

Are the medical needs of mentally handicapped adults being met?

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SUMMARY. *This paper reports on the apparent inadequate level of primary medical care provided to many of the 151 mentally handicapped people who attend an adult training centre. A large number of common medical problems were identified that were not known to the general practitioners and/or were not being managed, including problems known to be associated with Down's syndrome. Many trainees were further handicapped by unmanaged defects of hearing and vision. Contact rates with the general practitioner showed that the mentally handicapped adults did not place a greater burden on the doctor than the rest of the population. Comparing these rates with those for other vulnerable groups such as those aged over 75 years and under four years showed that only 28% of the trainees had an adequate consultation rate with the general practitioner.*

A lack of awareness among general practitioners of the special needs of this group is thought to be in part responsible but the major factor is the inherent problem of communication which exists almost universally in people who suffer from mental handicap. Ways of improving the situation are discussed with an emphasis on the need for a change in our attitudes towards mentally handicapped people. Reference is made to the desirability of increasing the cooperation between primary care and community mental handicap teams and the increasing importance of voluntary organizations.

Introduction

FOLLOWING decisions expressed in the 1971 white paper *Better services for the mentally handicapped*, government policies and priorities have been to facilitate the transition of care from hospital to community-based services.¹ Seebohm summarized the aims of the community care services as being 'to prevent human deterioration, improve the lives of the most vulnerable in our population and mobilise good will and voluntary effort within the community'.² When the recommendations of the Seebohm report were implemented in 1971 the creation of the new social services departments separated the social services from the then existing medical care services of the public health department, a move acclaimed by social workers but deplored by the medical profession which feared that a separate social services department would be incapable of providing the necessary integrated care. Is there now evidence to substantiate the misgivings of the medical profession? Certainly, many doctors have formed the impression that too many mentally handicapped patients have been discharged from hospital into the community where medical care is inadequate.³ The reality is that little is known about the current state of community care but there are suspicions that the medical needs of mentally handicapped patients are less well met than those of the general population.

Little data are available on the ways in which mentally handi-

capped people consult the family doctor. For the mentally handicapped the decision to seek medical advice is not autonomous but is devolved to the care-givers; the uptake of medical care by the mentally handicapped is thus the responsibility of the community.

There are 533 adult training centres in England and Wales which are attended on a day basis by over 50 000 people. (*Adult training centres for the mentally ill, elderly and young disabled*. Unpublished DHSS report, 1984.) Now often designated social education centres with the trainees called students they are administered by social services departments and represent the major community provision for mentally handicapped adults.⁴ The centres vary widely in the range of activities which they provide but they share a common goal which is to help the trainees to become more competent and to live more independent lives in the community. The populations of the centres are well-defined and relatively static. In this study the population of one adult training centre was surveyed to assess whether the medical needs of the trainees were being met.

Method

At the start of the study in January 1984 there were 151 trainees at the centre. During the year each trainee was examined in the presence of a member of the staff to whom the trainee was well known and who was familiar with his abilities. The general physical examination which included the recording of height, weight and testing of urine for glucose lasted approximately 45 minutes. This was followed by an assessment of comprehension of language and expressive language using a developmental check list (Gunzburg's progress assessment charts⁵). In most instances this assessment had already been carried out by members of the staff on a previous occasion and required only checking and updating. Behavioural factors such as physical and verbal aggression, hyperactivity and bizarre mannerisms which significantly increased the difficulties of the examination were recorded. Although it is recognized that psychiatric disorders such as depression and anxiety are common in the mentally handicapped and ought to be detectable and treatable by general practitioners,⁶ the mental health of the trainees was not recorded in the study.

No medical records were available other than brief notes on those trainees placed in centres prior to 1971. These notes were attributable to the old public health department and all were more than 14 years out of date. Nevertheless they were valuable in providing some useful background information.

The assessment of visual acuity was by means of the Snellen chart. Most of the trainees could recognize at least some of the letters but frequently testing was very difficult. In several trainees who were severely mentally handicapped vision could only be checked by an effort to attach his or her gaze to small interesting objects and to follow them with each eye separately. Hearing was also difficult to test in many of the trainees and in some cases was reduced to the observation of changes in facial expression in response to tuning forks of various frequencies.

