their protective diets before pregnancy. (See also Box 4).

Conditions of this type are individually rare, but collectively they account for 10–15 per cent of all severe 'mental handicap'. It should be noted that with X-linked states there is a one in two chance of the male offspring of non-symptomatic female carriers being affected.

Chromosomal disorders

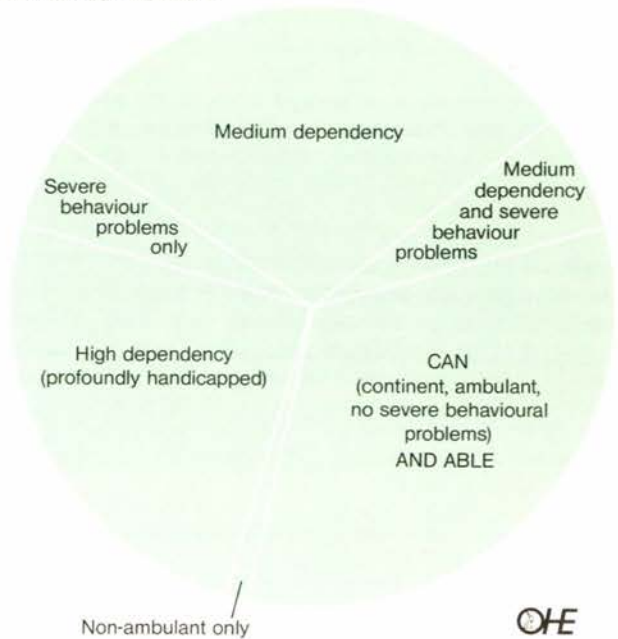
The most widely known chromosomal disorder is Down's syndrome. In over 90 per cent of cases this is caused by the presence of an additional chromosome 21 (trisomy 21). This is a chance event, and the likelihood of recurrence in the same family is thus small. Some 5 per cent of cases are, however, due to an inheritable translocation of an extra chromosome 21 on to another chromosome. This last occurs independently of maternal age.

Other less common autosomal trisomies, include trisomy 18 (Edward's syndrome) and trisomy 13 (Patau syndrome). Conditions arising from additional sex chromosomes usually produce only mild mental impairment, if any. A further disorder, known as Fragile X syndrome, has recently attracted attention. It may be a significant cause of both mild and severe impairment, particularly in males. (See Box 5).

For instance, up to a third of severely 'mentally handicapped' children and adults may suffer, or be at risk from, epileptic seizures, and in the order of one fifth also display some degree of spasticity. Impaired vision and or hearing affects similar numbers. (HMSO 1971, Bone *et al* 1972, Alberman 1978, HMSO 1979). The existence of such diversity within the severely mentally impaired population generates difficult care planning and delivery problems. Multiple disabilities also create unique difficulties which are often much more serious than might be anticipated from an analysis of the various single impairments.

Awareness of such complicating factors has led to greater efforts to identify the varying needs of different sub-groups of severely 'mentally handicapped' individuals. Perhaps even more importantly, emphasis has been placed on the

Figure 2 Degree of dependency of severely mentally handicapped people



Note Data collected on the populations of Bryn-y-Neuadd and Ely hospitals and clients outside hospital in the NIMROD catchment area. (There is very little difference between the characteristics of 'home' and hospital populations). Degree of dependency ratings derived from SSL (Speech, self help and literacy) and SPI (Social and Physical Incapacity) codings.

Source Welsh Office 1982.

need to keep detailed, person-by-person, records of progress. It may strongly be argued that the establishment of case registers and linked development records is an essential prerequisite of any really efficient and flexible system of care and support, regardless of the availability or otherwise of more generalised data on the abilities of the mentally impaired population such as those shown in Figure 2.

Although initiatives such as the present Office of Population Censuses and Surveys investigations into the situation of all categories of mentally and physically disabled children and adults in hospital and community settings are to be welcomed (results are expected by the late 1980s) they do not obviate the need for comprehensive, local, regularly updated, information systems. Without the latter it is unlikely that adequate monitoring of care standards or changes in the incidence of mental impairment will be achieved (see Box 3).

It is thus disturbing to note that despite pioneering work on 'mental handicap' case registers conducted in areas like Sheffield and Wessex, some parts of the country still lack such systems. And even where they have been established, they may quickly become inaccurate unless continuous effort is put into maintaining them (Mansell and Felce 1984). It is a challenging task for responsible managers in the health and social services to ensure that impetus and enthusiasm can be maintained in this sphere over the long term. One possible option is the creation of an integrated NHS/LA welfare services record linkage scheme, which because of its universality would not have the stigmatising

BOX 3**Trends in incidence and prevalence**

Towards the end of the nineteenth century a debate began as to whether 'mental handicap' was increasing in prevalence. Concern increased in the 1920s when research conducted for the Mental Deficiency Committee (Lewis 1929) indicated that the 'mental handicap' rate had doubled since the report of a Royal Commission some twenty years previously.

Subsequent research has tended to discount this finding, and the data available suggests that in children at least the overall UK prevalence rate of severe intellectual impairment has stayed relatively constant during this century. If so, this observation in itself must mean that since the 1960s the incidence of some forms must have markedly declined, given the rise in life expectancy of babies with Down's syndrome. (See Fryers 1984).

Recent advances in prevention, together with the fall in the underlying rate of neural tube defects, are likely further to have shifted the aetiological balance of 'mental handicap'. But comprehensive data are not available. To an extent the establishment of more generic local services in contexts such as social support, and the greater emphasis now given to each individual's personal needs, may have reduced the value of overall statistics. Nevertheless, national level planning would probably be significantly improved by the provision of more comprehensive information about the detailed composition and age structure of the 'mentally handicapped' population.

Government certainly appears to have recognised the desirability of adequate planning data in the potentially costly area of social security outlays. The fundamental reason for the current OPCS surveys on disability mentioned in the main text is to assess potential demand for such benefits.

50–60 range. By contrast, in the 'upper' (1 and 2) socio-economic groups the equivalent ratio was about 8:1³ In some parts of the country this variation between class specific mild mental impairment rates may at times have been further complicated or confused by issues related to cultural factors.

A probable explanation for such observations is that the greater the nervous system damage or abnormality suffered by an individual the more likely is that his or her intellectual performance will be markedly impaired, whatever the environment in which they are socialised. But in cases where a person has suffered only minor lesions, which may not be clinically detectable, the quality of their educational and social experience may influence considerably their achievement – or non-achievement – of 'normal' intellectual skills. Swedish researchers have referred to a cultural/familial syndrome affecting children reared in environments which are deficient in intellectual stimulus, and who may also show limitations or damage to their mental abilities.

Such possibilities have significant implications for the future prevention of intellectual impairment and its functional and social sequelae. The rate and consequences of severe 'mental handicap' may be influenced by the introduction of relatively specific preventive measures and the provision of more appropriate and specialised care facilities. Yet the alleviation of problems related to 'mild mental handicap' will require broad social and economic progress. Against this background awareness, the following section of this paper discusses the options available for the improved prevention of mental impairment.

potential of special registers. But the confidentiality and related barriers to such an initiative would be considerable.

Mild 'mental handicap'

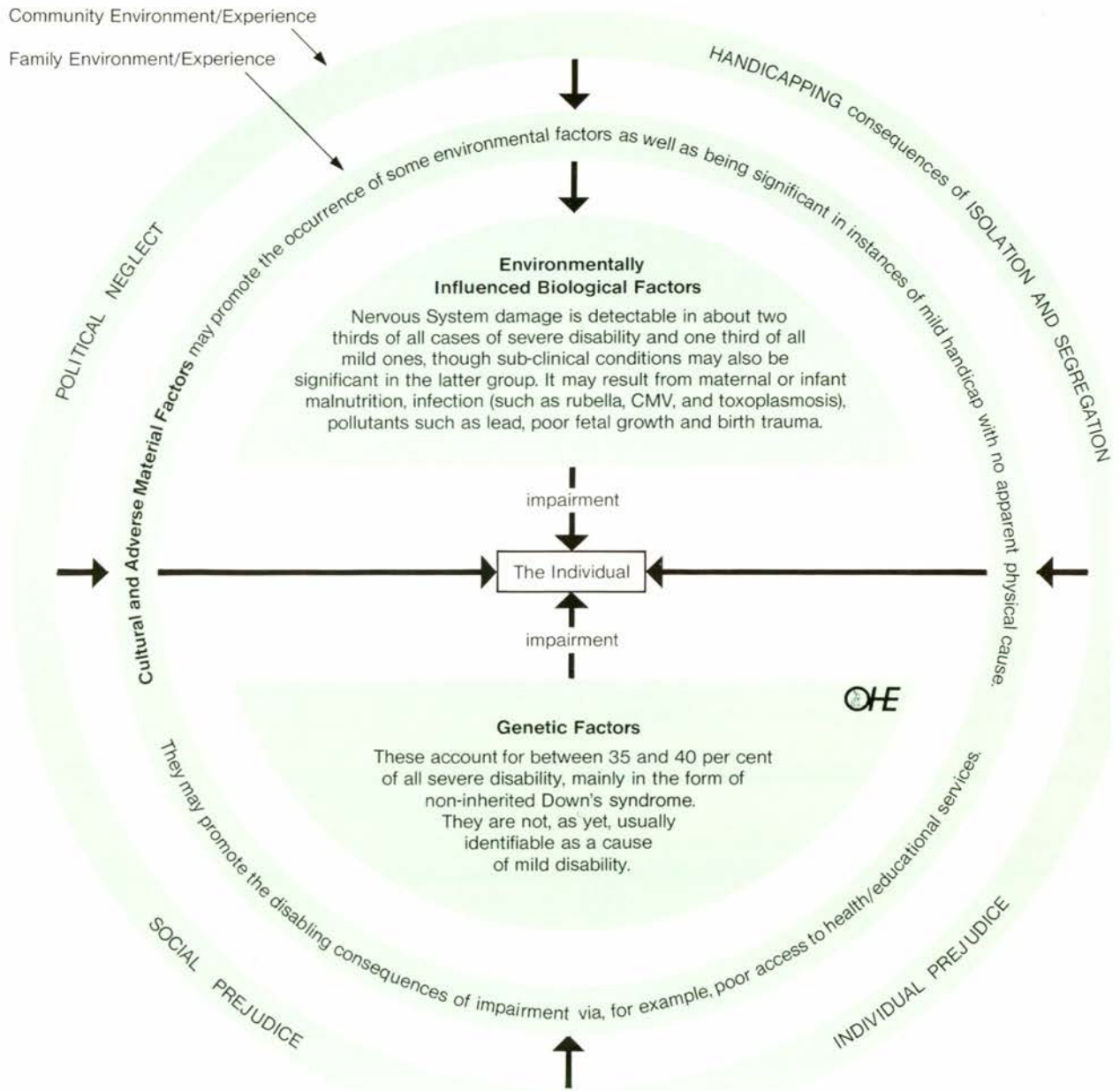
As indicated in Figure 3 the contribution of socially related factors to mild mental impairment is, in contrast to the apparent situation with severe disability, highly significant (HMSO 1976). It is estimated that in excess of 2 per cent of the total UK population, that is over a million people, have IQs in the 50–70 range. Of these, rather less than half will ever have been specifically identified by educational or other authorities as suffering impaired intellectual ability. Too free a use of the label 'mild mental handicap' could be positively harmful. But all intellectually less able people are likely to be vulnerable in relation to matters like, say, housing or employment difficulties, and could well need special help as they face the problems of old age.

Research amongst children, such as that of Birch *et al* (1970) in Aberdeen, indicates that nearly all of those whose intellectual abilities are at the upper end of the 'mildly handicapped' spectrum are from 'lower', socio-economic group 4 and 5, class backgrounds. The social distribution of those with greater impairments (that is, IQ 50–60) is rather less skewed.

However, even in the latter context the Scottish study referred to above found that for every severely 'mentally handicapped' child in the social class 4 and 5 population, there was another with mental abilities measured in the IQ

3 It has been suggested that the prevalence of mild mental handicap in Sweden is significantly below, and perhaps less than one fifth, the level recorded in the UK. This might not be unexpected, although there may be some confusion amongst commentators as to the distinctions between (and varying thresholds of) administrative versus true prevalence (Hagberg 1978, Stein and Susser 1984).

Figure 3 The causes of mental impairment, disability and handicap.



Since the start of the twentieth century, infant mortality in the United Kingdom has fallen from around 120 per 1,000 live births to about 10 per 1,000. Perinatal mortality has also declined dramatically, showing a particularly rapid improvement in the last decade or so. Such progress is very much to be welcomed, although some localities and social groups still experience relatively high death rates amongst the newly born.

The country's record with regard to the incidence of impairment amongst surviving infants is more difficult to monitor. As argued earlier, adequate data do not exist even to permit really close analysis of the achievements of the NHS in this context, much less to enable the formation of a detailed century long perspective. As mortality at around the time of birth approaches the minimum level possible it is logical to propose that more effort should be devoted to the collection of fully comprehensive information about impairment rates and the options available for their reduction.

Yet consciousness of the challenges still to be faced should not undermine awareness of advances already achieved. Post-natal screening and treatment for sufferers of phenylketonuria (PKU) and, more recently, congenital hypothyroidism; the use of anti-D-immunoglobulin to avoid haemolytic disease of the new born; preconceptional maternal immunisation against rubella; antenatal screening for neural tube defects; and improvements in obstetric practices and in the use of oxygen for vulnerable neonates. All are examples of valuable developments with the poten-

tial significantly to reduce the incidence of 'mental handicap' as well as some other forms of disability.

Box 4 illustrates the wide range of available services and interventions relevant to the prevention⁴ of mental impairment. Almost every area listed is complex, and to an extent controversial. In the case of rubella immunisation, this is exemplified by the fact that some authorities believe that Britain's selective strategy of immunising only girls in their teens is inadequate (Brook 1983, Miller 1985). In Sweden, a universal 'two dose' programme for children aged 18 months and 12 years is being introduced, which combines protection from rubella with immunisation against measles and mumps (Rabo and Taranger 1984).

This country's established practices in relation to the pre-partum employment of anti-D-immunoglobulin might also be regarded as unduly conservative (Akehurst 1986). And the impact of cytomegalovirus (CMV) infection and the possibilities open for immunisation against it provide a third locus of debate.

Recent studies put the number of CMV impaired children born in the United Kingdom at about 200 per annum (Peckham 1983) which is a rather lower figure than previously estimated. (See OHE 1978). Nevertheless, it would be highly desirable if an effective, safe vaccine could be deve-

4 Prevention here is defined as the reduction of the incidence of relevant forms of brain defect or abnormality at birth, and the early post-natal prevention of potentially damaging infections, trauma or deprivation.

BOX 4

The stages of prevention and relevant services

Pre-conceptual

Immunisation against rubella. At present about 85 per cent of schoolgirls aged 12-13 are so protected, but there is substantial variation between districts.

Genetic counselling. Limited services available. Couples are only likely to seek such support in cases where there is a known family history, or after the birth of a impaired child.

General services to improve the health of potential mothers. Advice on diet, smoking and alcohol consumption is relevant to the avoidance of low birth weight. Special medical guidance should be given to women with conditions such as diabetes.

Contraception and family planning. Such services, along with education in schools about parenthood, can help to ensure that pregnancies are desired and that people are equipped to face the challenges of having and caring for their children.

Prenatal

Genetic counselling and the identification of 'at risk' pregnancies. Factors like AFP levels and maternal age are relevant in this context. (See text). Immunity to and exposure to rubella infection may be checked at this stage. Blood tests may be conducted to identify potential cases of rhesus incompatibility.

Prenatal fetal screening. Fetal cells may be examined for genetic/chromosomal abnormalities - see main text. Diagnostic ultrasound may be used to detect intrauterine growth retardation, microencephalus, hydrocephalus and neural tube defects. Other risk factors such as multiple births and placental abnormalities may also be identified. The preventive value of prenatal screening largely depends, however, on the availability and uptake of terminations.

Early, attractive antenatal care services may enable appropriate help to be given to mothers most at risk of having low birth weight babies. Out reach services, taking

such care from the hospitals to GP clinics and patients' own homes, may be needed to support those whose domestic circumstances mean they cannot afford the time/monetary costs of out-patient attendance.

Perinatal/Neonatal

Obstetric and neonatal care of high standards may reduce mortality rates, especially amongst low birth weight babies, and the proportion, if not absolute number, of impaired survivors. The conditions to be avoided in neonates include anaemia, hypoglycaemia and trauma leading to intracranial haemorrhaging.

Neonatal screening and treatment for specific conditions like hypothyroidism and PKU. (See text).

Surgical interventions may protect the new-born from some forms of impairment. For instance, in cases of hydrocephalus shunts may be fitted to drain off excess cerebrospinal fluid which could cause brain damage.

Mothers at risk of future rhesus incompatibility problems may be injected with anti-D immunoglobulin to prevent anti-body formation. Non-immune women may be given rubella vaccination after birth to protect future children.

Postnatal

The damaging effects of encephalitis and meningitis in the young can be prevented by appropriate treatment and immunisation, as with protection against measles.

