OCCASIONAL PAPER 47

Primary Care for People with a Mental Handicap

ROYAL COLLEGE OF
GENERAL PRACTITIONERS

Published by
The Royal College of General Practitioners

The British Journal of General Practice

Journal of
The Royal College of General Practitioners

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Report of a Working Party on the Interface between the Primary Care Team and People with a Mental Handicap

**ROYAL COLLEGE OF
GENERAL PRACTITIONERS**

Published by
**The Royal College of General Practitioners
London**

November 1990

The Royal College of General Practitioners

Charter

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Recommendations

1. Communications

1.1 Formal communication between hospital, social services, education and primary care must be established.

1.2 When a child with a mental handicap is recognized, communication between the paediatrician and the general practitioner is of prime importance. Hospital maternity departments communicate well with midwives and health visitors and this is to be welcomed.

1.3 Similar arrangements must be made to work between hospitals and social services departments, and between primary care teams and social services departments. Resources should be made available to facilitate these arrangements.

1.4 During the first five years of life all services to the child should be co-ordinated by the health visitor, who should be nominated 'case manager'. In exceptional circumstances, such as where the child is in full-time nursery education or is regularly attending a family centre, another professional may fill this role.

1.5 In the school-age child the case manager may well be a member of the education authority; communication links to the primary care team, the social services departments and the district handicap teams will need to be kept functioning.

1.6 In adult life communication must be established between primary health care, further education and social services departments and the voluntary organizations, with a case manager having responsibility for ensuring that the necessary services to the individual and his carer are provided.

1.7 Any changes in treatment or medication made by medical officers during periods of respite care or admission to hospital or other types of accommodation must be communicated to the general practitioner caring for the individual on his return home.

1.8 Members of the community handicap team should include, and meet regularly with, members of the primary health care team.

2. Acute admissions policy

For effective care an acute admissions service must be established. It is well recognized that both hospital and social services provision is inadequate but that in each locality arrangements for emergency admissions should be made.

3. Medical care

3.1 This group of patients, whose morbidity is often hidden, should receive a regular medical examination and general assessment as of right.

3.2 People with a mental handicap who are resident in NHS hospital accommodation, local authority social services accommodation, or private accommodation should have ready access to a general practitioner.

4. Registers

The establishment by local authorities and health departments of registers of the names of people with a mental handicap is welcomed.

5. Education

All medical schools should include in their undergraduate courses a period of formal teaching on the problems of people with a mental handicap. During vocational training courses, trainee general practitioners should devote at least one full day to mental handicap. They should see, and perhaps examine, some patients and talk to their relatives to gain firsthand experience of the problems involved. Continuing progress in the management of handicap and the facilities available locally should be part of every postgraduate centre's education programme.

6. Carers' support groups

The development of self-help groups for carers is to be welcomed and general practitioners should be encouraged to promote their activities, working alongside other professionals and the carers themselves.

7. Information

Arrangements should be made to improve access to local and national information on all aspects of the care of people with a mental handicap.

8. Genetic counselling

In most regions genetic counselling is available but the Government should, through its publicity channels, inform general practitioners of the extent of the service and improve the input of recent genetic research into the teaching of undergraduates and practising doctors.

9. Facilities

9.1 Rigorous guidelines should be applied to the supervision of voluntary, private, social services and hospital accommodation for the mentally handicapped and should be enforced. Reports of inspectors should be readily available.

9.2 There is no adequate provision for:

- people with mental handicap who are psychiatrically ill
- people with mental handicap who are offenders
- people with mental handicap who are the victims of physical and sexual abuse.

Resources in terms of trained staff and service provision should be made available to correct this.

10. Speech therapy

Provision of speech therapy should be adequate nationwide. People with a mental handicap should have specialist help in overcoming communication problems. Carers point to an enormous need in this area which is not being met.

11. Consent

General practitioners would welcome clear guidelines from the legal authorities on the question of consent to treatment for the mentally handicapped, especially for adults.

Introduction

IN 1988 the Chairman of the Clinical and Research Division of the Royal College of General Practitioners initiated the formation of a working party to study the interface between general practitioners and people with a mental handicap.

It was decided at the outset to make this a multidisciplinary group so that all shades of opinion could be collected. It was felt that there was a gap between the attitudes of general practitioners to people with a mental handicap and those people's expectations of their doctor. In defence of the general practitioner it must be said that undergraduate and postgraduate instruction in this area is sparse. Added to this the average general practitioner will have on his list only a handful of people with a mental handicap so that his opportunities to learn by experience are limited. In 1988 the Government was actively encouraging the closure of long-stay hospitals and promising the concept of 'normalization' and care in the community. It was felt within the Royal College of General Practitioners that this could lead to problems in primary care.

The working party

The general practitioner members of the working party were selected on the grounds of proven long-term interest; most had worked part time in the field, some had a relative with a mental handicap. The voluntary organizations were invited to send representatives and they responded magnificently, their expertise proving of enormous value. They offered information on the workings of their organizations and provided feedback to the working party on the problems of carers. The rest of the group represented the hospital and social services sectors. The general practice members of the working party are extremely grateful to the other members for their support and instruction.

Quarterly meetings over two years have led to the production of this report. Inevitably there have been areas of discussion where members of the working party have held differing views, and since contributions were also invited from people with relevant experience who were not members of the working party, the report has been compiled as a series of chapters by individuals. This is seen by the group as one of the strengths of the report.

Terminology

Some problems of terminology arose during the meetings, but it was generally agreed that throughout the report the phrase 'people with a mental handicap' should be used. The term 'people with learning difficulty' has recently gained favour with some professionals, most often applying to children in an educational setting, but to some people the words 'learning difficulty' appear to diminish the seriousness of the issues. In other parts of the world other terms are used, for example in Australia 'intellectually disadvantaged citizen' is used and in New Zealand, 'people with intellectual handicap'.

Problem areas

The working party is aware that this is not a comprehensive report. There are large areas which it has not been possible to cover. For example, in the general population the problems of physical and sexual abuse are becoming apparent — the whole of the iceberg is beginning to emerge — but as yet, although anecdotal evidence suggests that these problems are serious ones which will need to be addressed, they have not been delineated in people with a mental handicap. Also at present there is a significant lack of information about mental handicap amongst the ethnic minority groups.