All the physical findings were recorded and these included physical associations of mental handicap, for example the clinical signs of Down's syndrome, the presence of microcephaly, hypertelorism and various abnormalities of the limbs and external ears. Although these signs were recorded, the primary pur-

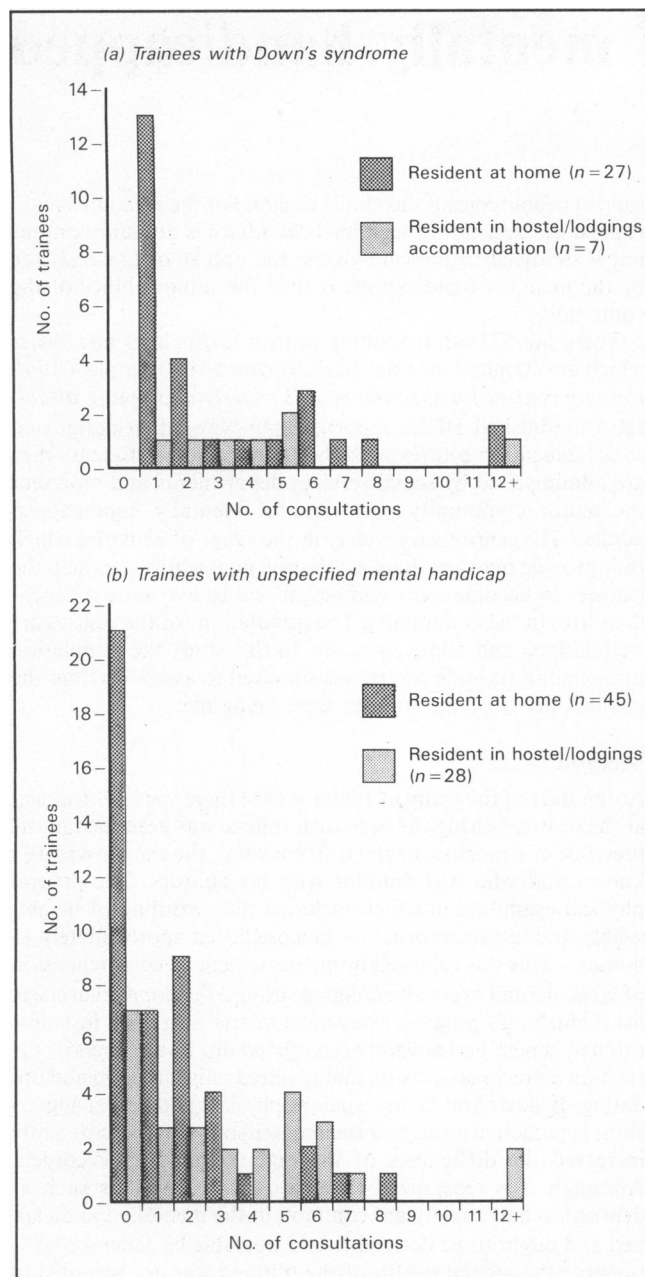


Figure 1. Number of consultations with the general practitioner in 1984 by place of residence for (a) trainees with Down's syndrome ($n=34$) and (b) trainees with non-specified mental handicap ($n=73$).

pose of the examination was to focus on physical conditions that were potentially remediable.

The newly discovered findings and inadequately managed conditions were for practical purposes combined under the heading 'unmanaged'. These included conditions which were either treatable and relievable or curable and requiring organized medical management. For example a trainee who was known to suffer from severe hypertension but who had not had his blood pressure taken for over a year would be seen as not being managed to a conventionally acceptable standard. Conversely a trainee suffering from epilepsy whose anticonvulsant levels were being measured and reviewed by his general practitioner would be placed in the managed column. Another diverse group of conditions including herpes simplex, ill-defined skin conditions, mild arthritis and mild varicose veins were not tabulated as these

were considered for the purposes of this study to be tolerable and not requiring specific treatment.