Impaired babies and children can, if identified and treated, be protected from further damage. Examples include the control of infections in those with Down's syndrome, effective medicinal therapy for those with epilepsy, and physiotherapy for the non-ambulant.

General support for families can enhance infant and child health and minimise developmental delays. Services delivered in this context might reduce the incidence of brain damage resulting from abuse and other trauma associated with poor environments. The latter include traffic and home accidents.

loped particularly to protect women against primary CMV infection during pregnancy.

However, it would be beyond the scope and objectives of this paper to attempt to discuss such issues in depth. Rather, the analysis provided in the sections below is confined to two key areas of interest, the use of antenatal screening techniques to detect fetal abnormalities and the options available for reducing the numbers of babies affected by problems associated with low birth weight. This is followed by a brief examination of certain questions relating to Britain's social, economic and political values and policies in this field.

Antenatal screening

Down's syndrome is the most common single condition associated with severe intellectual disability. As noted previously about 30 per cent of severely 'mentally handicapped' children are so diagnosed. Because of increasing survival rates – due partly to the availability of modern medicines and vaccines – its relative significance has increased over the last half century. Thanks to more appropriate education and a fuller recognition of their potential, so too has the average level of ability of people with Down's syndrome.

In the great majority of cases, the condition is not related to inheritable factors. Rather, it is caused by the random occurrence of a chromosome abnormality, the risk of which is related to maternal age. A pregnant woman of 20 has a 1 in 2,000 chance of having a baby with Down's syndrome, whilst a woman of 40 has a 1 in 100 probability of so doing.

To date, the early detection of Down's syndrome cannot lead to any form of curative treatment. If a fetus is found to be affected the choice confronting parents is whether or not to abort and probably to begin a fresh pregnancy, or to face

the life-time responsibilities of care and support which having a 'mentally-handicapped' family member carries.

Screening for Down's syndrome was first made possible by the technique known as amniocentesis. This involves drawing off amniotic fluid from the uterine cavity and culturing the cells it contains, which can then be tested for genetic abnormalities of various types (Box 5). The drawbacks to this process include the possibility that it may accidentally cause the abortion of a normal fetus (the risk of which is around 1 in 100–200) and the fact that it can only be conducted relatively late in pregnancy. A positive diagnosis cannot be provided before 18–20 weeks, by which time some people may find the thought of a termination particularly distressing.

Relatively recently, an alternative technique known as chorionic villus sampling (CVS) has been developed. This permits the extraction of placental cells, which will not for detecting Down's syndrome have to be cultured before testing. It has the potential to allow a diagnosis to be made at about the eighth week of gestation, which is before most pregnant women are first referred to hospital for antenatal care. But for the moment, the safety and efficiency of CVS have still to be evaluated (Modell 1985, Henderson and Mugford 1985).

Against this background, screening for Down's syndrome in the United Kingdom has been confined to older mothers.⁵ (Of the roughly 1,000 British babies born with Down's syndrome in 1980, it may be estimated that approaching a quarter were to women aged over 35.) In part, this policy has been the result of the limitations of the available cytogenetic services. It may also have been based on crude analyses of the financial costs to the health service of such screening against those of supporting a person with Down's syndrome.

More justifiably, perhaps, service provision has also been restrained by awareness of the potential costs in terms of normal fetal loss, and perhaps also by maternal reluctance to consider the abortion option. A study in NE Thames (Murdray and Slack 1985) recently reported that just under a half of pregnant women aged 38 or over received amniocentesis. The suggested reasons for this, apart from straightforward lack of services, included fear of miscarriage, moral concerns, lack of information and language difficulties. To date, it appears that only 50–100 Down's births are being prevented each year as a result of screening.

Some ethical aspects of the prevention of Down's syndrome and other forms of impairment by the abortion of abnormal fetuses are discussed later in this paper. But if it is accepted that it is desirable to try to reduce the birth incidence of 'mental handicap' by such methods, the options currently to be considered include:

1 Improved information and counselling for pregnant women in the target age group (See Modell 1985).

5 The impact to date of measures to reduce the birth incidence of Down's syndrome is difficult to evaluate for a number of reasons. One of the most problematic is that OPCS records are necessarily incomplete, being collected within one week of birth. The estimate of 1,000 British Down's syndrome babies born in 1980 given in the text is about twice the officially recorded figure. It may be that the rates of diagnosis shortly after birth have changed over time. However, the available data indicates that the incidence rate of Down's syndrome amongst children born to women aged over 40 now stands at about half the level recorded in the 1970's (OPCS 1983, 1985).

BOX 5

Fragile X syndrome

Some estimates suggest that up to 5 per cent of males with severe learning difficulties have an X-linked disorder known as Fragile X syndrome, and that for every one with severe intellectual impairment three may have milder disabilities (Ferguson-Smith 1983, Stene and Mikkelsen 1984, Stein and Susser 1984). If this data is accurate, Fragile X syndrome must rank as a relatively important cause of 'mental handicap'. However, precise projections regarding its incidence and consequences cannot be made on the basis of current knowledge, not least because of uncertainties as to its impact on the female population. (Overall, there are significantly more severely 'mentally handicapped' males than females.)

Fragile X is inheritable, and thus potentially in part preventable by genetic counselling followed by screening and pregnancy termination. Yet this is problematic in that a special folate deficient culture medium is required to generate the relatively large numbers of cells needed. Not all will show the fragile site, the range typically being 30–40 per cent in symptomatically affected males.

The same factors would complicate any wider ranging screening programme. However, it may be of interest that trials are underway on supplementing the diet of affected males with folic acid. If this is to some degree effective, it could open the way to a form of prenatal or neonatal therapy.

2 Improving the acceptability of the service by facilitating earlier detection. If chorionic villus sampling is employed to achieve this, the necessary costs may well include those of reorganising primary maternal health care in order to identify more at risk women in the first two months or so of pregnancy, and an increase in first trimester 'spontaneous' abortion rates.

3 The identification of those women under 35 (or whatever the main target group's age threshold is) who are at special risk as compared to their peers and screening them selectively.

Regarding (3) a safe, non-invasive means of testing the entire pregnant population for some preliminary indicator of Down's syndrome would obviously have great utility, provided it could be offered at an acceptable unit cost. Cuckle and Wald (1984) have observed that unusually low levels of a substance known as alphafetoprotein (AFP) in maternal blood serum is associated with Down's syndrome.

These authors suggested that a policy of screening based on both maternal age and serum AFP levels could permit the detection of some 40 per cent of all Down's syndrome fetuses, whilst limiting the proportion of unaffected pregnancies exposed to the risks of amniocentesis to between 6 and 8 per cent. Such a possibility deserves careful attention, particularly as the maternal population is already screened for raised AFP levels in the context of the existing neural tube defects (NTD) prevention programme.

The latter have themselves significantly been associated with mental impairment (Alberman 1978), notably in cases involving hydrocephalus. However, there has in recent years been a dramatic fall in the incidence of conditions like spina bifida, the notification rate for which in 1984 was only a third of that recorded a decade earlier (OPCS 1985). This may in part have been due to changes in environmental factors, including the diet of the population.⁶ The Medical Research Council is currently conducting a trial on the role of folic acid and multivitamins in this context; but some authorities already appear convinced of the preventive value of the former.

Despite the fact that certain commentators have questioned the need for continuing screening for NTDs (Hibbard *et al* 1985) it was almost certainly a key factor underlying the falling NTD birth incidence rate during the last decade (Wald 1986). When a pregnant woman has been identified as having a high serum AFP level, diagnostic ultrasound can be used to detect open spina bifida or

anencephalus with accuracy rates of about 80 and 95 per cent respectively. Regarding the incidence of mental impairment in association with NTDs, it may in the case of hydrocephalus (which occurs in roughly one third of spina bifida births) be noted that surgical techniques such as the use of shunts to reduce excessive fluid pressure can today help to prevent brain damage amongst surviving infants and children.

Low birth weight

Recent advances in the standards of obstetric and neonatal care have led to the achievement of major falls in the number of low birth weight babies dying in their first year. And Table 2 shows that in the seven year period 1977–1984 the overall perinatal (still births plus first week) mortality rate amongst babies born weighing less than 2,500 grammes (5.5lbs) fell by over 40 per cent. That experienced by babies weighing between 2,000 and 2,500 grammes at birth more than halved.

This has undoubtedly avoided great amounts of suffering and grief amongst the parents of babies that otherwise would have died. The available evidence suggests that despite past fears that such gains might only be achieved at the cost of increasing the proportion and or overall numbers of impaired survivors (Drillien 1967), this appears not to have been the case (Hagberg *et al* 1984, Chalmers and Mutch 1984, Powell *et al* 1986).

Follow up studies should in time be able to provide definitive data, but for the moment it appears that the total of impaired low birth weight survivors is remaining about constant. This means that, given the greater numbers living, the impairment incidence rate must in fact be falling. Such a finding is not inconsistent with the long standing observation that severe 'mental handicap' is evenly distributed across the population, despite highly significant differences in perinatal mortality between the social classes.

However, from the viewpoint of those mainly concerned to reduce the rate of mental impairment in the population – and also that of disabling conditions like cerebral palsy which in a half or more cases is associated with some degree of intellectual limitation – the figures shown in

6 There may also have been significant changes in the medical management of neonates with severe spina bifida since the early 1970's.

Table 2 Low birthweight babies (2,500g and under), England, 1977–1984

Year	Low birthweight as a percentage of all birthweights		Perinatal mortality rates (stillbirths plus deaths under 1 week per 1,000 live and stillbirths) for low birthweight groups					
	Liveborn	Live and stillborn	under 1,001g	1,000g–1,500g	1,501g–2,000g	2,001g–2,250g	2,251g–2,500g	all under 2,501g
1977	6.5	7.0	811	499	187	71	38	154
1978	6.6	7.1	792	437	173	64	31	142
1979	6.5	7.2	772	415	152	56	30	132
1980	6.9	7.3	742	362	144	51	27	121
1981	6.8	7.2	679	298	120	46	24	105
1982	6.9	7.2	649	280	109	44	22	99
1983	6.8	7.1	601	254	103	44	21	93
1984	6.8	7.1	570	239	87	42	21	89

Table 2 present some reasons for concern. For example, the proportion of low birth weight babies in Britain stayed constant at around 7 per cent throughout the period 1977–1984, close to twice the level recorded in Sweden (Wynn and Wynn 1979).

Several studies have indicated that low birth weight is associated with lowered intelligence later in life (Illsley and Mitchell 1984), particularly when babies are born light for their gestational age rather than simply prematurely. (Even where no severe impairment is present, a combination of minor physical problems and social disadvantages may well promote mild 'mental handicap'.) It is also relevant to note that while it is correct to argue that small, frail babies are particularly a risk of damage resulting from conditions like anoxia, cerebral haemorrhaging and hypoglycaemia at around the time of their birth, the cause of conditions like cerebral palsy may more often relate to problems occurring earlier during the antenatal period (Drillien 1978, Dennis and Chalmers 1981, Niswander *et al* 1984).

The main implication of these observations is that although intensive (and expensive) care around the time of birth may be fully justified in terms of the life years saved, greater effort devoted 'upstream' in pregnancy (or even to the preconceptional stage – Box 4) could prove to be particularly rewarding in terms of disability reduction. Perhaps the most important questions relate to whether or not this country can decrease the overall proportion of babies which are born 'light for dates' in a manner capable of reducing subsequent morbidity (and mortality) rates.

The regional and district birth weight variations shown in Figures 4a and 4b strongly suggest that social factors are important in this area, although their relationship with other biological and environmental variables is clearly complex. At present no adequate understanding of the avoidable causes of low birth weight exists.⁷

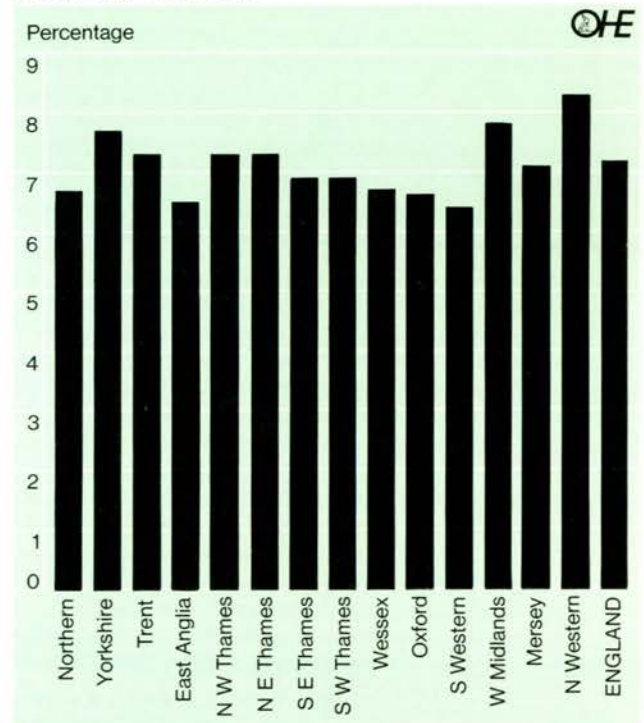
Clinical progress in antenatal care, such as the development of better management techniques in, say, cases of maternal diabetes or placental insufficiency, has an important role to play. But international data suggest that greater social support for women at special risk of having low birth weight babies could have a similar potential (Holland 1986). Experience in countries such as Canada indicates that individual support in relation to matters like diet (see Rush 1982) and the identification of warning signs and symptoms which should serve as cues for more sophisticated professional care might help significantly to lower the numbers of low birth weight babies.

This type of 'outreach' provision, which improves communication both to and from the client, may be offered by health personnel such as community midwives, or even appropriately trained local community volunteers. A trial of enhanced social support during pregnancy for 'at risk' women is currently being conducted in Britain (National Perinatal Epidemiology Unit 1984). It may be of relevance to note that research on increased health visitor contact with 'at risk' mothers of young children already indicates that interventions of this type may be of value in preventing avoidable infant deaths (Carpenter *et al* 1983).⁸

Policies for prevention

The brief review presented above suggests that substantial opportunities exist for further reductions in the numbers of babies born each year in Britain with conditions which cause their subsequent intellectual development to be

Figure 4a Births below 2500 grammes as a percentage of all births by RHA, 1982



Source OPCS

markedly restricted. Precise figures are hard to provide, given the limitations in the data available. But Alberman (1978) has argued that a 20 per cent decrease would be a viable medium term – say 5 to 10 year – goal; this figure still appears reasonable today. It implies a reduction in each annual cohort of severely 'mentally handicapped' British children of over 500.

Such observations raise a number of important questions about prevention policy – or the lack of it – in all parts of the United Kingdom. Despite the fact that a number of influential bodies, including the WHO (1985), favour the introduction of performance targets for prevention, this country has no such publicly stated national or local plans/projections.

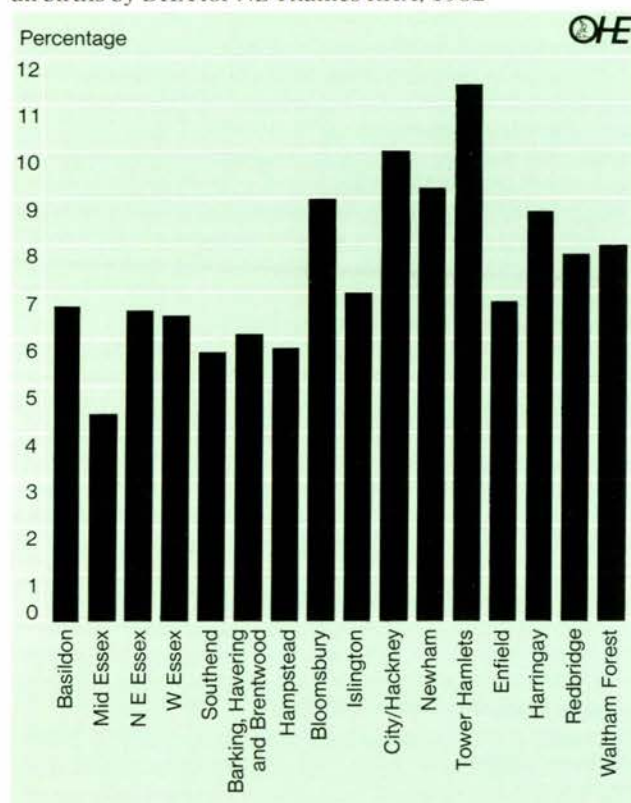
Should clearer UK prevention objectives be stated? If so, what techniques should be employed to determine socially and financially acceptable levels of cost and benefit? What are the ethical and related implications of encouraging the abortion of fetuses with conditions like Down's syndrome? And how should policy makers regard the problem of 'mild mental handicap' associated with low birth weight and post-natal social and material disadvantage? These are examples of the issues in need of resolution today.

The strongest argument in favour of prevention targets is

⁷ Data limitations are one reason for this. It is inappropriate, for example, that the Registrar General's figures in such areas are based on a classification of relating to male occupation rather than the characteristics of mothers themselves.

⁸ One mechanism involved here could be an increased rate of detection of early stage infection. It has recently been suggested, for instance, that the true level of mortality (and perhaps permanently damaging morbidity) due to whooping cough is much greater than that officially recorded.