At the time of writing, the government White Paper on community care (Secretaries of State, 1989) had not become operational, making it difficult for the working party to make firm comment on its content.

Among many troubled areas discussed by the group have been the difficulties of siblings of people with a mental handicap, the current dangers of hepatitis B and AIDS, the everlasting shortage of resources with which to provide adequate care, and the real problems of diagnosis and treatment.

A key role

There was no doubt, however, that the general practitioner can play a key role in the lives of people with a mental handicap and their families. He or she is in the unique position of having knowledge of the physical and emotional well-being of all members of the family and responsibility for their ongoing care. Three basic kinds of help are needed:

1. Understanding just what the child's handicap is, how it will affect development and how it will affect their lives
2. Contact with parents of children with similar problems. This is important not only in terms of practical information and advice, but also in terms of social support
3. Factual knowledge of rights to benefits, allowances and services.

As an essential member of the primary health care team, the general practitioner is in a position to offer this help. Fundamental to care in the community is the acknowledgement that people should be able to enjoy as normal a life as possible, receiving the same services as any other member of the community with special help where necessary.

The members of the working party hope that the report will contribute to an improved understanding of people with a mental handicap by members of primary care teams.

Reference

Secretaries of State for Health, Social Security, Wales and Scotland (1989) *Caring for People. Community Care in the Next Decade and Beyond.* Cm 849. London, HMSO.

CHAPTER 1

Mentally handicapped people, community care, and the general practitioner

David Livingstone, MRCGP

SIR Roy Griffiths observes that "... the family doctor service is unique in having near universal contact with the whole population ..." (Griffiths Report, 1988). Good practice at present works in harmony with other agencies where non-medical needs are concerned. Sir Roy recommends that a general practitioner's duties should be sharply defined. Paragraph 6:14 of his report states:

> "The contract between the family practitioner committee and the general medical practitioner should be amended to specify that the GP, either directly or through his practice staff, should inform the social services authority of possible community care needs of any patient registered with him who seems to have such needs which are not being met and which appear to be unknown to the social services authority. The GP should also be able to satisfy himself that the social services authority has considered the case. The authority should therefore confirm that it has received the referral from the GP, and tell him what action it proposes to take."

The general practitioner is well placed to act his modern part as a co-ordinator of care between different agencies. No carer is entitled to play god, but a doctor has a duty to define and protect the medical needs of his patient.

Changes in attitude

The general practitioner, if he comes to study the changes in mental handicap care over the past two decades, must feel bewildered by the mass of government papers and reports. However, to understand the sources of the impetus for the changes which have taken place and are being contemplated, he must follow the evolution of mental handicap care from the time of the industrial revolution onwards. Bit by bit throughout the nineteenth century a process of segregation of mentally handicapped people took place. At the beginning of the twentieth century this became conscious official policy. The reason for this was the belief that unless they were kept separate from the rest of the population, mentally handicapped people would lower the intellectual level of the 'race'. After this theory was discredited, custody was oriented towards the medical and nursing professions.

Hospital care came to be seen as exclusive and regimented. The scandal connected with Ely Hospital in 1969 prompted a resolve that mentally handicapped people should no longer remain 'out of sight, out of mind'. The White Paper *Better Services for the Mentally Handicapped* (Secretaries of State, 1971), was followed by a 30% drop (by 1986) in the population of the mentally handicapped in hospital. The 1971 Education Act recognized the educational needs of mentally handicapped children, yet there is no legal obligation to meet the needs of adults with a mental handicap.

From the 1950s onwards it became fashionable to believe that psychiatric and behavioural disturbances in people with a mental handicap could be managed in community facilities. Day (1986) contends that there is no evidence to support this belief.

The mass exodus of mentally ill people from hospital, especially in the United States and Italy, has proved that the ideological transfer of people out of hospital without a credible alternative having been thought through is a recipe for disaster. The transfer into the community of the 1500 residents of Darenth Park hospital in Kent, researched over a five-year period (1981-1986) by Dr Lorna Wing, benefited no more than a third of those transferred. On the other hand, many excellent services for the mentally handicapped have been set up all over Europe, especially in Sweden, where the concept of normalization originated. In the UK the Welsh scheme, NIMROD, which offers places in normal housing, has received acclaim.

Ideas on community and residential care are constantly in the melting-pot, and the Independent Review of Residential Care (1988) says: "... people need no longer be faced with the stark choice between staying in the community or moving into residential care ..." The concept of a plurality of care is beginning to take shape. Kathleen Jones, Professor of Social Policy at the University of York, describes the architect John Burrell's 'new communities' model for the development of mental hospitals as small towns. This pattern could also be followed for mental handicap hospitals (Jones, 1987).

Many people nowadays think that mental handicap should not be regarded as a medical problem at all, and the term 'mental handicap' is considered by some to be distasteful.

In their policy survey entitled "Community care in Britain" Hunter and Wistow (1987) searched amongst a maze of statistics for a common policy and found none. They placed Scotland, in spite of higher financial input from the exchequer, at the bottom of the community care league table, Wales at the top; England they deemed to be "good in parts".

Towards a definition

What is community care? The writers do not attempt a definition. Neither do the Office of Health Education and MENCAP (Taylor and Taylor, 1986): "... Even the *Care in the Community* Green Paper," they concede, "failed to define or discuss what it meant by community services, limiting its analysis to the development of classical services like adult training centres and residential hostels ..."

Community care is a controversial term, interpreted by some, who regarded the hospital service as a complete anathema, as a means of providing a domestic environment for all but a few. Others, while accepting that integration into the community is suitable for some who are at present hospital residents, believe that the hospital should be regarded as part of, not distinct from, the rest of the community. They see it as a resource medical centre, as a haven for those whose families are in crisis and as a refuge for mentally handicapped people whose parents are ageing. Many people believe that rather than placing its emphasis on transfer to the outside world of a small minority group, community care should concentrate its attention on the provision of services for those who live at home.