The number of contacts between the trainees and their general practitioners during the year was established by sending a questionnaire to the care-givers; any doubtful replies were clarified by interview. Care-givers were also interviewed whenever possible to provide background medical information relating to each trainee. In general it was not possible to conduct these interviews at the time of the medical examinations.

Results

The range of mental handicap varied from mild to severe with multiple handicaps. Ninety-six of the trainees lived at home, 29 in lodgings, 19 in social services hostels and seven in hospital-type accommodation. By the end of 1984 there were minor changes in this situation. The age distribution of the trainees at the centre was as follows: five trainees aged less than 24 years, 50 trainees 25–34 years, 45 trainees 35–44 years, 24 trainees 45–54 years, 14 trainees 55–64 years and 13 trainees 65 years or over.

Contacts with general practitioners

Figure 1a illustrates the number of contacts with general practitioners in 1984 for the Down's syndrome group by place of residence and shows that all had consulted their general practitioners on at least one occasion during the year. For the larger group suffering from non-specified mental handicap Figure 1b shows that only 62% had been seen by their general practitioners. There was a striking difference between the ease with which data were available in the two groups. For the Down's group all of the carers appeared to be enthusiastic about producing the information. For 44 of the trainees suffering from non-specified mental handicap, on the other hand, the care-givers were unable or less willing to cooperate and all the missing data refer to this group.

If 'adequate' contact with the general practitioners for a vulnerable group is defined as four or more consultations per year, Table 1 shows that for the Down's group the adequacy of the consultation rate was found to be independent of the place of residence. For those with non-specified mental handicap Table 1 shows that trainees were more likely to have an 'adequate' number of consultations if they lived in supervised social services hostels or lodgings.

Table 1. Adequacy of contact with the general practitioner by place of residence for trainees with Down's syndrome and with unspecified mental handicap.

	Living at home	Living in hostel/lodgings	Total
<i>Trainees with Down's syndrome</i>			
Adequate GP contact ^a	9	4	13
Inadequate GP contact	18	3	21
Total	27	7	34
	NS		
<i>Trainees with unspecified mental handicap</i>			
Adequate GP contact ^a	4	13	17
Inadequate GP contact	41	15	56
Total	45	28	73
	$P < 0.01$		

^a Adequate contact with the general practitioner was defined as four or more consultations per year. NS = not significant.

Table 2. Medical problems already managed and newly discovered or inadequately managed in the 151 mentally handicapped adults in the training centre.

	Managed	Unmanaged
<i>Disorders of the circulatory system</i>		
Severe hypertension		2
Moderate hypertension		6
Arrhythmia		3
Chronic left ventricular failure		1
Non-cyanotic congenital heart disease	8	1
Peripheral vascular disease		1
Varicose ulceration		2
<i>Disorders of the respiratory system</i>		
Chronic bronchitis	10	18
Acute bronchitis		2
Bronchiectasis		1
<i>Disorders of the nervous system</i>		
Epilepsy	3	10
Cerebral palsy		10
Spina bifida	1	2
Old poliomyelitis	1	
Peroneal muscular atrophy		1
Drug induced parkinsonism		3
Tardive dyskinesia		1
<i>Disorders of metabolism</i>		
Diabetes mellitus	2	2
Hypothyroidism	3	1
Acromegaly		1
Gross obesity		20
<i>Disorders of the bones and joints</i>		
Arthritis		5
Congenital dislocation of the hip	3	
Gross spinal deformity	8	
<i>Disorders of the skin</i>		
Psoriasis	1	2
Seborrhoeic dermatitis		1
Alopecia areata in Down's syndrome		5
Severe acne	1	5
Scabies		1
Head infestation		6
<i>Disorders of the eyes</i>		
Errors of refraction	30	30
Squint		6
Cataract	2	2
Blindness	1	
<i>Disorders of hearing</i>		
Hearing impairment	2	34
Chronic suppurative otitis media		1
Otitis externa		2
Total occlusion of external auditory meatus by wax		3
<i>Disorders of digestive tract and abdominal wall</i>		
Abdominal hernia		2
Ulceration of skin overlying abdominal hernia		1
Inguinal hernia		2
Prolapsed haemorrhoids		2
<i>Disorders of genitourinary system</i>		
Hairgrip in urethra		1
Hydrocoele		1
Undescended testis		1
Urinary infection		2