Table 4b Births below 2500 grammes as a percentage of all births by DHA for NE Thames RHA, 1982



Source OPCS

that they may serve as powerful tools of management to influence the overall behaviour of large, disseminated and politically influenced systems like the NHS. The publication of precisely defined indicators of desired performance, together with comprehensive and reliable statistics on relevant achievements, would help to focus more attention on matters like the prevention of intellectual impairment. Responsible individuals in bodies such as the NHS Districts and Regions and Department of Health might all become more vigorously motivated if there were easy to comprehend, publicly available records of success and failure. More Parliamentarians could also become sensitive to prevention issues.

In the face of the argument that it is technically extremely difficult to set appropriate goals in such areas (let alone to measure accurately their attainment) proponents of the 'target approach' stress that its main significance is to provide bench marks for activity outcomes in constantly evolving systems, and to encourage a wider 'check list' awareness of the ways in which prevention can be achieved. Should a target prove unrealistically optimistic – or too conservative – it can always be revised in the light of experience. What is more important is to encourage movement in a desired direction, and the ability to identify more efficient techniques of service provision.

Despite the existence of objections such as those related to a desire to give local health service managers the greatest degree of autonomy possible, such arguments appear convincing. But, in advocating a rather more planned and incentive driven approach to prevention, the supporters of this view should be careful not to create systems which

become inflexible, so tending to deny individual service consumers the right to exercise choice based on their own values.

The need to maintain a sensitive awareness of value differences within the community is not reduced if techniques like cost benefit analysis are employed to aid policy formation. For instance, to some people the abortion of a fetus represents the sacrifice of a human life, and is an unacceptable cost in any normal circumstance. To others life does not begin until after birth, and so an early stage abortion conducted in order to give parents a greater chance of having a fully healthy child in the future may seem a relatively low cost, high return, option. Naively employed, some forms of economic analysis could result in the unacceptable aggregation of material relating to profoundly conflicting individual preferences.

Another point of relevance to economics is that relatively little work has been conducted on the prevention of mental impairment, either in the United Kingdom or elsewhere (Akehurst and Holterman 1978). Such studies that have been done have usually focussed very specifically on the financial outlays and savings that the health service would incur in relation to preventive activities, rather than the harder to quantify but possibly much greater benefits and costs at stake for consumers. Improper use of data of this type could lead agencies such as the NHS to fail to supply valuable services.

Turning back to the question of aborting fetuses affected by Down's syndrome or other similarly caused conditions, a serious ethical issue arises if it is suggested that it is acceptable to abort a fetus simply because it is 'abnormal', but not to do so if it is 'normal'. Certainly this paper is based on the assumption that 'mentally handicapped' individuals have the same right to life as all other members of the population.

A less discriminatory approach to abortion would arguably be one that ensures that women (and their partners) have choice as to the termination of pregnancy, regardless of whether it is desired for 'medical' or 'social' reasons. Indeed, the distinction between these two areas is difficult clearly to define in this context. Unwanted children may well be at unusually high risk of being impaired at birth and/or of failing subsequently to attain their full developmental potential.

Environmental deprivation is the most dominant single factor underlying the relatively poor intellectual performance of low birth weight children (Illsley and Mitchell 1984). Prevention here is likely to demand interventions of a socially very much more far reaching nature than efforts to reduce the already comparatively low birth incidence of severe impairment. The problem of mild intellectual disability as it can be said to affect around a million people in this country raises the entire politically sensitive topic of the distribution of national resources between the various sub-sections of the community. For to a considerable extent the uneven distribution of intellectual abilities within society appears to be a result rather than a cause of the existing social order.

This last observation clearly suggest that the numbers of mildly 'mentally handicapped' people in Britain could be reduced by improvements in the living standards of and the services available to those most in need. However, the scale of the social changes that progress in this area is likely to demand make it a daunting political issue. It is one touched on again in the main conclusion of this study.

FROM SEGREGATION TO COMMUNITY LIFE?

In pre-industrial Britain the 'village idiot', though no doubt often mocked and exploited, may at least have had some form of accepted place in his or her community⁹. Indeed, the relatively simple intellectual demands of many of the tasks essential to basic agricultural production before the nineteenth century would have enabled most less able individuals to play a genuinely useful role. And given that life expectancy generally was very limited, it is also likely that a high proportion of the more severely impaired individuals who survived infancy would have died in childhood.

However, as the nineteenth century progressed and people began to move from the country to the towns, where they had to adjust to the demands of industrialisation and the loss of their traditional way of life, problems associated with both mental handicap and mental illness became more overt. The government's response was to extend Poor Law provision, particularly in the institutional context (Jones 1972). This originally dated from the beginning of the seventeenth century. Before the 1830s it offered a mix of out-relief and workhouse accommodation to those who, as a result of sickness, disability or other disadvantage, became impoverished. But in the Victorian era the emphasis of services shifted more overtly towards social control, albeit that an increasing number of Poor Law infirmaries were opened.

In the 1850s legislation was passed through Parliament which instituted the establishment of asylums for 'lunatics' throughout Britain. The latter were confusingly defined as being people of unsound mind and 'idiots', although it is of note that an all age 'Asylum for Idiots' was opened in Highgate in 1847. In the 1870s, London services were extended by the Metropolitan Asylum Board.

With regard to education, the Forster Education Act of 1870 set up independent School Boards across the country to provide elementary education in areas where voluntary facilities were inadequate. For the first time, a significant number of children with marked intellectual limitations entered schools, despite the fact that the 1870 Act made no mention of their needs. Even with regard to training, there was no official recognition of any such requirement until the 1886 Idiots Act.

However, the Leicester School Board established a class for 'feeble minded' pupils in 1892, the same year as the London Board opened a special school for physically and mentally 'defective' children. In 1899, legislation was passed further to permit School Boards to provide education for children who today might be regarded as mildly 'mentally handicapped'¹⁰. But no effort was made to educate, either in asylums, Poor Law institutions or schools, those classified as 'imbeciles'.

The century thus closed with a patchwork of services in place, which had evolved as the cumulative result of many piecemeal reforms affecting several autonomously functioning systems. To the extent that it tended to isolate 'mentally handicapped' people from the community, the pattern of provision was largely an accident of history rather than the outcome of a grand design (NDG 1977a). Yet in the period leading up to the first 'World War' segregation became more the goal of official policy, rather than a byproduct of well meant attempts to give protection – asylum – to a vulnerable group.

Intelligence testing was first developed by Binet in 1908. The technique was based on the belief that mental ability is a single entity, innate and inheritable. Eugenic theories

circulating at that time (when scientific understanding of areas like genetics was relatively crude and the concept of biological evolution still controversial and startling) suggested that people of limited mental ability would bear children of similarly below average skills. They would therefore undermine the quality of the 'racial stock' if their fertility was higher than that of more able citizens.

Since individuals in more advantaged social situations enjoyed not only better educational opportunities but also lower mortality risks than did poorer people, they were by the early twentieth century in Britain starting to have relatively small families. And they and their offspring tended to score better in intelligence tests than less advantaged adults or children. As such trends were observed eugenic fears for the future of British society increased, one consequence of which was the emergence of a more custodial approach to the care and control of 'mentally handicapped' persons. The latter were no longer the only ones seen as being in need of protection: the rest of society was also thought to require safeguarding from them.

The 1913 Mental Deficiency Act was in certain respects intended to create a more segregated system of care. It distinguished between 'idiots', 'imbeciles' and 'the feeble minded' in accordance with perceived levels of intellectual disability. Further, it introduced a fourth category of 'moral defectives', which for females included those bearing an illegitimate child whilst in receipt of poor relief. This Act remained on the Statute Book until 1959; hence there could even today be some older people in long stay mental handicap institutions who were placed there under such provisions.

The 1913 Act also required local education authorities (which came into being in 1902 when the powers of the School Boards were transferred to the local authority system¹¹) to ascertain which 'defective' children were capable of education in special schools, and which were 'ineducable'. The latter became the responsibility of local mental deficiency committees. A duty to provide for the educable was enacted the following year, although extensions of school services were delayed by the advent of the 1914–18 war. The number of 'defective' children in special schools rose from 12,500 in 1913 to some 17,000 in 1939, or by little more than a third.

The 'medicalisation' of mental handicap

The 1913 Mental Deficiency Act additionally imposed on local authorities a duty to provide training, occupation and supervision for 'defectives' in their areas. In the interwar

9 Romanticism about the attitudes of rural communities should be avoided. Recent research in Britain indicates that people living in urban areas are more likely to have a positive attitude towards 'mentally handicapped' individuals than their rural neighbours (Sinson 1986).

10 The 1899 Elementary Education (Defective and Epileptic Children) Act allowed School Boards to provide additional services for children who were not 'imbeciles' on the one hand or 'merely dull' on the other. Although additional grants were made available, only 133 of the 327 local education authorities were making such provision 10 years later (HMSO 1978).

11 The current format of local government in Britain first took shape in the late 1880s.

period 'occupational centres' were gradually instituted. By 1938, there were 60 local authority run and 95 voluntary facilities of this type, offering around 4,000 places.

Much more importantly, the responsibility of local government bodies for the care of intellectually disabled individuals had been radically increased by the transfer of the Poor Law institutions to their administration. This occurred when the Poor Law system was ended in 1929. The bringing together of most public sector educational and health and social care provision under the local authorities in the first three decades of the twentieth century was a major act of administrative rationalisation, though the plurality of the voluntary/private sector remained.

By the late 1930s, there were about 50,000 'mentally handicapped' individuals in local authority run hospitals. Perhaps in part to distinguish the new mode of administration from the old, medical responsibility for the provision of care and support for this client group came generally to be assumed at around this time. There remained, however, a considerable confusion between mental illness and mental handicap. This could have helped to account for such a change in authority; but it may also have been exacerbated by it.

Regarding educational services, a national Mental Deficiency Committee (the 'Wood' Committee) was set up in the 1920s. It estimated that some 105,000 school children were mentally 'defective', of whom only about 1 in 6 were receiving special education. It also found that a further 10 per cent of the school population was 'retarded' and failing to make progress in ordinary schooling.

In marked contrast to the establishment thinking of less than two decades previously, the Committee recommended that educational provision for all those with intellectual limitations should be integrated, and brought closer to the mainstream. Special schools should, it argued, not be seen as 'distinct and humiliating' but as a 'helpful variation of the ordinary school'.

To an extent this philosophy was embodied in the 1944 Education Act, although this still classified severely 'mentally handicapped' children as ineducable. And it was arguably divisive in that it created three types of secondary school and no less than eleven types of special school.

Of the latter, those with by far the largest potential pupil population were the ESN (educationally sub-normal) schools. The number of children receiving education in them in England and Wales almost doubled, from 12,000 to 22,000, between 1947 and 1955. But at around that time there were still 12,000 more children officially waiting for places, with a further 27,000 estimated as being in need of ESN school education.

Within the NHS, which came into being in 1948 in an atmosphere of strong post-war support for more universally available health care, educational provision for all those in institutions remained virtually non-existent. Despite the enthusiasm and good-will accompanying the formation of the NHS, the buildings it inherited were in the main the old, isolated asylums established in the Victorian era.

To the extent that the main focus of medicine was by then shifting towards the curative opportunities in part being offered by new pharmaceuticals, the long term care and encouragement of intellectually less able people understandably became a 'backwater' specialty. Nevertheless, a number of studies conducted in the early post-war period provided a reassessment, by some at least, of the

potential for progress in the field (Malin *et al* 1980).

In the mid 1950s a Royal Commission was set up to study the existing arrangements. In the light of new knowledge about the educability of even the most severely impaired individuals, it recommended a move away from segregated institutional care towards more community services. The following 1959 Mental Health Act was, however, disappointing in its results.

This was to some degree because it served to perpetuate confusions between mental illness and mental handicap, and more generally because it did nothing to prevent severely 'mentally handicapped' individuals being regarded as 'ineducable'. Yet it did give parents a right to appeal against their children being so classified, as well as charging local authorities once again to offer some forms of residential accommodation in addition to training/occupational facilities provided in Adult and Junior Training Centres (ATCs and JTCs).

In the 1960s studies like that of Morris (1969) provided fresh evidence of poor conditions in NHS mental handicap hospitals, including a lack of personal space, possessions and occupation and the regimentation of routines to fit in with staff and organisational, rather than patient needs. There was also a growing awareness of the destructive social distance between those providing care in institutions and those receiving it. Concern about the latter had been stimulated by the seminal American book *Asylums* (Goffman 1961).

Yet it was the 1969 media scandal surrounding conditions in the Ely mental handicap hospital which finally generated sufficient political will for more effective service reforms to take place. In retrospect, it is clear that the publication of the 1971 White Paper *Better Services for the Mentally Handicapped* and the passing of the Education Act of that year marked a genuine watershed in the evolution of care and support for 'mentally handicapped' people in England, and the UK as a whole.

Against this historical background the remainder of this section examines aspects of the development of NHS and local authority residential and social care provisions for intellectually less able individuals. The following part of the paper looks at questions relating to educational and occupational issues.

Health and social care – a shifting balance

'Better Services for the Mentally Handicapped' envisaged a gradual decline in the total number of NHS hospital beds allocated to mental handicap, from around 60,000 in 1969 (England and Wales) to a required level of only a little over half that (in population adjusted terms) by the early 1990s. And it projected an increase in the number of community residential places of a similar order of magnitude (ie close to 30,000) together with a near 50,000 rise in the number of adult training/occupational places provided in the community.

Subsequently, developments in some fields have rapidly overtaken the White Paper's calculations. The most notable example of this is the fact that there are today only about 1,000 children under 16 in NHS hospitals and units in England and Wales, against an anticipated requirement of over 6,000 places¹². This disparity calls into question the basis upon which all the hospital bed requirements in

¹² Special funding to a total value of £10 million was made available in the early 1980s to help relocate children to appropriate non-hospital settings. The use of fostering appears to be a particularly satisfactory and cost-effective form of longer term care.