Prevalence

Over 160 000 people in the United Kingdom, that is 3 per 1000 of the population, are severely mentally handicapped (measured in terms of an IQ of under 50). Mild mental handicap on the other hand (IQ range of 50-70) affects over a million people. There is a quite distinct difference between mild and severe mental handicap in terms of distribution throughout the social classes. The majority of those with mild mental handicap are from the socially disadvantaged classes, groups 4 and 5. In view of the present commitment to community care, these figures are relevant not just to sociology and politics but also to general practice. If, as has been estimated, the average general practitioner's list (2000 patients) has a ratio of 30-40 *mildly* mentally handicapped people to 6-8 *severely* mentally handicapped people, one has to conclude that in poorer areas doctors' lists will have a greater proportion of people with a mild mental handicap to those who are more severely affected. Recognition that mild mental handicap is principally to be found amongst socially disadvantaged groups may have contributed to the belief that care should be vested solely in the community.

An increasing need

As genetic counselling becomes more and more important for the detection of abnormality during early pregnancy, the general practitioner will have to keep pace with new discoveries. New syndromes may be followed by new treatments which may add new dilemmas, such as whether termination of pregnancy should be offered or accepted.

Amongst both psychiatrists and geneticists, activity has intensified, not abated. Unless in the wake of devolution from hospital supervision specialist practitioners are appointed to fill the vacuum, general practitioners will have to undertake primary care for these patients.

Greater awareness of the educational, occupational, social and recreational needs of mentally handicapped people is a new and welcome reality, but general practitioners and psychiatrists alike have warned that their medical needs are never negligible and often paramount.

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CHAPTER 2

Mental handicap

Mary Holland and Carol Youngs, RGN

MENTAL handicap is a permanent condition and can occur in any family. It may be due to genetic or environmental factors, or indeed to both. The onset can be before, during or after birth. People with severe mental handicap may also have physical or sensory handicaps. The mentally handicapped cannot be cured, but their development can be improved with the right kind of education, training and social support.

The number of people in Britain with mental handicap is not recorded on any register. Calculation of the numbers is therefore approximate and based on prevalence rates. The most frequently quoted prevalence rate for all types of mental handicap is around 20 per 1000 population. Given a total population of 56 million people, one arrives at a figure of 1.25 million people with mental handicap — 2% of the population, or 1 in every 50 people.

Prevalence rates for severe handicap are considerably lower. The frequently quoted rate for severe mental handicap is 3-4 per 1000, suggesting that there are around 160 000 severely mentally handicapped people in the United Kingdom. About 1 in 3 severely mentally handicapped people have a sensory or motor disability in addition to impaired mental ability. Studies of mentally handicapped children have shown that 1 in 3 suffer from epilepsy, 1 in 5 have visual or hearing defects, and 1 in 20 is blind.

It has been estimated that on the average general practitioner's list of 2000 patients, there would be 6-8 people with severe mental handicap. However, about 50 000 of the total in this group are in hospital (1988); the figure is probably reduced to 4-6 per general practice list.

A study in Wealden

A study undertaken on behalf of Wealden MENCAP in East Sussex produced the following information about the mentally handicapped in that area who were living at home.

Classification

Nineteen per cent were classified by their families as 'mild'. This suggests that a large majority of those with a mild mental handicap are not receiving any specialist health or social services assistance; it may well be that they and their families do not need it.

Forty-nine per cent were classified as 'moderately' handicapped, and 32% 'severely' handicapped.

Over half (57%) of the mentally handicapped people at home also had some form of physical disability. Epilepsy and ambulatory problems were significant; 1 in 10 were partially sighted or blind (Table 1).

Table 1. Percentage of mentally handicapped people with physical disability.

	%
Fits/epilepsy	*26*
Walks with difficulty	*15*
Unable to walk at all	*10*
Partially deaf	*6*
Partially sighted	*6*
Blind	*4*
Deaf	*1*

Speech therapy

At least 6 out of 10 (63%) of the study group had a speech problem, including 30% who had little or no speech. It is no wonder that carers are clamouring for the services of speech therapists above all. Even those with good or reasonable speech may at some time have needed or will need speech therapy.

Behaviour problems

The biggest single problem area was poor or unacceptable behaviour. Communication difficulties were mentioned as leading to frustration and anger. It is obviously hard for some parents to rate their offspring in these terms. On personal interview there was a tendency for carers to underrate behaviour problems, even when these were causing significant difficulty. However, from the responses to several of the questions, it is clear that challenging behaviour is a major cause of stress within the household, and that effective help is not often forthcoming.

The behaviour problems encountered were:

- — non-cooperation, tantrums, swearing, aggression, violent temper (32%)
- — behaviour difficulty in going out (shopping, visiting) (11%)
- — communication problems, verbal and other (8%)
- — breaking or damage to furniture (3%).

In an open-ended question, parents were asked to describe the main problems they were facing, or had faced in the last year. As shown below, many of these related to the strain of giving continuous care. They were:

- — constant care, vigilance, having to do everything (18%)
- — tied, lack of freedom, social isolation (14%)
- — strains within the family, marital strain, not able to give enough attention to other members of family (14%)
- — all night care (12%)
- — personal suffering, mental/physical illness, fatigue (8%)

Problems with nursing/medical care

Many carers mentioned nursing or medical problems: 1 in 5 had problems coping with incontinence, and 1 in 10 with lifting. There was a catalogue of problematic health matters:

— incontinence (19%)
— non-ambulant, lifting/pushing/carrying (10%)
— worry about injury/illness/surgery to the patient (12%)
— bathing/washing/dressing/hygiene (8%)
— control of epilepsy/fits (4%)
— having to feed the handicapped person (4%)
— anorexia (4%)
— obesity/obsession with eating (3%)
— problems with teeth/dentist (5%)
— problems with sight/optician (3%)
— problems with feet/special shoes (3%)
— insufficient physiotherapy (3%).

Lack of support or the right type of assistance was another recurring theme. Many carers were not getting adequate breaks or help in the home, and 14% specifically mentioned poor service by professionals. Having a teenager or adult with a mental handicap for whom little social life was provided could cause feelings in the carers of never having time of their own. They felt the need for:

— sitters/minders, help in the home (15%)
— better arrangements for respite care (11%)
— social life, holidays, for their son or daughter (12%)
— someone (accessible) to talk to about the problems (14%).

Some families recounted problems with training centres or with schools (8%). The stress and anguish caused by such situations should not be underestimated. Several carers told of adults who had been upset or been poorly behaved at training centres; attendance had been stopped, with the result that the person was at home all the time.