Physical problems

The main findings are represented on Table 2. Down's syndrome comprised the largest identifiable group with a total of 34 subjects. Despite the fact that only two trainees had been subjected to any investigation of thyroid function none of the remaining 32 were placed in the 'unmanaged' column on this basis although it is recognized that they are at high risk of developing hypothyroidism.^{7,8} Nine of the care-givers were aware of the existence of an association between Down's syndrome and thyroid disease but had never discussed the problem with their general practitioners. Of the eight Down's syndrome trainees suffering from associated congenital heart disease only three had received any form of follow-up. One of these who was found to be breathless and cyanosed was later investigated in hospital and was found to have a shunt reversal. His symptoms had been regarded by the care-giver as a normal concomitant of the syndrome which did not require any special treatment.

Obesity in the Down's group was found to be common and had become a significant handicap in five trainees who, although their height was less than 1.5 m, weighed over 72 kg. In none of these had dietary restriction been considered; in fact two of the trainees were given sweets as rewards in ill-conceived programmes of behaviour modification. The incidence of hypertension (diastolic pressure persistently above 100 mmHg) in trainees aged over 30 years was 8%. This is lower than the incidence of 15% in the whole population aged over 30 years reported by Fry.⁹ This finding was not unexpected because of the lower levels of recorded blood pressure which have been reported in Down's syndrome.¹⁰ The incidence of chronic bronchitis in trainees over the age of 30 years was 29% compared with 20% in the whole population reported by Fry.⁹ Only three trainees were aware of any association between cigarette smoking and chronic bronchitis and of these none had been encouraged to stop smoking.

Epilepsy places a considerable extra burden on those caring for mentally handicapped people. In 1984 over 400 epileptic attacks were observed at the centre among the 13 trainees known to be suffering from epilepsy. Questioning of the care-givers and the trainees revealed that only three of the trainees had any regular review of anticonvulsant drugs prescribed and all three attended hospital outpatient departments. Three patients had been maintained on multiple drugs over periods of many years. The clinical signs of toxicity are difficult to elicit in mentally handicapped people¹¹ and so the monitoring of blood levels is of special importance.

Frequently visual impairment had been suspected by observations made by instructors in the work situation. The loss of eye contact which is of particular importance in communicating with mentally handicapped people comprised a serious additional handicap in seven of 30 trainees who were shown to have poor vision resulting from correctable errors of refraction and were therefore placed in the unmanaged column in Table 2. It was found that 34 trainees were further handicapped and isolated on account of hearing impairment. This finding was unexpectedly low, possibly due to the simple clinical method of testing used. A previous study at an adult training centre reported an incidence of hearing loss in the Down's group of 69% and in the non-Down's group of 40%.¹²

Disorders of speech production were common. Twenty-five of the 34 Down's subjects were difficult to understand on account of disfluency and lack of clarity even when they produced sentences of acceptable grammatical construction. In 30 of the non-Down's group (88%) the problems of communication were compounded by the existence of cleft-palate, neuromuscular and non-classifiable disorders affecting articulation.

The Gunzberg charts showed that for all trainees only 29 could relate experiences in a coherent way and on this basis might be expected to be able to describe medical symptoms. Whether this expectation is reasonable remains in doubt. For example one of the trainees placed in the most competent group was able to describe urinary symptoms but was unable to go on and explain that three years earlier he had placed a hair grip in his urethra and that he was able to feel this in his perineum. This was not thought to be due to reticence on his part.

Eleven of the trainees (6.5%) were difficult to assess because they presented various behaviour disorders, poor attention, hyperactivity, stereotyped activity and apparently threatening behaviour. This group would have been unmanageable in the normal consulting room situation.

Discussion

In the national morbidity survey of 1970–71, 67% of the population consulted their general practitioner on at least one occasion during the year.¹³ In this study all of the Down's group had consulted their general practitioner on at least one occasion and for the non-specified mental handicap group the corresponding figure was 62%. For the whole group the figure was 65%. In this respect at least the present results suggest that mentally handicapped people do not place a greater burden on general practitioners than do the general population.