Figure 5 Residential Places in England 1974 and 1984

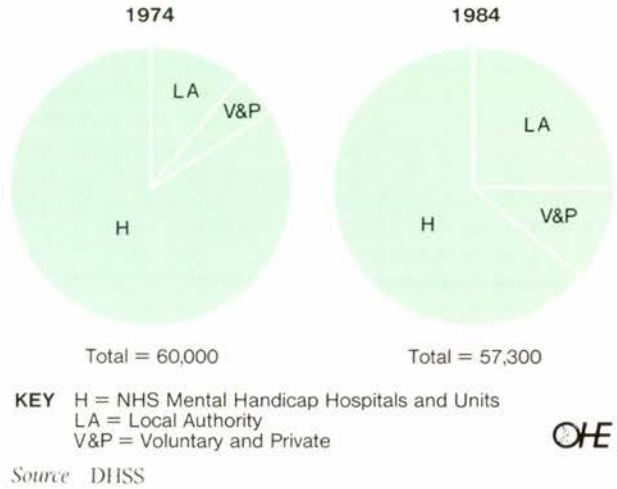


Figure 6 Adult training centre/social education centre places, England

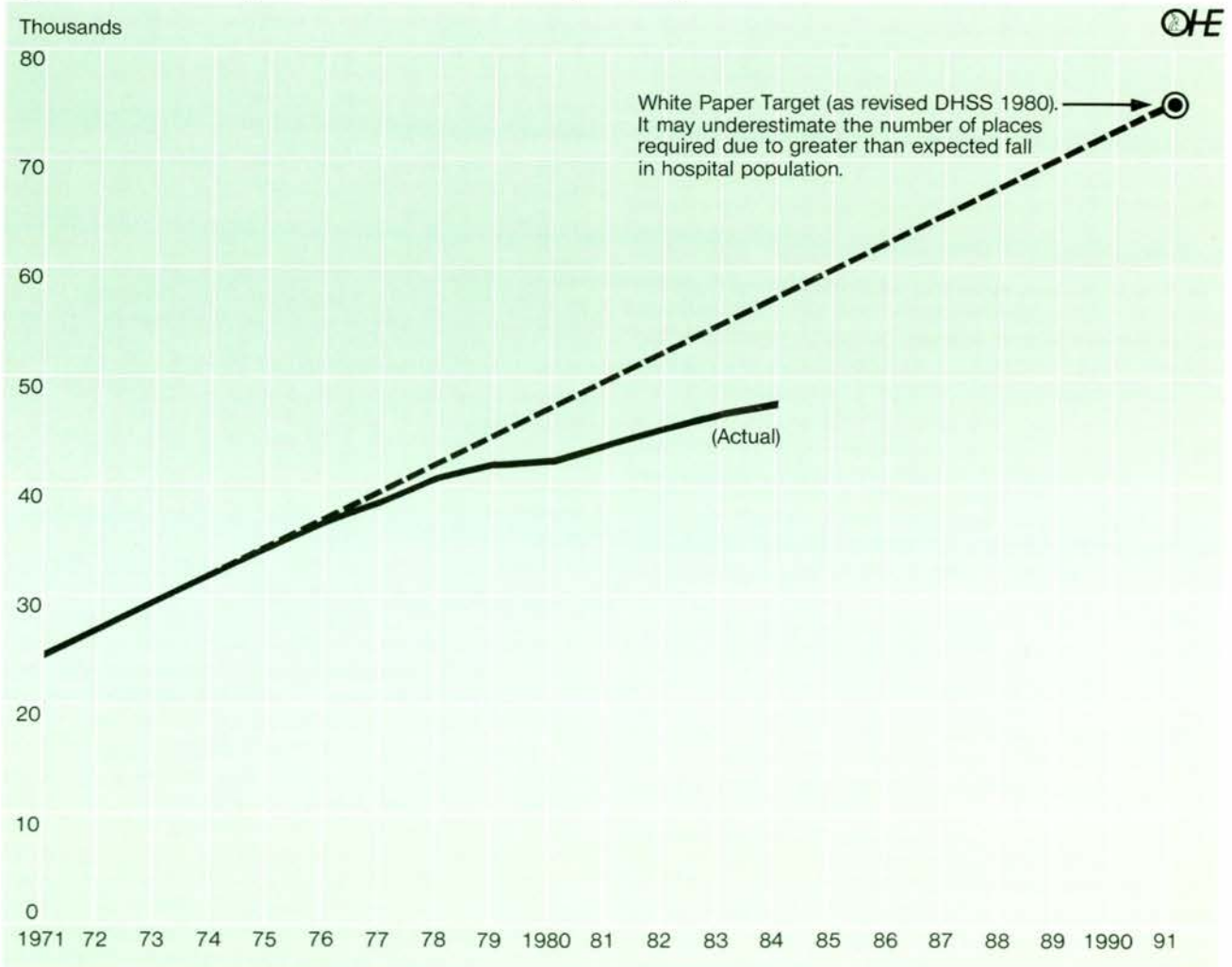
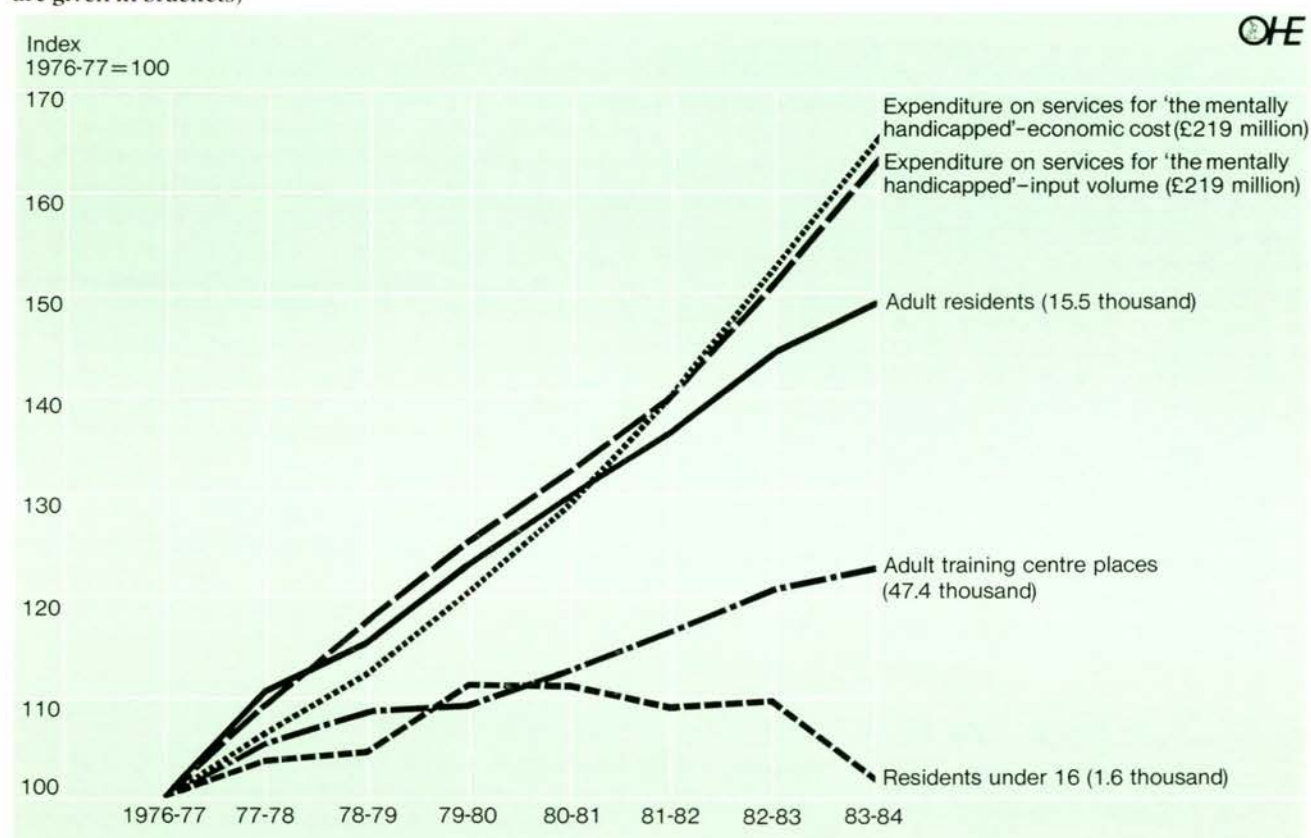


Figure 7a Local Authority services for mentally handicapped people 1976-77 to 1983-84 (1983-84 provisional figures are given in brackets)



Source DHSS

Better Services for the Mentally Handicapped were calculated, for adults and children alike.

Indeed, a number of commentators concerned with mental handicap have argued that the overall need for hospital places was considerably overstated in the government publication. The 1971 White Paper has been criticised for failing to detail precisely what types of patient would continue to require hospital care, and why; and it has attracted similarly adverse comment in that it provided no clear description of the types of support good community services should offer.

Nevertheless, the plans put forward by government in 1971 did trigger a process of real change. It was suggested earlier in this paper in the context of prevention that this is the true measure of the success of any target setting exercise. Figures 5, 6 and 7a and 7b indicate, together with the Tables presented in the statistical appendix to this paper, the scale of the progress achieved between the start of the 1970s and the mid 1980s.

In overview, the main points to be made about the evolution and funding of mental handicap services during this period are as follows:

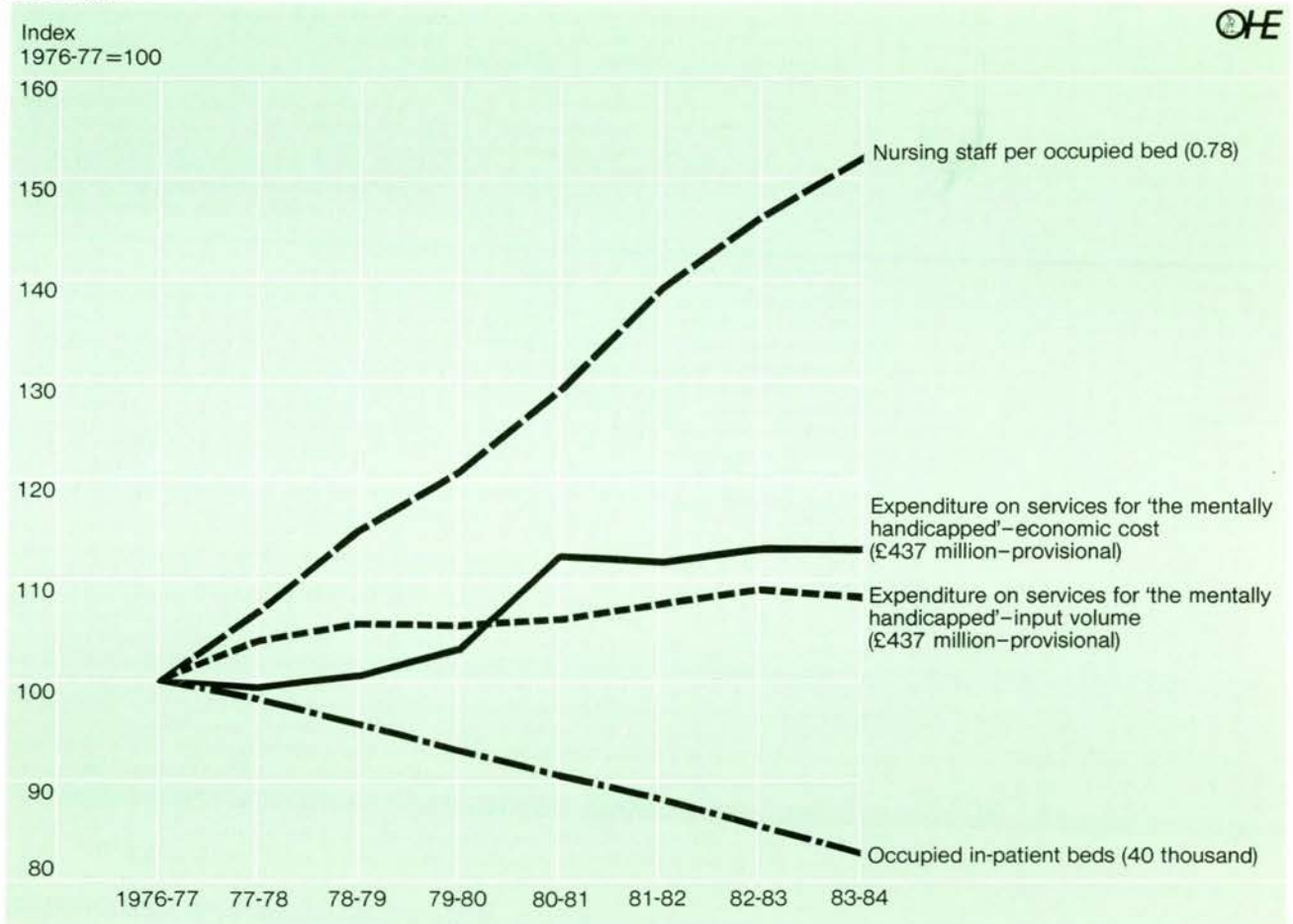
1. Broadly speaking, the overall number of hospital and residential places available has kept constant. Unlike the situation with the discharge from hospital of mentally ill patients with conditions such as schizophrenia, there is relatively little evidence that progress towards community care has in practice lead to previously institutionalised 'mentally handicapped' adults being 'put out on the streets'

even though on occasions this may have happened. More frequently, however, community and day care services are inadequate.

2. Few NHS mental handicap hospitals have as yet been closed¹³. Rather they have reduced in size (DHSS 1980) while the total number of hospitals and units has increased markedly. This means that the cost savings associated with the falling inpatient population have been limited. In the last decade, the total number of residents in NHS mental handicap hospitals and units fell most rapidly in England. Yet Wales still has in relative terms rather lower mental handicap hospital/unit usage, equivalent to 70 per 100,000 population in 1984. The English figure was 78 per 100,000 in that year (with significant regional fluctuations) while the Scottish rate was 116 per 100,000. Recent research (as yet unpublished) calls into some question Scotland's performance in this field, in that it suggests that 'mentally

13 A recent study by the Campaign for people with Mental Handicaps found that between 1979 and 1985 only 13 mental handicap hospitals were approved for total closure (Wertheimer 1986). It estimated that two thirds of the residents were simply 'trans-institutionalised', that is moved on to other NHS mental handicap hospitals. Two major closures in 1986 are the Royal Western Counties Hospital Starcross in Exeter and Darenth Park, Dartford. The process surrounding the latter has been criticised in some respects. For example, one local authority may have applied to take an undue proportion of non-local patients back 'into the community', perhaps because of long term financial inducements offered. Careful monitoring and planning based on the individual programme plan approach is needed to guide closures appropriately.

Figure 7b Hospital services for mentally handicapped people 1976-77 to 1983-84 (figures for 1983-84 are given in brackets)



Source DHSS

handicapped' people in institutional care there are as able as their counterparts in the community. Scotland's overall NHS current spending is over 20 per cent above the average for the rest of Britain, which makes this apparent neglect of a 'Cinderella' service all the more surprising.

3. To a considerable degree, reductions in the longer stay population in mental handicap hospitals have been a function of the rate of 'new' long stay patients entering care. The most recent figures on the decline of 'old' long stay patients in England show a roughly 50:50 split between the numbers discharged and the numbers dying. At the same time, short stay admission rates for social (respite) and other reasons have risen dramatically. In 1983, nearly 29,000 people left English NHS mental handicap hospitals/units after a stay of under 3 months, compared with 8,000 in 1973 and 5,000 in 1964. By contrast, 2,362 were discharged or died after a stay of 5 years or more in 1983. The equivalent figure in 1973 was 2,592; in 1964 it was 1,880.

4. In retail price index adjusted terms, NHS current spending in England on mental handicap hospitals and units rose by about 50 per cent between 1972/73 and 1983/84. As a proportion of total hospital spending, mental handicap outlays remained constant at around 6 per cent during this period. By contrast, local authority (LA) personal social services (PSS) revenue spending on ATCs and accommodation for 'mentally handicapped' adults and children rose by

150 per cent between 1972/73 and 1983/84. The share of total English PSS funds devoted to mental handicap rose from 5.5 per cent to 8.5 per cent. In 1983/84 the ratio of NHS to LA mental handicap spending (current) was 2:1. In 1972/73 it was 7:2.

Mechanisms and objectives

One important factor associated with the process of change described above was the creation of joint finance arrangements between the NHS and the local authorities in 1976. This scheme, introduced at a time when local authority capital investment rates were falling (along with those of the NHS), was primarily intended to facilitate enhanced joint planning and action in those areas where health and social service authorities share overlapping responsibilities. In effect, it involves the routing of a proportion of central government funds intended for local authority use on services for the elderly, mentally ill and mentally handicapped via the NHS.

At present (1985/86) about £120 million¹⁴ is available for

14 Ministerial sources quote the figure £105 million. The estimate given here is based on the Supply Estimates. These figures mean that joint finance resources amount to no more than 1 per cent or so of NHS gross funding. See statistical appendix.

joint finance in England. Of this, some two thirds is presently being spent on revenue as opposed to capital. In the order of one third of the overall total goes to mental handicap. Projects can now be fully funded for up to 10 years, after which resources are tapered down for a further 3 years.

Subsequently, local authorities are fully responsible for service costs, to be met out of their limited funds. Concern about long term revenue consequences likely to follow the take up of joint finance money may perhaps account for the falling proportion of the total going to local authority as opposed to health service and voluntary projects in recent years¹⁵ (McCarthy 1984, DHSS 1985). Ten to thirteen years is, however, a very long planning horizon in political terms.

Following the publication of the consultative document *Care in the Community* (DHSS 1981), the DHSS in 1983 announced further provisions designed to enable patients to be moved from hospital to community facilities. Health authorities can now transfer, either on a lump sum or an open-ended annual basis, funds in addition to the joint finance allocation to local authority social service, housing and education departments or voluntary agencies in order to pay for the care of given individuals. And about £17 million of joint finance money has been reserved centrally over 4 years in order to fund 28 pilot or demonstration projects designed partly to 'catalyse' the relocation of patients to community care. Eleven of these relate to mental handicap.

These initiatives have been generally welcomed. Nevertheless, a number of widespread reservations about policy in this area exist. At a general level, some fear that the drive towards community care is partly disguising the fact that valuable services are being dismantled. Psychiatric provision is a case in point (Goldberg 1986). More specifically, doubts relate to continuing uncertainties over the economic cost that the provision of 'good quality' community care is likely to impose; to concerns that, despite the measures outlined above, enough financial provision has not been made for the 'bridging' costs health and social care authorities inevitably incur in the process of substituting community for institutional care; and to confusion as to what precisely 'good quality' community care involves, who should receive it, which staff should deliver it, and how best it might be planned and managed. Even the *Care in the Community* Green Paper failed to define or discuss what it meant by community services, limiting its analysis to the development of 'classical' services like ATCs and residential hostels (Mittler 1982).

On the issue of the cost of non-hospital provisions, research by Wright and Haycox (1985) suggests that modern small scale NHS units are likely to be substantially more expensive than the traditional wards they may replace. In the case of children, for instance, the units they investigated were in average cost terms some 28 per cent more expensive than comparable wards, and they required to run them virtually twice the 'marginal' resources released when similar wards were closed within a hospital. These are disturbing data, although it should be noted that figures generated by the 'NIMROD' project in Wales (see Box 6) are rather more reassuring (NIMROD 1983).

15 In 1982/83, 80 per cent of joint finance money went to local authorities, 5 per cent to voluntary bodies and 15 per cent to health service projects. In 1984/85 these figures stood at 75 per cent, 6 per cent and 19 per cent respectively.

The latter indicate that, although the cost per client week in permanently staffed houses suitable for more dependent adults is slightly above that of hospital accommodation, the expenditure required to support lower dependency clients in their own homes or in unstaffed houses is well below the hospital figure. The picture regarding the costs and benefits

BOX 6

An ordinary life

A growing awareness during the 1960s of the unsatisfactory aspects of long term care offered in large institutions led to a number of pioneer projects offering alternative patterns of support. Examples include the work of Kushlick and his colleagues in the Wessex Region (Kushlick 1970) and the Sheffield Development Project (Heron 1982). This last received considerable DHSS finance.