Some carers (14%) commented on the difficulties encountered in having to make frequent trips to hospitals, clinics and general practice surgeries. In rural areas, this can be exacerbated by transport problems. Then, on arrival at the appointment, it was often found that staff were ill-informed and inexperienced in treating someone with a mental handicap. The questionnaires made it clear that doctors were among the worst offenders.

Communication needs

In general, the health care needs of the mentally handicapped are similar to those of the rest of the population. However, many parents have said that the existence of mental handicap tends to obscure other health needs. There is also the problem of failed communication. General practitioners should be particularly sensitive to improving their ability to communicate with people with a mental handicap. Too often the "Does he take sugar?" syndrome persists; discussions are held over the person's head and not *with* him or her. Time spent establishing some form of communication which acknowledges the mentally handicapped person as an individual will be time well spent.

Similarly, some parents continue to 'infantilize' their adult mentally handicapped son or daughter, and may be all too ready to answer questions which the individual could answer for himself or herself, given the opportunity.

CHAPTER 3

The medical needs of adults

Martin Barker, FRCGP *and Gwyn Howells,* RD, MRCGP

AT the age of 19, when people with a mental handicap leave school, they leave the umbrella of the school medical service and their contact with both medical and dental services appears to decrease.

In 1977 a national survey of adult training centres was undertaken (Whelan and Speake, 1977). In all, 24 000 trainees were assessed and only 17% were considered to be capable of using the medical, dental or social services. In this study inadequate levels of communication were found to be the major obstacle to proper medical assessment.

A study of trainees

In a study of 151 mentally handicapped people attending an adult training centre (termed 'trainees'), Howells (1986) found an alarming number of common medical problems which were not known to the trainees' general practitioner, and were not being managed — including problems well known to be associated with Down's syndrome. He also pointed out that many trainees were further handicapped by undiagnosed or unmanaged defects of hearing or vision.

Of the group of 34 Down's syndrome patients, only two had been investigated for hypothyroidism, although it is well recognized that these people are at high risk of developing the problem (Mittler, 1979; Gunzberg, 1984). Nine of the carers knew of this association but had never discussed it with their general practitioner. Eight Down's adults were suffering from congenital heart disease, but only three were under medical supervision.

Eight of the trainees had hypertension (diastolic pressure persistently above 100 mmHg), while in two cases there was a sustained diastolic pressure above 115 mmHg which had not previously been identified.

Gross obesity was common (20 trainees), and in five cases was a significant handicap, but weight reduction had not been considered for any of them.

Chronic bronchitis seemed more common than in the general population, 29% against 20%, but little attempt had been made to discourage smoking.

Epilepsy is a major problem, but of the 13 trainees known to be suffering from epilepsy, only three were under regular review, which was being conducted by the local hospital outpatient department.

Howells also found a case of undiagnosed scabies, six trainees with head lice, three with ear wax, and two with chronic otitis externa. Other minor unmanaged problems which came to light were: two trainees with prolapsed haemorrhoids, two with inguinal hernia, two with abdominal hernia and one with undescended testicles.

Deficiency in care

The medical management of mentally handicapped adults is, then, apparently deficient. There are many reasons why this may be so; some of the lack of primary care may be attributed to the following problems:

1. *Whose responsibility?*

General practitioners often assume that the medical care of the adult mentally handicapped is the province of someone else, but the specialist in mental handicap is usually a psychiatrist by training, not an expert on the management of common medical problems; nor are the community physician and clinical medical officer experts in primary care. The general practitioner may assume that, although these patients live at home, their general medical care is the responsibility of the hospital.

2. *Under-reporting*

Kinnell (1987) highlights some of the difficulties involved, pointing out the under-reporting of physical and mental symptoms. The mentally handicapped person may not communicate his symptoms. His perception of what is tolerable physical discomfort may be distorted by his everyday experience; he may have learnt to suppress mention of bodily functions as being inappropriate; his vocabulary or speech articulation may be limited; or he may not have been given the opportunity to indicate his problem, especially in the context of a family under stress or a busy community home.

3. *Extent of care*

The mentally handicapped patient may seem a difficult one. Howells (1986) found that 10% could not be managed within the normal surgery setting. It is unfortunate that there is often the feeling that they are 'not nice' to deal with, even 'not worth the effort'. A perceived negative response from the general practitioner may alienate the carers so that they do not consult him again. This may be due to the doctor's lack of training and experience in dealing with the mentally handicapped, or to a feeling that his role does not extend beyond the provision of general medical care to the normal population. For example, when a mentally handicapped woman is seen at the surgery, she is rarely offered a cervical smear. If she has a behavioural disorder in addition to her mental handicap it is not surprising that it is difficult to accommodate her within the routine clinic.

4. *Difficulty for carers*

Carers may unwittingly be at fault. Often they are elderly and increasingly unable to address problems on behalf of their relative. Sometimes, in view of the major handicap involved, a common and treatable condition is regarded as too trivial to trouble about, or to 'bother the doctor' with.

5. *Logistical problems*

It is important to appreciate that medical care is not normally available at training centres and social education centres. To obtain primary medical care, therefore, the trainee must make contact outside his 'working' hours or arrange time off from his daytime placement and, if necessary, arrange suitable transport. This often creates overwhelming logistical problems for both patient and carer.

Need for improvements

The solution to these problems is not clear, but as more mentally handicapped people find their way into the community, it has become a matter or urgency to find a way of improving the situation. In 1990 it is projected that nationwide more than 70 000 mentally handicapped adults will attend social education or training centre facilities (even so, places are not available as of right to all those who wish to attend). These people will need regular access to primary care (Taylor and Taylor, 1986).

Attitudes are changing. Many receptionists, nurses and doctors are trying to make their system work for the mentally handicapped, and in many areas this is being facilitated by the community mental handicap nurse, but there must be a case for the regular screening of people with a mental handicap by a general practitioner. The need for this type of screening is well recognized in the young and the elderly — it is also important in the mentally handicapped.

Screening the adult mentally handicapped

The decline in the population of mental handicap hospitals from 60 000 in 1964 to a proposed 30 000 in 1990 has, in some areas, brought the expected improvement in the standards of care for those remaining in hospital. Units have been upgraded, staffing has been improved and patients are being regularly medically assessed by hospital staff, although much remains to be done within the hospital service.