The contact rates for the mentally handicapped may be compared with other vulnerable groups, for example those aged over 75 years and under four years. In the 1970–71 morbidity statistics the average number of consultations for those aged over 75 years was 6.0 per person per year and for children aged 0–4 years was 4.2 per person per year. For the Down's group in this study the contact rate was 3.5 and the corresponding figure for the group suffering from non-specified mental handicap was 2.2 per person per year. For all trainees only 28% had an adequate contact rate when compared with other vulnerable groups.

The lack of data concerning consultations to those people suffering from non-specified mental handicap is striking. It is possible that care-givers are seeking to expand the areas of development and life possibilities for the Down's syndrome person but that such opportunities are being missed by those caring for people with non-specified mental handicap. Another explanation may be related to the major differences in the pattern of mild mental handicap between socioeconomic groups. The prevalence of mild mental handicap has been found to be nine times greater among children of unskilled manual workers,¹⁴ and as care-givers they are less likely to be able to provide information.

The large number of unmanaged problems in trainees at the centre and listed on Table 2, demonstrates a need for a wide variety of medical intervention which was not being met. For the majority of sufferers this has meant a generally poorer quality of life but for others, for example two people found to have diastolic blood pressures in excess of 115 mmHg, the implications were more serious. What are the reasons for this situation? It is possible that the radical changes in the planning and delivery of services to mentally handicapped people and their families over the past few years have placed too great a burden of care on general practitioners. Another interpretation may be that among doctors there are widespread prejudices and low expectations regarding mentally handicapped people.

The report of the first national survey of adult training centres in England and Wales showed that only 17% of over 24 000 trainees were considered to be capable of using medical, dental and social services.¹⁵ The difficulties of communication

between mentally handicapped people and their advisers are considerable. Mental handicap implies language restriction even when the level of speech appears to be satisfactory. In this study inadequate levels of communication among trainees were found to be the major obstacle in their medical assessment.

Many of the trainees were cared for by ageing relatives who had increasing difficulty in speaking for their mentally handicapped sons and daughters. Several parents described how they felt worn out by the stresses of caring and how their own health was deteriorating as a consequence. Common treatable complaints were often seen by the carers as being relatively trivial when compared with the major handicaps which were untreatable and for this reason medical advice was not sought. Other parents described how when visiting the doctor's surgery they were embarrassed by the behaviour and appearance of their offspring who were seen as objects of pity.

How can the care of mentally handicapped adults be improved? The medical care of mentally handicapped children is supplemented by community medical officers. When the young person moves into the adult training centre this extra care ceases. A simple expedient would be to encourage community medical officers or general practitioners with an interest in mental handicap to provide this service. But this step would be inconsistent with the main thrust of current policy which is to manage mental handicap in a social context.

If we are going to provide an effective community-based service to meet the medical needs of mentally handicapped people we have to develop an increased awareness of their special needs. In a report concerning the mothers of babies with Down's syndrome, Murdoch found considerable neglect by the family doctors involved.¹⁶ Only 60% of cases were seen by their general practitioners when they were discharged from hospital and in only half of the cases did the mothers find the general practitioners helpful. Murdoch found that the discriminating feature about helpful doctors lay mainly in the attitudes which they conveyed to the mothers. A sample of general practitioners in Bristol did not believe that they had any special role beyond the provision of general medical care. Although few of them had received any training in mental handicap there was a mainly negative response to the proposal that more training should be offered.¹⁷

The task of general practitioners is made more difficult simply because they lack information on the way in which local services are organized. It is not generally appreciated that most health districts now employ one or more community mental handicap teams. The core membership of the teams usually consists of community mental handicap nurses and social workers with part-time input from a range of specialists. If support for mentally handicapped people in the community is to be maximized it is essential for the primary care team and the community mental handicap team to work together. Health visitors, in particular those who have undergone further training, can make a substantial contribution to care.¹⁸ We can look to voluntary organizations such as the National Society for Mentally Handicapped Children and Adults and the National Centre for Down's Syndrome to provide us with up-to-date information and also resources. Happily we are losing our scepticism about these highly professional organizations.