Initiatives of this type helped to develop service tools such as case registers and educational systems like 'Portage'. (See text). Assessment units have been established, and the evaluation programmes associated with these major projects have also provided important lessons.

Nevertheless, their use of 'mini-institutions' – local hospital units and hostels with 20 beds or more – has been questioned by the advocates of normalisation. This concept, which first emerged in Sweden and was developed by Wolfensberger in the United States (Wolfensberger 1974), rests essentially on the view that people with intellectual impairments are entitled to the same rights and opportunities as all other citizens. They should thus be able to live near their families (if they so desire) and in everyday contact with their peers, and to take part in the normal activities of their communities. Through such participation prejudice will be eroded, it is argued.

At a sociological level the shift away from institutions may also be seen as an attempt to avoid the unwanted sequelae of their often regimented and hierarchical social structures. 'Mentally handicapped' people living in them tend to end up on the lowest rung of their isolated 'pecking orders', deprived of normal freedoms.

Such ideas were contained in the report *An Ordinary Life* (King's Fund 1980) and have underpinned the work of the Campaign for Mentally Handicapped People. The project ENCOUR in America provides a demonstration of the viability of a fully 'normalised' service for intellectually disabled individuals, as does the Welsh scheme NIMROD. This last offers total community based care to a population of some 50,000 people in Cardiff; one aspect of this is that 'mentally handicapped' individuals in need of residential support are offered places in normal housing. The programme is rigorously being evaluated by the Mental Handicap in Wales: Applied Research Unit. (See Humphreys *et al* 1984).

A number of other pilot projects have been established under the governments 1983 *Care in the Community* initiative. To date they involve around 300 individual placements, and may serve as models of 'good practice' in moving individuals out of institutional settings. But the evaluation process (being conducted by the University of Kent) is, as with NIMROD, yet to be completed.

Such developments have evoked great interest. Nevertheless it is still argued by some that hospital or hospital-like provision will always be needed for a minority of intellectually impaired people with 'special needs'. These include the profoundly disabled, those with additional severe physical or sensory disabilities, and those whose behaviour is very disturbed (DHSS 1984). It is with regard to their ability to provide superior, comprehensive and cost beneficial support for such people that global locally based services like NIMROD will be most keenly monitored and ultimately judged.

of alternative forms of residential support is thus somewhat confusing at this stage.

Perhaps the most balanced conclusion to draw is that if populations can be moved in more or less their entirety to facilities based on normal housing rather than expensive purpose built units, then the overall outlays demanded for superior quality support (which will include a range of services in addition to housing or 'hotel' inputs) may not be much greater than those required by the traditional system. But if relatively large populations remain in mental handicap hospitals or hospital like units, then costs will probably rise significantly.

Following directly on from this point, it has been argued with some force recently that health authorities should be offered additional central government bridging funds to help them during the period when they are paying the double costs associated with maintaining traditional institutions and developing new services (HMSO 1985a). Neither the original joint finance scheme or more recent care in the community provisions address this problem; rather, they have given health authorities more flexibility and control in the direction of existing resources. Government has recognised the importance of this issue (HMSO 1985b). But no useful new proposals have emerged.

Turning to the more complex question of defining the nature of 'community care' and organising its delivery, the House of Commons Social Services Committee (HMSO 1985a) recently put forward the view that the term is so often and so vaguely used as to be almost meaningless. Sometimes it is taken simply to refer to any form of support for a vulnerable client group outside a hospital, however inadequate. On other occasions, community care is taken to refer to a precise, tightly defined set of values and provisions (IDC 1982).

In the context of mental handicap this last was so in the case of the Jay Report (HMSO 1979), which promulgated a particular model of services. The principles underlying the latter are outlined in Box 7. They may be taken to illustrate the concept of community care advocated in this paper.

During the 1970's there was a prolonged debate as to the relative merits of hospital or closed community provisions as against more disseminated, locally based care. (See OHE 1978). Yet there is today a much greater consensus to the effect that wherever possible care based on the individual needs of each mentally handicapped person and his or her family is the fundamental requirement. There is also wider agreement that the social dynamics of large institutions often work against the achievement of such patterns of support (King 1986).

In the past involvement in the 'hospital versus community care' debate on the part of professional groups which had members who feared their interests might in one way or another be undermined by change could have served to draw attention away from the requirements of 'mentally handicapped' people themselves. The great majority of the latter already live with their families or otherwise outside institutions. This paper therefore now turns to a consideration of some of the practical problems involved in ensuring that better services can be planned and delivered in each locality.

However, before so doing one final point is stressed. It is that although family support is a natural part of any individual's life, the normal development of most young adults in our culture involves increasing independence and, eventually, a move away from the family home after sexual

BOX 7

The 'Jay' Report's tenets of community care

Broad principles

'Mentally handicapped' people have a right to enjoy normal patterns of life within the community.

'Mentally handicapped' people have a right to be treated as individuals.

'Mentally handicapped' people will require additional help from the communities in which they live and from professional services if they are to develop to their maximum potential as individuals.

Community requirements

'Mentally handicapped' people should be able to live in a mixed sex environment.

'Mentally handicapped' people should be able to develop a daily routine like other people.

There should be a proper separation of home, work and recreation.

Individuality

The right of an individual to live, learn and work in the least restrictive environment appropriate to that particular person.

The right to make or be involved in decisions that affect oneself.

Acceptance that individual needs differ not only between different handicapped individuals but within the same individual over time.

The right of parents to be involved in decisions about their children.

Service principles

'Mentally handicapped' people should use normal services wherever possible.

Existing networks of community support should be strengthened by professional services rather than supplanted by them.

'Specialised' services or organisations for 'mentally handicapped' people should be provided only to the extent that they demonstrably meet or are likely to meet additional needs that cannot be met by the general services.

If the many and diverse needs of 'mentally handicapped' people are to be met, maximum co-ordination of services is needed both within and between agencies and at all levels. The concept of a life plan seems essential if co-ordination and continuity of care is to be achieved.

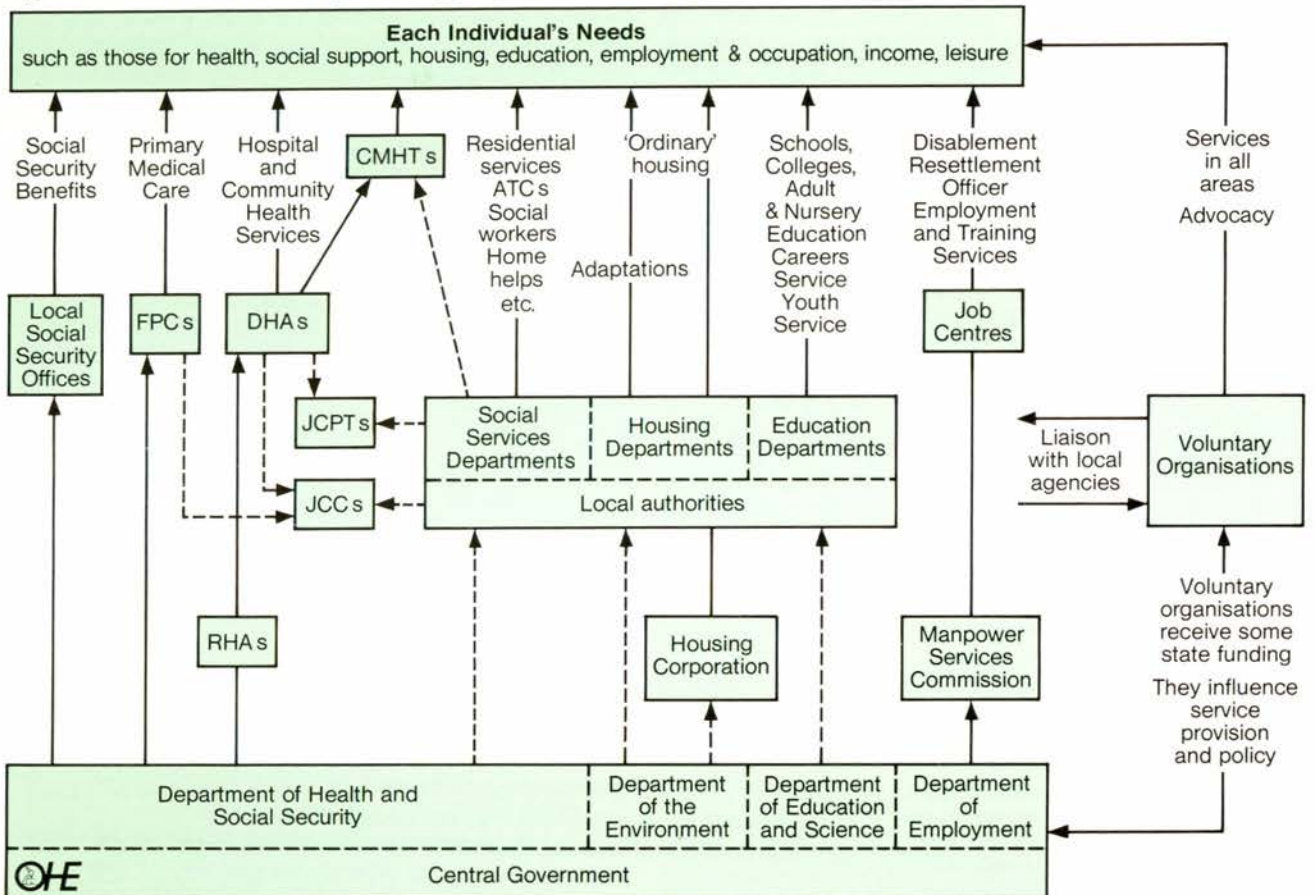
If high quality services are to be established and maintained for those who cannot easily articulate and press their claims, someone is needed to intercede on behalf of 'mentally handicapped' people in obtaining services.

Source: HMSO 1979

maturity is attained. There is no reason why this should not be so with most mentally handicapped people. Indeed, if they are to live on happily after their parents' deaths it would seem beneficial that their parents should themselves help them to achieve the necessary emotional, as well as physical, transitions.

Although good quality community care must usually seek to involve parents and other community members in establishing a satisfactory life style for each intellectually impaired adult, there is a danger of care 'in' the community degenerating into care 'by' the community (and in particular unsupported family members) if professional resources

Figure 8 Services for mentally handicapped people in England



Note In some areas of the country education and housing are at different tiers of local government.

are overstretched or undermotivated. The implications of this observation should be clearly understood by all those concerned to ensure the successful progress of Britain's mental handicap services; particularly when it has recently been restated that government policy is to 'enable each mentally handicapped person to live with his (or her) own family, if this does not impose an undue burden' (HMSO 1985b). The decision making process to identify precisely what an undue burden constitutes remains undefined as do the specific needs of many families with disabled members.¹⁶

Planning, organisation and management

The 1974 NHS reorganisation was intended to permit better planning and management within the NHS, and improved co-operation between the NHS and other relevant agencies. In a complex area like the support of people with intellectual impairments and perhaps also additional physical disabilities, this is an essential requirement. Figure 8 indicates the wide range of local authority, NHS and other statutory and voluntary services which may potentially be involved.

Under the arrangements introduced in 1974 Joint Consultative Committees (JCCs) were set up, consisting of members of both Area Health Authorities (AHAs) and Local Authorities. These latter bodies were in the main coterminous on a one to one basis. However, in 1982 the AHAs were disbanded with the NHS input to JCCs devolv-

ing to District Health Authorities (DHAs). And from 1985 Family Practitioner Committee members and local voluntary sector representatives also began to attend the JCCs as of right.

At officer level the equivalent liaison and planning bodies are the Joint Care Planning Teams (JCPTs). A recent survey by the National Council for Voluntary Organisations has shown that in 1985, there were in England, 94 JCPTs with mental handicap sub-groups, out of a total of 108. Seventy of the 94 involved the voluntary sector (NCVO 1986).

This last clearly has a potentially major contribution to make in fields such as identifying current need, stimulating service changes and direct service provision in, for instance, areas like housing – Box 8. To a significant degree the future viability of community care will depend on releasing and channelling energies and resources offered by people with relatives who have intellectual impairments and those members of the public who form social contacts with 'mentally handicapped' persons as their segregation is

16 MENCAP has recently established a project which entails a survey of the main support needs of parents of individuals with profound intellectual impairments and multiple disabilities. Pilot results indicate that key problem areas include the provision of care during periods of holiday from school, physiotherapy, help in the home, speech therapy, feeding problems, and the need for respite care. Many of these are of concern to the parents of less severely handicapped children and adults.

BOX 8

Housing Associations

Housing Associations are independent bodies with voluntary management committees, the activities of which are closely regulated by statutory provisions. They receive funding mainly through the Housing Corporation via its Approved Development Programme (currently standing at about £700 million) and by local authorities (currently £100 million). Of the 3,000 Associations registered with the Corporation, some 500 are active.

At present around 400 new Housing Association places for people with 'mental handicap' are being provided each year. Payment for them may be made from personal income, including social security benefits. In many instances voluntary organisations like a local MENCAP branch may be responsible for the day-to-day running of premises for people with special needs, whilst the Housing Association is responsible for property management (Brazil 1986).

Demand for Housing Association accommodation is now such that the Corporation receives bids for loans which total about three times its available funds. In the future it may be that more health authority money could be channelled, via the joint arrangements, into Housing Association provision for individuals with intellectual impairments. It is of note that the Lewisham and North Southwark DHA is already funding about 60 such places.

reduced¹⁷. And voluntary bodies may perhaps even more importantly provide a natural forum for 'mentally handicapped' individuals themselves to exchange views, participate in social processes like planning, and press for new or changed services. 'Self advocacy', with or without the aid of facilitators, is now widely recognised as valuable and necessary (GLC 1985, King's Fund 1984b).

Yet with regard to JCCs and JCPTs it would be wrong to exaggerate the efficiency with which they work at present, or the communication difficulties which exist between professional and 'lay' members. Glennerster *et al* (1983) have also pointed to the fact that instead of enabling partnership between the health service and local government, the interaction which sometimes takes place in such committees is more partisan in nature. This opens up the entire question of how, in circumstances where separate bodies operating with limited funds share overlapping responsibilities, co-operation rather than 'buck passing' can genuinely be encouraged.

To some commentators this area seems so problematic that the only solution appears to be to transfer all mental handicap services to a single body, such as the local authority social service departments (HMSO 1985a). In the context of such options, the creation of a new professional group mid-way between social work and nursing has been discussed (HMSO 1979). The current North West Thames Regional Health Authority strategic plan states that local authorities should be the main providers of all mental handicap services (Smith 1985).

However, the overall probability of such a reorganisation taking place in the immediate future seems remote. Given the reality of existing human and material resources, a more practical future approach towards the organisation of mental handicap services might well take the form of the creation of joint LA/NHS 'sub-authorities' in each locality, operating with an 'earmarked' budget derived from the parent DHAs/LAs (Glennerster *et al* 1983). The admini-

strative structures of projects like NIMROD and the mental handicap 'management partnership' in Newcastle (NCVO 1986) serve as indicators of the model which might be developed. Yet it must be stressed that this type of initiative remains experimental. For the present, perhaps, it may be more productive to concentrate energies simply on finding ways of making existing structures work better.

With this philosophy in mind there are four levels at which relevant efforts may be focussed:

1. On the ground inter-service and inter-professional co-operation, which may be facilitated by the formation of more Community Mental Handicap Teams (CMHT's) working in localities with catchment populations of around 50-80 thousand people. Their goal should be improved support for each individual and family based on a specific assessment of their situation and needs. The 'key worker' concept should also be used to enhance service coordination and efficiency.
2. Local planning procedures designed to promote the most productive use of all relevant resources, and clearly to identify those individuals responsible for decision taking. The recent findings of the joint working party on this topic published under the title *Progress in Partnership* (DHSS 1985) are relevant here.

3. Active monitoring of both planning procedures and the quality of service provision.

4. Good management practice, particularly with regard to communicating with existing staff the objectives of change and the nature of their collective and individual places in any future pattern of care.

As to the first of these areas, the core membership of each CMHT should be a community nurse and a social worker. They may be joined by psychologists, speech, occupational and physiotherapists and doctors as appropriate, and should have adequate links with all health service and social service personnel involved in mental handicap. Relevant examples of the latter include ATC staff and the designated DHA medical and nursing officers responsible for the co-ordination of clinical information for child assessments and who act as contact points for the educational services.

The CMHTs may, where they in practice exist, serve to support families with mentally impaired members, and as a resource to assist other local professionals, like family doctors. (The latter's workload may be significantly affected by the presence of more people with intellectual impairments in their local communities - see Box 9). However, the CMHT's prime professional accountability should be clearly to their clients. Each 'mentally handicapped' person should have a detailed - although naturally flexible - individual programme plan. Full case registers should be maintained. And the use of the 'key worker' approach may help ensure that families know which particular individual has a special interest in and knowledge of their situation.

Turning to *Progress in Partnership*, the report suggested that one unfortunate aspect of the present working of the joint finance and allied schemes is that it tends to concentrate all joint planning activities on matters relating to marginal change, rather than any consideration of global resource allocation options. It recommended that named

17 The voluntary sector offers a flexible employment base for many active and committed people. To the extent that it is in receipt of substantial amounts of state funding the line between voluntary and public effort is in reality a blurred one.

senior officers in health and local authorities should be made accountable for joint planning, partly to link the latter more firmly with each public body's own central planning process. The joint working party supported the concept that special 'bridging' finance is needed to facilitate transitions from institutional to community care.