For those living in the community the picture is much less favourable. These people are dependent on their general practitioners for primary care. For those attending adult training or social education centres there would seem to be a simple solution: these centres are seen as key components of mental handicap services in the community and could have the capacity to develop a network of relationships with community organizations and agencies. Already some of them use a variety of specialist advice from community nurses, speech therapists, dentists and other health service staff. It would seem reasonable to encourage general practitioners to provide the medical input into this group. They could provide three useful services:

1. Medical screening for the trainees
2. Facilitating referral to appropriate hospital specialists where necessary.
3. Providing advice to the training centre staff regarding the trainees' general medical problems. Often, members of staff are able to alert doctors to the possibility of sensory problems and changes of mood or behaviour which might signal the onset of psychiatric or physical disease.

Although in line with care of other vulnerable groups, screening of this population will be more time consuming and possibly more difficult to perform than for other groups. The presence of the usual carer and/or community mental handicap nurse could be of value. During screening, the following points should be covered:

1. Social and family history should be recorded to give some insight into the patient's background.
2. Past and present medical history and the existence of acute or ongoing problems will need to be documented and updated.
3. A review of immunization status may help to remedy earlier omissions caused by the mistaken belief that there is danger in immunizing mentally handicapped children. Clear guidelines in the *British National Formulary* indicate that, taking into account the contraindications as set out, tetanus, diphtheria, pertussis, poliomyelitis, MMR and BCG can all be administered in the usual way.
4. A full physical examination should be made.

In men, examination of the external genitalia is important: both herniae and undescended testicles are more common in the mentally handicapped.

In women, with the help of the community mental handicap nurse, breast examination, and when indicated, pelvic examination and cervical smear can be undertaken along the usual Department of Health guidelines. This part of the examination gives the general practitioner an opportunity to ask about menstruation and contraception.

Menstruation

Many mentally handicapped girls suffer from amenorrhoea or oligomenorrhoea. For others, the onset of menstruation is a major problem both for them and for their carers. The menarche has often been the precipitating factor in admission to a mental handicap institution.

Usually, pubescent girls are initially guided by their mothers but they rapidly adopt their own methods of coping with menstruation. The handicapped are more dependent on their carers and consequently, external devices are almost always used. Neat adhesive pads are much more satisfactory than old-fashioned belt and loops; most handicapped girls can be taught how to use them, although patience may be required on the part of the carer.

It is just as common for the handicapped woman to suffer premenstrual tension as for those in the normal population, but in this case it may give rise to behavioural disturbances which will need appropriate treatment. If menstruation is unusually heavy this can be treated by hormonal or non-hormonal methods as the doctor feels appropriate, or the woman may be referred to a consultant gynaecologist. Drug metabolism is in most cases normal although it must be remembered that anticonvulsants such as carbamazepine, phenytoin and phenobarbitone are less effective when co-prescribed with the contraceptive pill; sodium valproate is unaffected.

Malnutrition

Malnutrition occurs in the mentally handicapped: Down's syndrome sufferers appear to have a malabsorption syndrome which results in a suboptimal vitamin and mineral intake; some autistic people exhibit pica, which can result in severe anaemia. Obesity can be a significant extra handicap in itself and requires active and sympathetic management.

Sensory impairment

It is important to prevent the development of secondary handicaps. Because mentally handicapped people are in a continuing learning situation, sight and hearing tests are particularly important. The incidence of visual problems is increased in this group: as many as 30%-40% may have refractive errors. The prevalence of cataract, glaucoma and squint falls within the range of the normal in non-specific mental handicap, though in Down's syndrome the prevalence of visual problems is extremely high. Apart from an increased prevalence of minor problems such as wax and otitis externa, as many as 60%-70% of these patients will have measurable hearing loss and many will be amenable to correction by the use of hearing aids.

Examination of the heart

Examination of the heart will yield an increased number of abnormal findings: many of the disorders, such as Down's syndrome, Noonan's syndrome and William's syndrome include a cardiac abnormality. Some are amenable to treatment.

Pulmonary problems

In Howells' (1986) survey pulmonary problems seemed to be directly related to heavy smoking. People with a mental handicap who smoke should be made aware of the dangers in the same way as the rest of the practice population.

Stool examination

Unfortunately, in mental handicap hospitals examination of stools has revealed high levels of infestation with all types of worm. Threadworms, roundworms, whip worms and even tapeworms have been reported (Silverstone N, personal communication). This is presumably a problem of institutional living and it is to be hoped that it will recede with the change to community care.

Skin problems

All the common skin diseases affect the handicapped and will require the usual treatments. A special search should be made for scabies and infestation by lice, as these are both more common in people who may have lived in institutions.

Incontinence

Where incontinence is present an assessment may be helpful. Routine urine analysis should be undertaken to exclude infection. The expertise of the district nurse in dealing with incontinence is invaluable, especially where appliances are needed. In some cases bladder training will be successful, and a behavioural approach could be introduced where appropriate. Nocturnal enuresis in the mentally handicapped may be treated as in the general population.

Down's syndrome

In the population of the mentally handicapped, Down's syndrome is the largest identifiable group (40%). It presents its own unique screening protocol which is fully dealt with in Chapter 7.

Drug therapy

Drugs being administered must be evaluated and then reassessed, especially in epileptics; possible drug interaction should be noted (Chapter 8).

Dental health

An examination of the mouth will reveal the state of dental hygiene. Referral to a specialist dental centre may be appropriate; many areas have this specialist facility available.

Social assessment

Any screening procedure will also inevitably include some assessment of social attainment, use of language, level of comprehension, and assessment of personality and mental state. Dementia and depression may co-exist as they do in the elderly.

Conclusion

Diagnosis and treatment of all these conditions in people with a mental handicap is well within the scope of the general practitioner and can be of enormous value. Screening clinics would seem to be the way to provide necessary services to this vulnerable group.

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CHAPTER 4

The child with mental handicap

Gwyn Howells, RD, MRCGP

CHILDREN with learning difficulty without any obvious neurological or other disability, together with those children with specific defects of the nervous system, comprise the largest group of handicapped children in the community (Schutt, 1980). Frequently the paediatrician will identify the handicapped child in the neonatal period. Some children will appear to be quite normal at birth but are later shown to be handicapped. Often the mother or grandmother will be unhappy about the child's development, or the general practitioner or health visitor may recognize delayed milestones.

Aetiology

Mild mental handicap

No apparent cause will be found in the majority of cases especially in the large number of children with mild mental handicap who come from families in the lower socioeconomic groups. Usually they are of normal physical appearance.