Part of the explanation for the disappointing findings of this study is that general practitioners often assume that the medical care of mentally handicapped people falls within the orbit of the specialist and tend to ignore the fact that the discipline of the consultant in mental handicap is psychiatry. The medical care of mentally handicapped people living in the community

must be seen as the responsibility of the primary care team. We have to ensure that their needs are not overlooked and that they are referred whenever necessary to the appropriate specialist service. There is an urgent need to screen mentally handicapped adults, particularly those with Down's syndrome, for additional sensory handicaps.

References

1. Department of Health and Social Security. *Better services for the mentally handicapped (Cmnd 4683)*. London: HMSO, 1981.
2. Department of Health and Social Security. *Report of the committee on local authority and allied personnel social services. The Seeborn report (Cmnd 3703)*. London: HMSO, 1968.
3. Wilkinson G. Community care: planning mental health services. *Br Med J* 1985; **290**: 1371-1373.
4. Mittler P. *People not patients*. London: Methuen, 1979: 125.
5. Gunzburg HC. *Progress assessment charts*. Birmingham: SEFA Publications, 1974.
6. Benson BA, Reiss S. A factor analysis of emotional disorders in mentally retarded people. *Aust NZ Dev Disabil* 1984; **10**: 135-139.
7. Baxter RG, Martin FR, Myles K, et al. Down's syndrome and thyroid function in adults. *Lancet* 1975; **2**: 794-795.
8. Murdoch JC, Ratcliffe WA, McLarty DE, et al. Thyroid function in adults with Down's syndrome. *J Clin Endocrinol Metab* 1977; **44**: 435-458.
9. Fry J. *Common diseases, their natural incidence and care*. 2nd edn. Lancaster: MTP Press, 1979.
10. Richards BW, Enver F. Blood pressure in Down's syndrome. *J Ment Defic Res* 1979; **23**: 123.
11. Pond D. In: Craft M (ed). *Tredgold's mental retardation*. 12th edn. London: Balliere Tindall, 1979.
12. Nolan M, McCartney E, McArthur K, Rowson VR. A study of learning and receptive vocabulary of the trainees of an adult training centre. *J Ment Defic Res* 1980; **24**: 271-286.
13. Department of Health and Social Security/Office of Population Censuses and Surveys/Royal College of General Practitioners. *Morbidity statistics from general practice 1970-71. Second national study*. London: HMSO, 1972.
14. Birch HG, Richardson SA, Baird D, et al. *Mental subnormality in the community*. Baltimore: Williams and Wilkins, 1970.
15. Whelan E, Speake B. *Adult training centres in England and Wales: report of the first national survey*. Manchester: National Association of Teachers of the Mentally Handicapped and Hester Adrian Research Centre, 1977.
16. Murdoch JC. Experience of the mothers of Down's syndrome and spina bifida children on going home from hospital in Scotland 1971-1981. *J Ment Defic Res* 1984; **28**: 123-127.
17. Ineicher B, Russel O. *Mental handicap and community care. The viewpoint of the general practitioner. Mental handicap studies research report 4*. Bristol: University Department of Mental Health, 1980.
18. Cunningham CC, Aumonier M, Sloper P. Health visitor support for families with Down's syndrome infants. *Child Care Health Dev* 1982; **8**: 1-19.

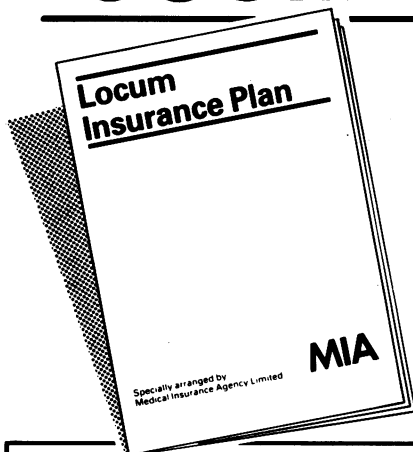
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