Further, it argued that Regional Health Authorities (RHAs) should monitor the quality of the joint planning conducted by DHAs, and reject proposals based on inadequate local liaison. In some specific contexts, the realism of this idea is limited, in that Regional imperatives may themselves be formed by internal NHS rather than broad community interests (Wertheimer *et al* 1984). But the general concept of enhanced monitoring of both planning and the services actually provided is to be applauded.

The use of checklists such as those offered by the National Development Group for the Mentally Handicapped in *Improving the Quality of Services for Mentally Handicapped People* (NDG 1980) and the MENCAP *Stamina* publications should enable local service providers themselves to identify areas where the quality of their provision is questionable. Activity of this type may be supplemented by the work of Community Health Councils¹⁸ and voluntary organisations; procedures like the NHS District and Regional Reviews; and the monitoring and evaluation conducted by central bodies like the Health Advisory Service (which owes its origins to the Ely hospital scandal) the National Development Team for Mentally Handicapped People and the Social Services Inspectorate.

Nevertheless, it may be felt that even today too few really probing enquiries are made into the services and conditions provided in, say, local authority run hostels or the ATCs. Some hospitals and NHS units may also be significantly substandard. Major variations in care quality exist across

the country, as indeed may certain private and voluntary facilities. And it could be that government policies with regard to mental handicap care themselves are subject to too little really informed debate and independent 'option appraisal'. Some commentators believe that one factor underlying the disbanding of the National Development Group at the start of the 1980s was resentment in some quarters about its policy questioning – and setting – activities.

Against this background the role of the voluntary sector in planning (NCVO 1986) monitoring and policy formulation clearly has considerable further potential. The formation of the Independent Development Council for People with Mental Handicap in 1981 has already gone some way to realising the latter. (See, for instance, IDC 1984, 1985).

Finally, with regard to management practices in the personnel field in particular, a recent review of mental handicap services (DHSS 1980) pointed to the large and growing numbers of unqualified staff in mental handicap facilities of all types. Mental handicap is an area which has all too often been regarded as a 'backwater' in which personnel training has frequently been inadequate. So too have pay levels, career prospects, and staff/management communications. Even today groups like the 10,000 or so individuals working in ATCs or the 12,000 qualified and 17,000 unqualified nurses in English mental handicap hospitals alone (see the statistical appendix) may have good reason to suppose that their interest have been as ignored and neglected by the wider community as have those of the people they serve.

This field is arguably one of the most crucial currently facing individuals such as the new NHS unit general managers for mental handicap services appointed in the aftermath of the 1983 'Griffiths Report'. Its significance has already been recognised in some of the best planning exercises (Welsh Office 1983). If an atmosphere of greater staff confidence and understanding of and commitment to the goal of service improvement can be generated, then rapid and genuine progress will be possible.

But this is not likely to be an easy task, given the past lack of adequate, skilled, management. The adverse reaction to the 'Jay' Report's in some ways logical but understandably threatening proposal that all residential care staff involved in mental handicap services should in future be trained under the aegis of the Central Council for Education and Training in Social Work¹⁹ illustrates the extent of the sensitivity and insight needed in this area.

BOX 9

The delivery of health care

Recent shifts in the perception of 'mental handicap', from being a medical 'problem' to essentially an educational and social support issue, are welcomed in this paper. Nevertheless, people with intellectual impairments often have particular as well as general health care needs – especially in cases of multiple disability – and good quality medical attention is an essential aspect of an adequate pattern of service provision. Failure to provide rational pharmaceutical and other therapies to remedy treatable physical and psychiatric complaints could no more be justified than improper medical interventions. On occasions inter-professional rivalries may have served to obscure this fact (Aman and Singh, *in press*).

A number of particularly important questions relate to general practice. As more highly dependent individuals enter (or remain in) forms of community care, so the demands on family doctors will tend to increase. The data available suggest that such patients are likely to require at least twice the number of consultations that an average patient will receive in any one year. Little is as yet known about how the NHS family practitioner services are responding to such challenges, or whether or not it would be desirable to introduce special postgraduate training or other provisions in order to try to ensure that satisfactory standards of health care delivery to 'mentally handicapped' individuals living in the community are achieved.

18 CHCs should, it may be suggested, have greater powers to inspect local authority and indeed voluntary and private provisions/services, where they overlap with the activities of the NHS.

19 The CCETSW and the Nursing Councils are now co-operating to introduce a common element into their training programmes (GNC/CCETSW 1982/1983).

EDUCATION AND OCCUPATION

The 1971 Education Act finally established the principle of universally available education in Britain. Previously the only provision for severely 'mentally handicapped' children was that offered in local authority Junior Training Centres (JTCs) as laid down in the 1959 Mental Health Act. But the JTCs only catered for about half the population of such children; the education of many, living both in their own homes and in hospitals, was neglected.

The 1971 changes transferred the administration of the JTCs to the LA Education Departments. They became known as ESN(S) special schools (Educationally Sub-Normal-Severe). Many new facilities were built during the first half of the 1970s, and a cadre of teachers with skills especially relevant to the requirements of severely intellectually impaired pupils has emerged. New techniques, such as the sign language Makaton and the Derbyshire Language System (involving repetition and picture association) have been developed and widely used (DHSS 1984). As a result the average functional abilities and social skills of populations such as that of younger people with Down's syndrome appear significantly to have been enhanced. This record is one of genuine success.

Shortly after the formation of the special schools for pupils with severe impairments the government of the day set up the 'Warnock Committee' to investigate the provision of special education generally, and to recommend measures for further progress. It reported in 1978, arguing that there were three levels at which further integration between the country's 'special' and other educational facilities could be, and by and large should be, encouraged²⁰. They are:

- 1. Locational Integration** where there is a special class within an ordinary school or a special unit on the school site.
- 2. Social Integration** where children from a special class or unit eat, play with and share some more formal activities with others. This can be facilitated by locational integration, but may also be achieved by, for example, regular class exchanges and visits between schools.
- 3. Functional Integration** where children with special educational needs normally attend ordinary classes, although perhaps with some periods of withdrawal for specialist teaching.

Following the publication of the 'Warnock Report' some local projects designed further to integrate 'mentally handicapped' peoples' educational lives with those of the rest of the community were established. For example in Oxfordshire a project involving the full-time teaching of about a half of one SLD (severe learning difficulties) special school's pupils in neighbouring primary and comprehensive facilities was begun at the start of the 1980s. It involves all three

types of integration (Centre for Studies in Integration in Education 1985). Evaluations of such schemes show that they may benefit both disabled and non-disabled pupils alike (National Foundation for Educational Research 1981).

At the national level there was extensive public discussion of Warnock's recommendations. After the 1979 general election the government proposed the legislation embodied in the 1981 Education Act. This came into force in 1983, abolishing all the previous categories of handicap. Its main provisions are shown in Box 10. There is now a single concept of special educational need, which includes not only the 1-2 per cent of children in special schools but also the 20 per cent or so of the mainstream population who will at some stage in their school career require a degree of special help.

The 1981 Act has been to an extent welcomed by those concerned with special education. Some have regarded it as a significant further step towards the 'normalisation' of 'mentally handicapped' children's lives, and as part of an overall process of increasing integration (Taylor 1983, Peters 1985). However, such conclusions may in reality be premature (Swann 1986), and in some instances the Act's provisions have already had questionable effects.

For example, one perhaps unforeseen consequence of the creation of a single category of 'handicap' is that the flow of official data relating to specific groups of children with physical or intellectual/psychological problems has come to a halt. This loss of information could impede independent attempts to evaluate future progress.

With regard to the introduction of statements of educational need for each child with learning difficulties sufficient to demand that special resources be allocated it is of course desirable that a proper process should exist for identifying their requirements and planning each individual's place in the educational system (DES/DHSS 1983). But the decision as to what should be provided for each child subject to statement is under the control of the individual education authorities (DES 1981). Rather than any single direction of development being assured, therefore, provisions will continue to vary widely on a locality to locality basis, depending on past investments and current policies.

Parents wishing to see their child educated in a more

²⁰ It recommended that the term 'children with learning difficulties' be used to describe all those previously categorised as 'ESN' and those in receipt of special support in the mainstream schools. The latter were defined in curricular requirement terms as having mild learning difficulties. Children previously described as ESN (moderate) and ESN (severe) are now usually referred to as those with moderate and severe learning difficulties respectively, although the Warnock terminology has not 'officially' been adopted.

Table 3 ESN (M) and ESN (S) Special school pupils aged 5-15 1978-1982

Category	1978		1982		% change in prevalence 1978-82
	Special school pupils	Per 10,000 total school population	Special school pupils	Per 10,000 total school population	
ESN (M)	52,530	65.7	54,317	73.1	13.5
ESN (S)	19,734	24.2	19,495	26.2	8.5

Note Numbers in special schools are not the total number of children in special provision. Some are educated in special classes and units in mainstream schools. Alternatively some children on the register of a special school may spend part or all of their time in a mainstream school.

integrated setting than that suggested by the relevant LEA, or otherwise to question its proposals, can appeal, ultimately to the Secretary of State. It is of interest to note that in Inner London, for instance, the number of 'statemented' children being educated in an ordinary school rose from 5 in 1982 to 149 in 1985. Yet the appeals procedure can be daunting and lengthy, taking up to two years.

Despite, therefore, the availability of help and advice from voluntary agencies many parents may in practice be discouraged from challenging 'official' decisions. Factors like local professional opinion, and the personal attitudes of given head teachers, could well remain more dominant forces in the process of service evolution in many areas.

Further, the available statistics do not support the common assumption that a trend towards greater integration of 'mentally handicapped' children had been established by the late 1970s/early 1980s (Swann 1985, 1986). Table 3 shows that between 1978 and 1982 there was in fact a significant rise in the ESN school populations relative to that of all schools. And slightly later data show that between 1978 and 1983 the size of the primary age ESN (M) group rose by 31 per cent as against the overall primary school population. Given continued questioning and uncertainty regarding the curriculum provided for children with moderate learning difficulties such observations are of considerable importance.

The close links between mild 'mental handicap' and social disadvantage were recently highlighted by research in London which showed that only 20 per cent of children in MLD (moderate learning difficulties or ESN(M)) schools there have fathers with skilled or professional employment backgrounds. The equivalent proportion for 'all schools' is 45 per cent (ILEA 1985). The same study also showed that children in MLD schools are more often than would normally be expected in local authority care, or members of families supported by the social services. Their parents are themselves relatively likely to have been educated in special schools. And they are less likely than are the parents of other disabled children to be supported by voluntary bodies.

The overall conclusion to draw in the context of 1981 Education Act seems to be that its discernable impact on the provision of services for 'mentally handicapped' people of school age has as yet been limited. (This area is currently being researched by the Institute of Education.) Although some education authorities many choose to take relatively rapid action to change the role²¹ or number of their special schools, the national picture is likely to remain reasonably stable. To some commentators this prospect is disappointing.

However, the most important priority at present is to ensure the highest quality of service, whatever the setting in which it is delivered. This involves not only improvements in the training of teachers, especially those in mainstream schools, regarding the needs of children with learning difficulties (DES/DHSS 1983). It also requires greater liaison between those concerned with education and other service agencies, like health and social services, to ensure that all children's needs are understood and met in a coherent manner. Indeed, the basic purpose of the 1981 Act may be seen as facilitating a more careful appreciation of and commitment to each individual's unique requirements.

The achievement of this goal is likely to demand a considerable shift in the traditional focus of educational acti-

BOX 10

The Education Act 1981

(Came into force April 1983)

Main provisions

- ★ The categories of different types of handicap are abolished and replaced by one of special educational need.
- ★ LEAs have a duty to provide special educational provision in ordinary schools provided this is compatible with:
 - a) receiving the necessary special provision
 - b) the efficient education of other children
 - c) the efficient use of resources.
- ★ Governors have a duty to ensure that all children in their schools, whether special or ordinary, with special educational needs are having those needs met.
- ★ LEAs have a duty to identify and assess those children for whom they are responsible who have, or probably have, special educational needs. If as a result of the assessment the LEA is of the opinion that special educational provision is necessary, it makes a statement of the child's needs.
- ★ Parents must be informed of the assessment and can make written representations to it. They can appeal against the statement of needs.
- ★ If District Health Authorities consider that a child under five has special educational needs they have a duty to inform the parents and the LEA. They must also tell parents of any voluntary organisations that may be able to help them.
- ★ Children under two with special needs may be assessed with the consent, or at the request, of the parents.

vity towards regarding learning as a 'whole life' process. This in part will require more emphasis on pre school and immediate post school services. It is to topics related to the support of the under 5s and over 16-19s that this section now turns.

Before school

As Box 10 describes, the health authorities now have a duty to inform LEAs (and parents) of any children under 5 who they have reason to believe may have special educational needs. Children aged over 2 must then be formally assessed under the provisions of the 1981 Act. Those under 2 (for whom the LEAs have no clear powers to provide services) may also be assessed with the consent of their parents.

Prompt action to initiate early educational support can be important for two main reasons. First, because of its potential directly to enhance the individual's child's learning. Second, because of its potential to support and encourage parents who may themselves be isolated and uncertain as how best to help their children in the everyday domestic environment. Informal education in early life is a pro-

21 One option for the future is that such schools might be developed as general resource centres, assisting other schools and non LEA agencies like social service departments to develop more appropriate services. This would, however, require a major re-orientation of the part of existing staff, who could in effect become members of a peripatetic expert advisory teams.

foundly significant determinant of every individual's intellectual development.

There is evidence that many parents of impaired children have not felt that they have had adequate, sensitively given help, and many have been confused by conflicting advice from different professional sources (HMSO 1978). In such circumstances, the creation in some districts of comprehensive assessment centres provides a valuable example, despite the fact that to date the educational input to these has been unsatisfactory. Initiatives like the Honeylands Family Support Clinic in Exeter, which offers assessments plus additional play and related facilities (Ward 1982) and the 'Portage' educational scheme operating in Wessex are also encouraging examples.

Under this last teachers visit families with pre-school 'mentally handicapped' children on a weekly basis. They give guidance on the tasks each child is ready to tackle, and the most appropriate ways to teach her or him. Obviously, the main constraints on such schemes relate to pressures limiting the time and effort parents themselves can afford to invest. But it appears that a majority of families successfully participate in Portage type programmes.

As to non-familial pre-school education, 45–50 per cent of British children aged over 2 and under 5 now attend a nursery school for at least part of the day/week. This is still below the level achieved in many other countries. Under this age children may be cared for in facilities like day nurseries. There are in total some 600,000 maintained or registered day care places (for ages 0–5 – figure includes play group provision) in the UK (CSO 1986).

The extent to which such services are of value to 'the mentally handicapped' and their families cannot, unfortunately, be calculated. The only generally available figure is that there were in 1985 over 4,500 children in the nursery classes of special schools, but this total covers disabilities of all types. Hopefully, many more intellectually impaired children are benefitting from normal social contacts in other universally used settings. Local education authorities have been urged to give priority to the needs of very young clients with identified learning difficulties. And in some instances 'opportunity groups' specifically designed to encourage disabled and non-disabled children to play together have already been set up via social service supported play group schemes.

After school

Many young people, especially in times of high unemployment, face considerable difficulties in negotiating the transition from school to adult life. The challenges this presents can be especially stressful for 'mentally handicapped' adolescents and their families. Hospital admission rates peak amongst those in their late teens and early twenties.

Local education authorities have a statutory duty to provide full time education in schools or colleges for all young adults aged 16–19 who request it. Placements of this type are likely to be of special value to those with learning difficulties, both severe and moderate. Like everyone else such individuals will not have reached their full potential by the age of 16; and they often show a particular need for a more prolonged period of learning in a relatively structured environment.

Indeed, there is evidence that the potential development rate of many intellectually impaired individuals is in relative terms unusually high throughout their second (and

probably third) decades, and of a danger of regression if an appropriate environment is not available after the age of 16 (HMSO 1978, NDG 1977b). Yet research conducted at the request of the Warnock Committee indicated that young people attending special schools in the mid 1970s were five times more likely to have finished their formal education by the age of 18 than were their non-disabled peers.

In recent years the number of places offered for 'mentally handicapped' students in Colleges of Further Education appears substantially to have increased. But no adequate central statistics exist to indicate the scale and nature of this provision, or the extent of the continuing shortfalls. It is also a matter of concern that some young people and their families may be discouraged from taking advantage of what provisions there are available because of uncertainties relating to the social security system and the payment of supplementary benefit. (See Box 11). Such factors could in part explain the recent (1984) ILEA data presented in Table 4.

Relatively little is known about how people with moderate learning difficulties cope in adult life once they have lost contact with the education system. There is, however, evidence that they often remain in unskilled or semi-skilled employment (McLaren and Richardson, unpublished) and that they are at special risk of becoming un(der) employed (Walker 1982). The longer term significance of the provisions outlined in Box 12 is also extremely difficult objectively to measure, particularly as regards the employment situation of intellectually less able people in their 30s and above. Rather more information is, however, available about the numbers and experience of more severely handicapped persons attending Adult Training Centres (ATCs).