Environmental problems like poor housing, poor nutrition, excessive smoking and alcohol or drug abuse can affect the fetus and can slow the development of the young child. Premature birth, difficult delivery and low Apgar scores compound the problem. Similarly a child deprived of learning opportunities will not develop to its full potential. Inadequate parenting resulting from separation from the mother, either physically or emotionally, may also give rise to handicap.

Severe mental handicap

Usually these children do not look normal. More often than not their parents are of normal intelligence. The handicap in these cases has its roots in a primary biological impairment.

Where the cause of the handicap is apparent, the aetiological factors can be divided conveniently into prenatal, perinatal and postnatal abnormalities:

Prenatal:
- chromosomal abnormalities
- metabolic disorders
- intra-uterine growth disorders
- cerebral malformations
- infections (rubella, toxoplasmosis, cytomegalic inclusion diseases)

Perinatal:
- gestational disorders (prematurity, small-for-date babies, postmaturity)
- hypoglycaemia
- hyperbilirubinaemia
- asphyxia
- intracranial haemorrhage

Postnatal:
- infection (encephalitis, meningitis)
- trauma (including child abuse)
- hypothyroidism
- gross brain disease of the postnatal period (neoplasms and heredogenerative disorders).

Diagnosis

Whenever developmental delay is suspected the child should be referred to a specialist in developmental paediatrics. A full history, examination and routine investigation are obligatory. These would include a urine analysis and blood count. Further diagnostic tests might include serum and urine assays, and TORCH titres. X-rays of the skull are necessary when the head is of abnormal size or shape and in infants where prenatal infection producing calcification is suspected. Thyroid function tests should be carried out where hypothyroidism is a possibility. Chromosomal analysis is desirable when the infant is of unusual appearance or if there is a family history of chromosomal disorder.

Although the number of positive tests is small and often precise diagnosis is of little benefit to the child, it is important that thorough investigation is carried out.

It is wise to consider the fragile X syndrome as a diagnosis in any child with unexplained developmental delay and normal neurological signs. The chances of finding it in such a child are between 1 in 10 and 1 in 15. The mother is always the carrier (Bundey, 1990).

The diagnosis of mental handicap may become complicated when there are associated defects such as cerebral palsy where the involvement of the speech centre or the muscles producing speech may cause the child to appear mentally handicapped. A number of conditions, including impairment of vision and hearing, can also lead to an erroneous diagnosis of mental handicap.

Sometimes it is possible to identify *when* damage has occurred, but not the cause. Even this is useful to the parents because it can end speculation about other imagined causes of damage. When parents can be given a specific diagnosis they are often better able to come to terms with their handicapped child.

Assessing the needs

Under the existing policy of 'normalization', medical services, general practitioner and specialist should all be readily available to mentally handicapped children, but whatever the attractions of this theory, the practical problems for parents will be obvious to anyone who has sat in a surgery waiting-room with a noisy, overactive, socially impaired, mentally handicapped child. The general practitioner should try to anticipate these problems. Seeing the child at home has advantages for the parent and gives the doctor the opportunity to observe behaviour in the normal environment. It is clear that the medical care needs of the mentally handicapped child will be greater than those of his normal siblings. Pre-eminent is the special need to have the same human value as other children, to have his or her individuality recognized and not to be stereotyped, no matter how profound the handicap.

The average general practitioner would expect only one mentally handicapped child to be born in his practice every two or three years and on this basis could not claim any special expertise. What matters is not a detailed knowledge of every syndrome but a willingness to offer support and warmth and an ability to gear the available resources to meet the needs of the handicapped child.

During the past few years radical changes have been made in the design and delivery of services to mentally handicapped children. The first objective is to assess the unique needs of the individual child. The second is to have an individual plan based on that assessment; this has to be modified as the needs change.

The preschool child

In those babies whose impairments are recognizable at birth, the health visitor will work with the family before the baby leaves hospital. As the child gets older the health visitor or paediatrician may ask for a home intervention service such as 'portage'. Portage is a method of providing help for those children whose development is slower than normal. It is based on the idea that the best teacher for a young child is his own mother — the person who spends most time with him and who knows him best. The portage worker will visit the infant at home every week at a regular time for about an hour. She and the parents will fill in a portage checklist to find out exactly what the infant is able to do. A teaching target for the week will be set with the teacher explaining how a small step in development can be achieved. An activity chart will be written to help the mother to remember the details. At the end of the week the results can be assessed and a new teaching target decided. The portage programme normally ceases when the child attends school.

The school child

Mittler (1979) has made three important points in relation to intervention. First, the age of the child is not a good basis for planning. Not only will the child be developing very slowly but his development is likely to be patchy and uneven so that its various aspects appear 'out of step'. Secondly, normal children rush through critical periods of development so rapidly that their parents are hardly aware of their significance, and rarely stop to think whether they need to be systematically taught; but when development is slowed or distorted by additional handicaps the parents may easily settle for a particular stage of development and may become insensitive to the signs and signals given by the child that he is ready to move on to the next stage. The third point is that parents may become unnecessarily pessimistic and assume that because the child is handicapped in one area he is inevitably slow in all.

Whether the child is put in a main-stream school or placed in a special school, he will require an individual education programme. The 1981 Education Act demands a detailed 'statement' of each child's educational needs with a written commitment by the authorities. Each child's progress must be reviewed annually and the parents have a statutory right to take part in the discussion and decision-making. A visit to the school by the general practitioner can be of mutual benefit.

The child with special needs has the same general medical needs as other children. He will require to be immunized in precisely the same way as other children. Pertussis vaccine should be withheld only in the presence of the established contraindications. The special needs are most commonly visual or hearing impairments, speech and communication problems and behaviour disturbances.

A multi-axial classification

The medical model works well in patients whose disease is acute or remediable but is less effective when the problem is chronic or has profound social implications. The understanding and the management of mental handicap in children can be helped by means of a multi-axial classification (Rutter et al., 1975). This is particularly helpful when a multidisciplinary approach is necessary. Kirman (1985) suggests the following as some of the possible axes:

1. Level of intelligence
2. Recognizable syndrome or disease process
3. Additional disabilities or 'complications', i.e. features not regularly expressed
4. Social situation, e.g. one-parent families.