As described earlier, the ATCs owe their origin to the 1913 Mental Deficiency Act which empowered Local Authorities to establish Occupation Centres. In the post 1939–45 war period, and particularly after the passing of the 1959 Mental Health Act, these provisions were extended. The 1971 White Paper showed that by the start of the 1970s there were about 25,000 ATC places provided in the community (England and Wales). It projected that by the early

Table 4 First Destination of School Leavers in Inner London, 1984.

Destination	Type of School/Percentages	
	Moderate Learning Difficulties	Severe Learning Difficulties
Daycare (ATC)	0.5	31.1
Residential Care	0.5	1.1
Further Education	36.7	56.7
Youth Training Scheme	17.0	0
Sheltered Employment	0.8	0
Open Employment	11.0	0
Unemployed	9.2	2.2
Remained in school	9.0	8.9
Other	1.4	0
Not known	13.8	9

Notes 1. These figures relate to first destination. It is not known how many of those moving into open employment retain that job for a significant period. The subsequent destination of those completing further education courses or youth training schemes is similarly unknown.
2. Further education provision may vary considerably in different parts of the country.

Source ILEA 1985

BOX 11

Social Security Benefits

The piecemeal evolution of Britain's social security and allied systems of support for disabled people has created a notoriously complex (and locally variable) network of provisions. They range from supports like telephone rental schemes and holiday facilities offered by social service departments, through the transport concessions offered by British Rail and many local authorities to housing benefits such as rate relief. There are also a number of different forms of income support for those who may never have had the opportunity to join contributory schemes. These are of special relevance to individuals with lifelong intellectual and/or physical impairments, and in some cases their carers. They include:

Attendance Allowance Introduced in 1971, this is tax free and available to all severely disabled individuals who have needed intensive support/supervision for at least 6 months. Those requiring day and night attention received just over £30 in 1985/86, whilst those demanding either day or night attendance were entitled to a little over £20. The allowance is payable directly to disabled adults, and to the mothers or foster parents of children. Those in residential care are not entitled to it, but people living in ordinary board and lodgings can claim.

The Invalid Care Allowance This was first paid in 1976. It is available to people who do not work because they are caring for a disabled person for 35 or more hours per week. In 1985/86 its basic value to recipients was £23. ICA is taxable and the level of supplementary benefit support any claimant receives is discounted directly against it. However, recipients are credited with national insurance contributions. Women living with male partners – including mothers of mentally handicapped children – have only recently become entitled to ICA.

Mobility Allowance (1976) This may be claimed by or on behalf of any person aged over 5 who is unable or 'virtually unable' to walk. It is non-taxable, and worth just over £21 per week (1985/86). Regarding 'mentally handicapped' individuals whose problems are mainly behavioural rather

than physical the Social Security Commissioners have recently found in a test case that the Allowance can be paid in severe circumstances. That is, for those whom mobility is practically impossible.

The Severe Disablement Allowance This replaced the Non Contributory Invalidity Pension and the Housewife's Non Contributory Invalidity Pension in 1984. It is for people who are too disabled to work and do not have national insurance cover. The basic 1985/86 value of SDA was £23 per week.

Supplementary Benefit This is the 'safety net' available to all people over 16 whose income is below the level officially deemed to be the necessary minimum. Two aspects are of particular relevance to disabled people. First, payments can be made for additional requirements such as heating, laundry, domestic help and special diets. Second, although Supplementary Benefit is not normally paid to young people in full time education it may be if their employment prospects are poor because of disability.

It should be noted that current government plans involve the replacement of Supplementary Benefit by 'income support'. This will pay an extra amount over its basic level to certain groups, including the disabled, but the existing additions to Supplementary Benefit will cease.

The latter are to be replaced by loans from the 'social fund'. For some, therefore, support could be reduced. The 'social fund' may also be used to help individuals re-establish themselves in the community, to avoid institutional care or to ease exceptional pressures on families. How precisely it will be administered is as yet uncertain, but it is proposed that it will be means tested.

One form of social security support worthy of special note is the residential (and nursing home) care allowance system, which meets the cost of care (up to prescribed national limits) provided in registered voluntary and private homes. It has proved an important source of resources to these sectors in recent years. The sums available to individuals in the 'mental handicap' category range up to £200 per week.

For further information, see Disability Alliance (1985) and subsequent special publications.

1990s there would be a total requirement of 74,000 (15 per 1,000 total population) plus a further 22,000 occupation and training places in hospital settings. By 1984 there were almost 47,500 community ATC places in England, indicating a growth rate about 20 per cent below that demanded by the government's 1971 plans. (See statistical appendix and Figure 6 page 35). South East England is, interestingly, the least well endowed part of the country in this context (DHSS 1980).

The National Development Group for the Mentally Handicapped (1977) called for a substantial reorganisation and reorientation of the goals of the ATCs. Noting the findings of Whelan and Speake (1977) that fewer than 4 per cent of the people attending ATCs passed on to open employment, and that the staff of the Centres appeared to have low expectations of their clients' abilities, the NDG argued that more emphasis should be given to improving severely 'mentally handicapped' individuals' social skills. It advocated the establishment of special care units for the most severely disabled within the ATCs, and the renaming of the latter as Social Education Centres (SECs) to reflect their changing role.

Since then notable progress has been made in some localities. For example, in Greenock (Scotland) an

'Outreach' programme which involves a very active employment seeking/client placing function has been established in cooperation with the local ATC. And in Camden (London) the ATC is being split into physically separate special care, workshop and 'employment agency' divisions.

But across the board rather less appears to have been achieved. There has been renewed questioning of the existing structure of the ATC/SECs, with some authorities arguing that they serve undesirably to segregate those attending them from the rest of society (Kings Fund 1984a). There is also continuing debate as to the service they should provide to older 'mentally handicapped' persons, growing numbers of whom are now approaching retirement age.

Wherever possible, it is clearly desirable that severely intellectually disabled people should take part in the ordinary activities of life, including attendance at mainstream facilities like clubs and evening classes. But in practical terms the ATCs often provide the only source of occupation and continuing education for many of their clients, who may also have a deep need for regular contact with their peers. What basically is required is a further increase in the number of ATC places, including those designed

BOX 12**Employment Schemes**

As with income support, the employment services available to disabled people are wide ranging and together comprise a complex system. Its components range from the Employment Rehabilitation Centres and sheltered workshops to various training schemes, employment quota requirements and a registration system. With regard to the latter the Manpower Services Commission (MSC) keeps a record of disabled people, including in a second section those so severely affected that they are unlikely to obtain ordinary work unassisted. Firms with more than 20 employees should employ about 3 per cent disabled staff. The effectiveness of this requirement's enforcement appears, however, to be limited.

At the Job Centres Disablement Resettlement Officers provide employment services for all disabled people. Some of the special schemes they may direct clients to are described below. However, it is of note that ATCs and voluntary organisations are also active in these areas. For example, the MENCAP Pathway Employment Service utilises the Job Introduction Scheme (see below) together with a 'foster worker' approach.

The Job Introduction Scheme

Through this the MSC will pay £45 a week to a firm for a 6 week trial period in return for the latter giving a disabled person the opportunity to demonstrate their skills and positive abilities in a given work role.

Sheltered Employment

Workshops may provide employment for groups of disabled people, operating either as independent institutions or as enclaves within a larger factory or other work place. They are run by voluntary bodies, local authorities and Remploy.

The Sheltered Industrial Groups Scheme

Offers severely disabled individuals an opportunity to work alongside non-disabled persons (not only in industrial environments). The worker is legally employed by a sponsor such as a local authority or voluntary body. The host firm where she or he works pays a proportion of their wages (30-70 per cent) whilst the sponsor makes them up to the full amount with MSC money. There were 629 such placements in 1984.

Cooperatives

These are owned and controlled by those who work in them. They may be set up to provide work for 'mentally handicapped' individuals and/or others. Many local authorities have experts able to advise on the establishment of cooperatives, and may be willing to offer initial financial assistance if disabled individuals are to benefit from such projects.

The Youth Training Scheme

Under this MSC funded scheme young people can obtain places on two year courses, through which they may gain work skills and experience and further general education. There are now a number of YTS initiatives designed specifically for intellectually disabled school and college leavers.

Sources See King's Fund (1985) Disability Alliance (1985) and IDC (1985).

adequately to care for more dependent people, together with a general change of direction towards more external links wherever possible.

Concerned policy makers considering this area would thus be well advised to conclude that greater efforts should be made to ensure that the ATCs are adequately equipped, in both material and human terms, to provide a full, stimulating and life-long support service. To this end there still seems to be a pressing need for more appropriately trained and remunerated personnel.

The situation of people with markedly below average intellectual abilities in British society has moved through three main stages since the era of urban industrialisation began in the early nineteenth century. The first of these involved the emergence of 'mental handicap' as a 'problem' and then (falsely) as a perceived threat.

As Britain's population moved away from the land, and the structure of family, work and community life changed, the difficulties faced by those with intellectual disabilities became more visible. And 'solutions' offered in terms of institutional asylum opened the way to the increasing segregation of the 'mentally handicapped'. This trend was deliberately fostered at the start of the twentieth century because of ill-founded fears that the free circulation of individuals such as those labelled 'moral defectives' would impair the quality of the 'racial stock'.

After the 1914–18 war eugenicist ideas about the need to protect the rest of society from its vulnerable, mentally disabled members properly faded. But in this second stage of development 'mental handicap' became seen as a primarily medical condition.

At a time when cure rather than care dominated much medical thought this was unfortunate, even though it probably reflected a genuine desire on the part of many decision takers to 'solve' the 'problem' of 'mental handicap' as humanely as possible. An inadequate appreciation of the social determinants of mental performance and personal behaviour led to the perpetuation of destructive, authoritarian, institutional regimes which served to undermine the situation and skills of those receiving care in them. One facet of this was a continued confusion between 'mental handicap' and 'mental illness', together with phenomena like an improper use of sedative medicines as agents of custodial control.

Since the 1950s there has gradually emerged a more balanced and rational public awareness of the needs of individuals with intellectual impairments and a stronger commitment to helping such citizens to achieve a satisfactory way of life. The growing use of terms such as 'integration', 'normalisation' and 'community care' in the 1970s reflected this development, although the imprecise use of 'jargon' may sometimes have served to confuse rather than to clarify underlying issues. At times excessive emphasis on the location of care delivery rather than its nature and extent has also been counterproductive.

The way forward today as regards the services which ideally should be available to more severely 'mentally handicapped' people and their families is relatively clear. Support tailored to the needs of each individual requires close coordination between, and planning of, the activities of agencies like the NHS, local authority education, housing, and social service departments, employment services, and the voluntary sector²². It must be based on a strong respect for the cultural diversity of the community and the expressed preferences of those using services. And constant attention to the quality of provision should be paid by the agencies directly involved, and by external monitoring groups at both local and national levels.

But a key restraint on the provision of better local services described in the main body of this paper is the financial one. In this context the DHSS's 1980 Review *Mental Handicap: Progress, Problems and Priorities* commented:

'The disparity between the resource assumptions underlying the (1971) White Paper and those which must under-

lie planning at the present time must obviously cause us to consider . . . whether the policy of building up local services should be abandoned or at least deferred.' Yet it went on: 'We consider, however, that to suggest doing this at the present time would be a counsel of despair . . . uneven but real improvements have been made in the facilities and services provided. It is surely right to try and build on this progress rather than abandon it.'

Since 1980 real advances have continued, though the overall rate of service development is disappointingly slow. And future progress could prove vulnerable to the imposition of additional resource constraints in areas like local authority and social security provision. The nature and amount of social and economic support available to more mildly handicapped people is still more problematic (DHSS 1980).

Why should this be so in a field which now appears to be relatively well understood? How best can a better, adequately resourced, future actively be pursued? Some outline answers to these questions may be approached by further consideration of the historical overview offered above.

Many of the official reports prepared for government in even the nineteenth century show, on examination, a surprisingly enlightened understanding of the difficulties faced by people with 'mental handicap' and how they might be resolved. There was admittedly a deviation from this general record at the start of this century, but it was short-lived. For example, the educational recommendations of the 'Wood' Committee in the 1920s have a striking similarity to those contained in the 'Warnock' Committee's report of the 1970s, and the measures enacted in the 1981 Education Act.

The conclusion to draw seems to be that although social change has in practice been slow, those close to the centre of political power appear long to have known what 'should' be done. The true problem of 'mental handicap' could thus reasonably be described as a deficiency of political will. It is of note in this context that the critically important events at the start of the 1970s, marked by the publication of *Better Services for the Mentally Handicapped* and the passing of the 1971 Education Act, were precipitated by the political scandal following media revelations of the conditions at Ely mental handicap hospital. Decision takers in the NHS and elsewhere had been privately aware of the latter, and other similar situations, throughout the 1960s (Crossman 1977).

In response to such observations those involved with the relevant political and administrative processes may perhaps argue that 'history has its own pace', and that changes in social attitudes towards people like those with major intellectual impairments cannot be imposed from above. They might in addition draw attention to the problems which surround any process of resource reallocation in the community, and the human capital limitations applying in the 'mental handicap' care sector. That is in part to say that the rate of change of service provision may be limited by the interests of those working in institutions like the existing mental handicap hospitals.

22 One practical example of the need for such coordination exists in relation to FPS dental services. As more severely 'mentally handicapped' people live in the community they will wish to attend ordinary dentists. But a lack of appropriate incentives and perhaps some fear of being 'flooded' with similar cases may be leading dentists to refuse to take on all such clients.

All these suggestions contain an element of truth; but none bear really close scrutiny in as much as they are all likely to be self fulfilling prophesies. For example, if people with 'mental handicaps' are isolated, segregated and surrounded with a disturbing mystery, others in the community may well retain negative attitudes towards them. The latter will only change as the care system itself changes as a result of central actions. Similarly in as much as groups like mental handicap nurses and the staff working in ATCs have themselves been poorly treated they may in the past have appeared to resist change. But with adequate communication and proper consultation and support this need not be so.

The task, therefore, for those concerned to help politicians and health and social service managers maintain and increase the momentum of progress in the mental handicap area is to create an environment in which positive action is clearly expected. This paper closes with some suggestions as to how such conditions may be achieved. They relate first to the role of voluntary bodies; second, to the need to create a far more positive emphasis on partnership throughout the formal and informal care system; third, to the potential which exists for the prevention of mental impairments and subsequent disabilities; and, fourth, to the uncertain area of mild 'mental handicap'.

Britain's tradition of voluntary action in the health and related arenas is a considerable asset. Regarding mental handicap its contributions range from service monitoring and the stimulation of innovation through to direct care provision. Today one of the outstanding challenges and opportunities facing the voluntary sector is to assist in liberating the energies of many more people in the community, so that they can constructively participate in both work and leisure activities which involve 'mentally handicapped' people. Recent changes in the tax system may serve to stimulate and improve the funding of voluntary bodies.

But at the same time, voluntary effort cannot obviate the need for publicly provided facilities and professionally guided care. Many people are rightly wary of moves which could, instead of instituting desirable patterns of support in the community for disabled people, result merely in inadequate care 'by' the community delivered on an unplanned, uncoordinated, 'charitable' basis. The voluntary sector must always strive to communicate that it seeks to pioneer, partner and applaud adequate national services, not to replace them.

Following on from the above, the title of this paper is intended to emphasise the need for cooperation and communication between all those involved in this field. Positive partnerships need to be encouraged between intellectually impaired people and those who provide support, family members and professionals alike; between different professional groups; and between voluntary, independent and state funded agencies. Without such an approach the community cannot expect to derive full value for the resources it channels into this field, and mentally disabled individuals, and their families, will experience needless distress.

There are a variety of specific ways forward. The general introduction of a key worker approach, aimed at making for each individual one person the chief gateway and guide to the network of provisions available could considerably improve accessibility and coordination. Enhanced arrangements for the assessment and representation of service users like those contained, albeit in weakened form as com-

pared with the original Bill, in the Disabled Persons (Services, Consultation and Representation) Act are also likely to be of value. And at the agency level revised planning arrangements of the type outlined earlier should also promote more constructive partnerships.

Turning to the prevention of intellectual disability, this paper has detailed some of the important advances in medical techniques which have recently been made. These may in time reduce by a significant percentage the proportion of the population born with life long impairments of all types. Financial savings for agencies like the NHS could result, even though some forms of sophisticated medical intervention are themselves expensive.

Policy makers should be encouraged to establish prevention targets as an aid to improving Britain's performance in this important field. However, an equally valuable message for the professionals involved in medical endeavours of this type themselves to receive is that society does not in the longer term face an either/or choice between the prevention of mental handicap and the provision of adequate social and educational services for all those affected by it.

Indeed, it could well be thought that the most relevant measure of the worth of efforts made to reduce infant death and impairment rates is the level of resources a community is prepared to devote to ensuring that those who do unfortunately suffer physical damage or abnormalities do not, in the terminology of Box 1, become needlessly disabled or handicapped by them. The implications of this understanding should not be lost during short term disputes over immediate allocation problems within the NHS and between the latter and related agencies.