The level of intelligence helps to indicate the child's future level of dependency on parents and community; children with IQs below 50 are unlikely to lead any sort of independent life. However, it must be recognized that mental handicap cannot be diagnosed exclusively on the basis of an IQ test if the child is coping normally in the areas of personal skills and social interaction. To make a diagnosis of mental handicap the subaverage general intellectual function must co-exist with deficits in adaptive behaviour.

The first level of diagnosis, the labelling of a condition or the recognition of a syndrome, would normally be made by the paediatrician. But effective diagnosis at the secondary level is almost entirely the responsibility of the general practitioner. For example, the primary diagnosis of Down's syndrome will normally have been made by the paediatrician, whereas the responsibility of making a secondary diagnosis such as associated hypothyroidism would be that of the general practitioner.

Importance of parents

The fourth axis, the social situation, is probably the most important. It is quite impossible to think of a handicapped child in isolation; the family must be considered as a whole. Effective care for the handicapped child is best provided by parents who enjoy stability and who have a supportive background — it is known that mothers of handicapped preschool children show significantly more psychiatric morbidity than mothers of healthy preschool children (Romans-Clarkson et al., 1986). Carers are exposed to many burdens and disappointments which limit the quality of their lives (Chamberlain, 1985). Learning to accept a handicapped child and to see him or her as a valued member of the family is a slow and painful process.

How can the general practitioner help? Doctors who are seen as helpful are those who are good listeners: they must be felt to be allies of the family, working with them and not against them (Hewett, 1970). In a study of mothers of babies with Down's syndrome, Murdoch (1984) found that the discriminating features about helpful doctors lay mainly in the attitudes which they conveyed to the mothers. Often most of the energies of the general practitioner are directed towards supporting the parents.

Success or failure in establishing the child in society may depend more on the relationships between the parents than on any other factor. In a child-oriented approach it is easy to overlook the conflict of needs between parents and their children. Getting the balance right is difficult in families with normal children; it becomes crucial in those with a handicapped child (Pomeroy et al., 1978). The work of Winnicott (1958) and Brody (1956) highlights the fact that the feelings of the mother and her personality can influence her ability to mother and can generate problems in the newborn infant and the preschool child. If the child is handicapped then the problems are compounded.

The early responses of the normal infant help to 'release' appropriate responses from the mother. By such abilities as sucking, rooting, grasping, turning his head when his cheek is stroked, by eye to eye contact and a social smile he is able to teach his mother how to respond to his needs. Not only may a handicapped child be unable to do this but his very existence may produce in the mother feelings of grief, shame, disgust, rage and disbelief (Bentovim, 1972). These feelings may, if not understood by the general practitioner, lead to long-term rejection. Gradually, by a process of mourning, parents appear to come to terms with the situation. Although the intense shock and grief usually dissipate with time, parents are left with a lifelong chronic sorrow (Olshansky, 1962). The sadness parents experience never totally disappears but re-emerges at transition times during the child's life. General practitioners must anticipate that guilt, anger, sadness and grief will be a permanent part of the parents' lives. These feelings occur at predictable developmental milestones, for example when the child should walk, when speech should begin, when younger siblings pass the child in skill level, when school begins, and at puberty or when life care is discussed (Hurley and Hurley, 1987).

Parents experience their feelings of sorrow as a peak and valley phenomenon rather than a chronic unchanging sadness. Parents also report that the intensity of their feelings does not diminish with time. It does not become easier to accept the handicap merely because time has passed.

Services for mentally handicapped children are fragmented between the health, social, educational and voluntary services. The primary care team has a crucial role in negotiating the available help.

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CHAPTER 5

A protocol for primary health care

Gwyn Howells, RD, MRCGP and Martin Barker, FRCGP

REGULAR medical surveillance of vulnerable groups of patients is becoming the norm in general practice. A protocol for the care of children under the age of 5 and adults over the age of 75 years has been introduced by central government. People with mental handicap also have a greater number and variety of health care needs compared with those of the same age and sex in the general population (Ziring et al., 1988; Rubin and Crocker, 1989). Unlike the under fives and over 75s there is evidence that they do not benefit from high rates of consultation (Howells, 1986). However it is desirable that this group of people should be medically assessed on a regular basis. Unlike children and the elderly who are, despite their needs, regarded as being normal, mentally handicapped people are perceived as patients. By setting up a routine assessment programme doctors may unwittingly further medicalize this group of people. What matters is that they do not treat people with mental handicap as a homogeneous group but as individuals who differ as much from one another as any other group. Furthermore they must remember that the features of a labelled condition such as Down's syndrome are features of an impairment and not the characteristics of a person (Brain, 1967).

Social services departments are now charged with the responsibility of organizing registers of people with a mental handicap and data from these registers could be made available to practitioners. With the advent of computerization in practices accurate age/sex registers with a diagnostic index could also make the follow-up of these patients routine. For the average practice of 2000 patients, 30 to 40 people with a mild handicap and between 6 and 8 people with a severe mental handicap form a large group, but regular assessment should be possible. The assessment could be structured as follows.

1. Social assessment

The following facts should be established:

- Who the primary and secondary carers are, what their relationships are to the patient, and the relevant addresses and telephone numbers.
- A family tree with the help of the carers, possibly using a simplified version of Zander's charts.
- The services being provided for the patient such as respite care, day care, holiday relief.
- The availability of appropriate aids to independent living.
- Any allowances being claimed such as mobility or constant attendance allowances.
- Whether exemption has been obtained from liability to pay the community charge.

The following factors should also be documented:

- Any contact with the social worker, key worker or case manager.
- Other social factors including employment, housing and family circumstances.
- Assessment of the strain of constant caring (possibly increased by the problems of constant nursing) and available support, or lack of it.
- Whether genetic counselling has been offered, and if so, what positive advice given.
- The long-term aspirations of the carers and the handicapped patient.

2. Mobility assessment

Large numbers of people who are severely mentally handicapped have an associated neurological abnormality or multisystem disorder affecting locomotion. Many others may lose mobility because of obesity, arthritis or other abnormality about which no complaint is made. Often in these circumstances there is a need to consider home adaptations, walking aids or perhaps physiotherapy.