Finally, with regard to the topic of mild 'mental handicap', it was suggested earlier in this paper that this broad problem area is to a substantial degree a result rather than a cause of the existing social order. That is, that disparities of opportunity in areas like housing, income, employment and education serve to perpetuate differences in the functional abilities of various social sub-groups. The latter are thus to a considerable extent the outcome of material inequity, not its justification.

The size of the mildly 'mentally handicapped' population (which even if measured in terms of identified special educational needs alone is around half a million adults and children and may total in the order of one million) and the range of the areas in which its members may from time to time need particular assistance make it a difficult one for traditionally orientated policy makers to recognise and address. Nevertheless, it is one which should no longer be ignored.

This is in part because as and when the needs of the limited numbers of severely intellectually impaired individuals are more adequately met it will be logical to pay greater attention to those larger numbers of people on the less certain borderline between normality and potentially handicapping disability. And in part because continuing changes in the economy and the processes of production in countries like modern Britain may be ushering in a new era in which mildly intellectually impaired people are at unprecedented risk of being unemployed and so deprived of a vital aspect of ordinary life.

In the first instance a practical response to this problem would be the encouragement of a greater awareness of mild 'mental handicap' (together with the dangers of indiscriminate labelling) throughout the 'generic' health, social and educational services. More specific training and clearly

researched information about the special problems intellectually less able individuals may face during, say, life stage transitions, housing crises and old age could help to make all professional and voluntary workers sensitive to their needs. And in time such knowledge may spread

through society to create generally more understanding, positive and empathetic community attitudes towards all 'mentally handicapped' people. Arguably this last is what is most required to protect Britain against any continued deficiency of political will.

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STATISTICAL APPENDIX

Table 1 Mental Handicap Hospital and Unit Populations and Admission Rates, England, Wales and Scotland 1964–84

	<i>Mental handicap hospitals and units, England and Wales</i>							<i>Scotland (Mental handicap hospitals)</i>		
	<i>All ages</i>	<i>All admissions</i>		<i>First admissions</i>			<i>Residents</i>	<i>All admissions</i>	<i>First admissions</i>	<i>Residents</i>
		<i><15</i>	<i>>15</i>	<i>All ages*</i>	<i><15*</i>	<i>>15*</i>	<i>No</i>			<i>No</i>
1964	10,364	4,041	6,323	4,480	2,180	2,300	60,200			
1965**	10,226	4,101	6,435	4,475	2,188	2,288	60,430	1,003	529	6,698
1966	10,707	4,161	6,546	4,472	2,196	2,276	60,660	962		6,882
1967	10,836	4,697	6,139	4,600	2,437	2,163	60,866	897		6,989
1968	10,904	4,718	6,186	4,739	2,464	2,275	60,820	884		7,156
1969	10,337	4,515	5,822	4,364	2,357	2,007	60,267	1,211		8,397
1970	11,365	4,965	6,400	2,176	1,232	944	59,402	1,095	510	7,481
1971	11,942	5,477	6,465	2,048	1,223	825	56,892	980	451	7,234
1972	12,385	5,164	7,221	1,808	988	820	55,397	989	364	7,340
1973	12,240	5,026	7,214	1,547	780	767	54,220	1,056	345	7,276
1974	12,786	5,363	7,423	1,540	796	744	52,981	987	281	7,173
1975	13,789	5,740	8,049	1,364	695	669	52,006	1,000	310	7,085
1976	15,122	6,177	8,945	1,324	603	721	51,286	1,025	288	7,025
1977	16,040	6,455	9,585	1,213	542	671	50,262	1,178	289	6,958
1978	17,198	7,013	10,185	1,115	481	634	49,139	1,302	279	6,844
1979	18,174	7,201	10,973	932	376	556	47,865	1,752	273	6,723
1980	20,612	7,933	12,679	1,039	420	619	46,668	1,927	255	6,632
1981	23,758	8,867	14,891	1,120	476	644	45,244	2,160	261	6,538
1982	26,827	9,924	16,903	1,131	514	617	43,815	1,837	161	6,424
1983	33,091	11,267	21,824	1,377	574	803	42,247	2,163	205	6,176
1984							38,651			5,963

Notes *Prior to 1969, figures relate to England and Wales and thereafter England only.

**Data for 1965 relate to interpolated figures.

†All data in this appendix were derived from DHSS/SHHS/WO health statistics for various years.

Table 2 Residents in Mental Handicap Hospitals and Units, by Age 1976–84

	<i>Resident patients in Mental Handicap Hospitals and Units (31 December)</i>									
	1976	1977	1978	1979	1980	1981	1982	1983	1984	
Age <16	5,220	4,950	4,203	3,624	3,096	2,559	2,110	1,669	1,404	
England	4,263	3,878	3,287	2,839	2,421	1,994	1,629	1,274	1,074	
Wales	NA	199	154	110	101	84	77	63	48	
Scotland	957	873	762	675	574	481	404	332	282	
Age >16	50,764	52,270	51,780	50,964	50,204	49,223	48,129	46,754	43,541	
England	44,696	44,069	43,576	42,757	42,023	41,097	40,083	38,909	35,946	
Wales	NA	2,116	2,122	2,159	2,123	2,069	2,026	2,001	1,914	
Scotland	6,068	6,085	6,082	6,048	6,058	6,057	6,020	5,844	5,681	
All ages	58,287	57,220	55,983	54,588	53,300	51,782	50,239	48,423	44,612	
England	48,959	47,947	46,863	45,596	44,444	43,091	41,712	40,183	36,687	
Wales	2,303	2,315	2,276	2,269	2,224	2,153	2,103	2,064	1,962	
Scotland	7,025	6,958	6,844	6,723	6,632	6,538	6,424	6,176	5,963	

Notes In England in 1984, 333 children aged <16 resided in small NHS units in the community. Prior to 1984, this figure, which is included in the table, was not collected separately but was included in the totals.

	<i>Resident patients per 100,000 population (31 December)</i>									
	1976	1977	1978	1979	1980	1981	1982	1983	1984	
Age <16	44	41	35	31	27	23	19	16	13	
England	38	35	30	27	23	19	16	13	8	
Wales	NA	30	23	17	16	13	13	10	9	
Scotland	71	67	60	54	47	41	35	29	26	
Age >16	128	124	122	119	117	113	110	106	98	
England	127	125	123	120	117	113	109	105	97	
Wales	NA	99	99	100	97	95	92	91	86	
Scotland	157	157	156	154	154	152	150	146	141	
All ages	107	105	103	100	98	95	92	88	81	
England	106	103	101	98	96	92	89	86	78	
Wales	82	83	81	81	79	77	75	74	70	
Scotland	135	134	132	130	129	126	124	120	116	

Table 3 Mental Handicap Hospitals and Units (England) Residents by Age 1972–82

Age group	Resident patients					
	1972	1978	1979	1980	1981	1982
	<i>Numbers</i>					
All ages	52,950	46,637	45,419	44,444	43,091	41,712
0–		16	4	6	7	7
2–	336	85	63	57	61	61
5–	1,768	746	627	471	340	295
10–	3,188	2,094	1,797	1,406	1,131	908
15–	4,273	3,829	3,625	3,222	2,953	2,609
20–	4,825	4,108	4,214	4,162	3,987	4,021
25–	9,175	8,936	8,577	8,469	8,253	7,767
35–	7,829	7,141	7,204	7,338	7,471	7,633
45–	8,478	6,840	6,674	6,518	6,290	6,142
55–	7,354	6,543	6,319	6,187	6,031	5,854
65–	4,397	4,526	4,478	4,538	4,391	4,201
75 and over	1,327	1,773	1,837	2,070	2,176	2,214
	<i>Rates per 100,000 population</i>					
All ages	114	101	98	96	92	89
0–		1	—	1	1	1
2–	9	5	4	3	4	4
5–	46	21	19	15	11	10
10–	90	55	48	38	31	25
15–	134	106	98	85	77	67
20–	144	125	127	122	115	111
25–	152	135	130	128	124	119
35–	146	134	132	132	131	129
45–	148	127	126	124	120	118
55–	136	125	121	120	115	113
65–	109	105	103	104	100	98
75 and over	59	70	71	78	79	78

Table 4 Mental Handicap Hospitals and Units (England). Length of Stay of Residents Leaving or Dying

Duration of stay	1964	1973	1979	1980	1981	1982	1983
	<i>Number</i>						
All durations	9,325	12,654	17,883	20,078	23,260	26,227	32,505
Under 3 months	5,104	8,016	14,387	16,696	19,854	22,909	28,791
3 months –	1,007	931	647	557	569	552	608
1 year –	582	501	327	293	323	291	297
2 years –	752	614	478	518	446	441	447
5 years and over	1,880	2,592	2,044	2,014	2,068	2,034	2,362
	<i>Percentage</i>						
All durations	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Under 3 months	54.7	63.3	80.5	83.2	85.4	87.3	88.6
3 months –	10.8	7.4	3.6	2.8	2.4	2.1	1.9
1 year –	6.2	4.0	1.8	1.5	1.4	1.1	0.9
2 years –	8.1	4.8	2.7	2.6	1.9	1.7	1.4
5 years and over	20.2	20.5	11.4	10.0	8.9	7.8	7.3

Table 5 Mental Handicap Hospitals and Units (England). Whole Time Equivalent Staff Numbers, 1972-82

	1972	1973	1974	1975	1976	1977	1978	1979	1980	1981	1982
Consultant psychiatrists*	142	146	159	167	167	172	177	170	174	181	188
Qualified nurses** (Registered and Enrolled)	9,234	9,393	9,472	9,932	10,507	10,702	11,007	10,955	11,478	11,798	12,238
Other nurses**	10,267	10,803	11,553	13,291	13,227	13,813	14,252	14,566	15,923	17,413	17,571
Clinical psychologists	80	83	96	102	111	122	136	142	164	173	214
Speech therapists	25	20	22	23	31	32	38	45	44	59	69
Qualified physiotherapists	56	57	72	78	91	103	108	125	136	142	159
Physio-helpers	13					62	67	79			99
Qualified occupational therapists	85	91	78	98	105	113	121	135	141	149	171
Occupational therapists - helpers	193					484	554	609			603
Industrial work therapy and handicrafts											
Qualified	44					113	121	135			147
Helpers	225					484	554	609			393
Social workers assigned to hospital	72					170	177	181			215
Domestic services	3,769					5,781	5,930	5,922			6,409

Notes Not all hospitals and units have supplied every item for every year and the numbers are thought to understate the true totals by between 1 and 5 per cent in most cases.

*Consultants in mental illness, mental illness children and adolescents, and mental handicap.

**The increase in numbers of nurses (WTEs) between 1979 and 1981 is due partly to a reduction in standard working hours.

Table 6 Homes and Hostels for Mentally Handicapped People (England)
Local authority homes

	Staffed		Unstaffed		Voluntary and private homes		Total	
	Premises	Places	Premises	Places	Premises	Places	Premises	Places
1974	320	6,380	19	93	NA	3,007	339	9,480
1975								
1976								
1977	443	9,203	117	548	154	3,266	714	13,017
1978	484	9,964	163	719	176	3,595	823	14,278
1979	504	10,453	206	928	191	3,773	901	15,154
1980	534	10,941	253	1,121	192	3,746	979	15,808
1981	579	11,494	272	1,218	NA	NA	NA	NA
1982	593	11,862	290	1,282	NA	NA	NA	NA
1983	617	12,282	346	1,453	292	5,046	1,255	18,781
1984	647	12,800	375	1,550	363	6,271	1,385	20,621

Table 7 Adult Training Centre Places, England 1970-84

	Premises	Places	Places per 100,000 population ages >16
1971*	330	24,537	69.76
1972	366	27,182	76.99
1973	367	29,483	83.17
1974	371	31,604	88.89
1975	385	34,245	95.97
1976	409	35,811	99.86
1977	423	37,941	105.21
1978	431	40,787	112.43
1979	445	42,061	114.25
1980	451	42,337	114.13
1981	461	43,627	116.93
1982	474	45,152	120.48
1983	484	46,558	123.56
1984	496	47,464	125.04

Note *Interpolated figures.

Table 8 Joint Finance (England £ million)

F/Year	Revenue cash £m	Capital cash £m	Total cash £m	At 1976 prices*		
				Revenue £m	Capital £m	Total £m
1976/77	1	3	4	1	3	4
1977/78	9	9	18	7	8	15
1978/79	16	16	31	12	12	25
1979/80	23	16	40	16	12	28
1980/81	37	23	60	22	14	36
1981/82	49	24	73	26	13	39
1982/83	57	26	84	28	13	41
1983/84	66	21	87	31	10	41
1984/85	74	22	96	33	10	43
1985/86a	95	27	122	40	11	51
1986/87p	62	41	103	25	17	42

Notes a - allocated expenditure, p - planned expenditure.

Source: Supply Estimates.

*As adjusted by RPI based on calendar year.

Actual expenditure figures are not available from 1983/84. The Allocated Expenditure figures indicate the sum provided for during the year and may be subject to revision via Supplementary Estimates during the Autumn. Allocated spending does not, usually, match actual spending because of the switch from capital to revenue and also because of carry forward effects.

Table 9 NHS Hospital Revenue Spending, Mental Handicap, England 1970/71 – 1983/84 (£ million)

Cash Outlays

F/year	Total £m	Mental Handicap £m	% Total	Total Index	Mental Handicap Index
1970/71	831	49	5.94	100	100
1971/72	975	60	6.17	117	122
1972/73	1,117	71	6.34	135	144
1973/74	1,298	83	6.41	156	169
1974/75	NA	NA	NA	NA	NA
1975/76	2,487	156	6.27	299	316
1976/77	2,866	171	5.98	345	347
1977/78	3,214	195	6.06	387	395
1978/79	3,607	220	6.11	434	446
1979/80	4,342	262	6.03	523	531
1980/81	5,604	339	6.05	675	687
1981/82	6,291	374	5.95	757	759
1982/83	6,640	401	6.04	799	813
1983/84	6,995	419	5.99	842	850

Note Financial year ending 31 March.

At 1983 Constant Prices*

F/year	Total	Mental Handicap	Total Index	Mental Handicap Index
1970/71	3,810	226	100	100
1971/72	4,086	252	107	111
1972/73	4,367	277	115	122
1973/74	4,649	298	122	132
1974/75	NA	NA	NA	NA
1975/76	6,183	387	162	171
1976/77	6,115	366	161	162
1977/78	5,919	359	155	159
1978/79	6,133	375	161	166
1979/80	6,510	393	171	173
1980/81	7,122	431	187	190
1981/82	7,144	425	188	188
1982/83	6,944	419	182	185
1983/84	6,995	419	184	185

Note *As adjusted by RPI based on calendar year.

Table 10 Local Authority PSS Spending, Mental Handicap, England 1972/73 – 1983/84 (£ million)

Cash outlays

F/year	Total £m	MH accommodation			Total MH £m	% Total Children	% Total Adults	% Total ATC	% Total Total MH
		Children £m	Adults £m	ATC £m					
1972/73	355	2	5	13	19	0.5%	1.3%	3.6%	5.5%
1973/74	447	3	7	16	26	0.6%	1.5%	3.6%	5.8%
1974/75	644	4	10	22	36	0.6%	1.5%	3.4%	5.6%
1975/76	868	6	14	29	50	0.7%	1.6%	3.4%	5.7%
1976/77	954	8	18	35	61	0.8%	1.9%	3.7%	6.4%
1977/78	1,079	8	24	35	68	0.8%	2.2%	3.3%	6.3%
1978/79	1,223	10	29	41	80	0.8%	2.3%	3.4%	6.5%
1979/80	1,489	14	37	49	99	0.9%	2.5%	3.3%	6.7%
1980/81	1,844	19	47	60	125	1.0%	2.5%	3.2%	6.8%
1981/82	2,038	22	55	69	147	1.1%	2.7%	3.4%	7.2%
1982/83	2,249	26	66	79	171	1.1%	2.9%	3.5%	7.6%
1983/84p	2,573	33	87	99	219	1.3%	3.4%	3.8%	8.5%

Notes Financial year ending 31 March.
p = Provisional figures.

At 1983 Constant prices*

F/year	Total £m	MH accommodation			Total MH £m	Total Index	Children Index	Adults Index	ATC Index	Total MH Index
		Children £m	Adults £m	ATC £m						
1972/73	1,388	7	19	51	76	100	100	100	100	100
1973/74	1,603	9	25	58	92	115	134	132	115	121
1974/75	1,990	12	30	68	111	143	177	162	135	146
1975/76	2,157	15	36	73	123	155	213	191	144	162
1976/77	2,036	17	39	75	131	147	241	209	149	172
1977/78	1,986	16	44	65	125	143	223	238	129	165
1978/79	2,079	17	49	70	136	150	246	262	138	178
1979/80	2,232	21	55	73	149	161	294	295	145	196
1980/81	2,344	24	59	76	159	169	337	318	150	208
1981/82	2,314	25	63	79	167	167	360	337	156	219
1982/83	2,352	27	69	82	179	169	387	370	163	234
1983/84p	2,573	33	87	99	219	185	474	467	195	287

Note *As adjusted by RPI based on calendar year.

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