3. Mental assessment

People with mental handicap have a higher frequency of psychiatric illness compared with the general population. The evaluation of psychiatric symptomatology in this group is frequently difficult; referral to a specialist in the psychiatry of mental handicap is often necessary. The attention of the practitioner may be drawn to problematic behaviour. The paramount issue in the evaluation of behavioural symptomatology in people who are mentally handicapped lies in determining whether or not significant illness is a factor. It is useful to remember that maladaptive behaviour may be the mentally handicapped patient's only means of communicating distressful symptoms.

Adverse effects of psychotropic medication are a potential cause of behavioural disturbances. They include: paradoxical hyperactivity from the benzodiazepines or other tranquillizers, and dystonia, tardive dyskinesia, akasithisia and akinesia from the antipsychotic group of antidepressants (Kastner et al., 1990).

4. General medical examination

Ideally this should include a review of the medical history, current medical problems and a physical examination that would include recording the blood pressure and routine testing of the urine. Occasionally patients will be reluctant to co-operate owing to fear or unfamiliarity with the surroundings, procedures or examiner. The situation can be helped by the doctor not wearing a white coat, by offering to carry out the examination at home or by offering an appointment when the surgery is relatively quiet. Cervical smear and breast examination in women should be undertaken as a routine with appropriate arrangements being made to facilitate these examinations if necessary.

5. Immunization

Children who are mentally handicapped should be immunized in the usual way; only those with specific contraindications should be excluded. The occasion of the routine assessment can be used to remedy any previous deficiencies in administration. Whereas residents of institutions for people with mental handicap, especially those with Down's syndrome, are at increased risk of exposure to hepatitis B virus (HBV), this situation does not apply to those in the community.

6. Monitoring treatment

Patients receiving drugs must be carefully monitored, not only for clinical response but also for side effects. Unlike normal patients, people with mental handicap are often unable to complain of the adverse effects of drugs. Anticonvulsants such as phenytoin, valproate and carbamazepine require the monitoring of serum levels in order to avoid drug toxicity. All patients receiving psychopharmacological therapy should have a full blood count and blood chemistry as part of the routine assessment.

7. Special problems

In people with a mental handicap problems may occur in any system of the body but special attention should be paid to obesity, problems of sight and hearing, mobility, undescended testicles and hernias. An assessment of social and mental attainments including use of language and comprehension will be made during the examination.

An assessment of the patient's lifestyle should include enquiring into diet, exercise, use of tobacco, consumption of alcohol and contraceptive use. Sexual counselling may be appropriate at this point and introduced naturally into the assessment.

Direct questioning may be required to clarify problems resulting from epilepsy, incontinence and behavioural problems. Carers are reluctant to report these problems but a sympathetic general practitioner may be excellently placed to assess these problems and make appropriate referrals. Psychiatric problems, communication difficulties and challenging behaviours need to be evaluated carefully as referral can be valuable.

Some conditions are associated with special risks, for example diabetes associated with Prader-Willi syndrome. As has been described in the chapter on Down's syndrome (page 16), in addition to frequent congenital anomalies in this syndrome there is a high risk of hypothyroidism and Alzheimer-type dementia. Where mental handicap is associated with neurological damage there is a high risk of epilepsy. Carers will often introduce the topic of atlanto-axial instability in Down's syndrome. Screening for this condition is difficult to justify. It is rare for atlanto-axial instability to proceed to dislocation and cord compression. Depriving large numbers of people with Down's syndrome from various sporting activities based on an ill-understood radiological abnormality is much too restrictive (Davidson, 1988).

Conclusions

Simultaneous assessment of people with mental handicap and their carers must be a valuable undertaking in general practice. Carers are often patients as well and meeting their needs can be of vital importance both to their own well being and to the well being of the person they care for.

A short protocol

A short protocol for the care of people with a mental handicap in general practice is given in Appendix 1.

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CHAPTER 6

The family in the early years

Martin Barker, FRCGP

"The recognition that one's child has an impairment is always devastating. The subsequent development of the child, and of the family, will depend greatly on the family's way of responding to life's challenges, as well as on the child's ultimate disability" (Hattersley et al., 1987).

Care of the newborn

THE significance of any expected birth may vary enormously: the single girl may see it as a disaster, while an older, childless couple will count it as a great blessing; whatever the view of the pregnancy, the baby is expected to be normal.

The birth of a baby with a handicap will cause a conflict of emotions in its parents, friends and relations. They will experience feelings of grief and the loss of the expected normal baby. Feelings of rejection or of extra protectiveness are also common and are normal reactions. Maternity staff, paediatricians, health visitors and general practitioners need to be aware that they can by their attitude reinforce both negative and positive emotions; any sense of despair or helplessness they feel themselves may be quickly picked up by the parents. A fine balance needs to be achieved by professionals who, whilst adopting a positive approach which is honest and realistic, must allow the parents to grieve and must support them in loving and caring for the child.

The effect of the birth on the father, siblings and grandparents should not be overlooked; they may also need help in coming to terms with the family grief.

Studies show that where a handicap has been recognized at birth, the parents prefer to be told about the condition together and on the second day after the delivery. During the first few days counselling is usually undertaken by maternity staff and paediatricians; the same questions may be asked again and again.

Liaison between the hospital staff and the general practitioner is vital in these cases and is usually excellent. Similarly, communication between hospital and community midwives and health visitors is routine procedure, so that on the return home of the mother and child, the primary care team will be readily available to all members of the family.

Continuing care

Medical supervision is usually through the paediatric outpatient services in conjunction with routine developmental screening and surveillance by the health visitor, but the continuing care of the newly diagnosed mentally handicapped child is unfortunately fragmented, involving the health services, local education authority, social services departments and voluntary agencies. To help in coordinating the work, various systems have been instituted in different parts of the country.

In a few areas, the community mental handicap team is available to work with mentally handicapped children and their families; in others, where orientation is towards district handicap teams, members of the community mental handicap team regard themselves as available only to school-leavers and adult mentally handicapped people. In nearly all areas families are using primary care services for day-to-day medical help, maintaining contact with hospital services where ongoing assessment of the handicap is necessary, and using the handicap teams to facilitate liaison with all the other bodies.

Educational support

It is universally recognized that prompt action to provide early educational support is very important. This can not only considerably enhance the child's eventual learning achievement but also provide support and encouragement to parents. The Education Act (1981) lays a duty on health authorities to inform local education authorities of any child under five who they have reason to believe may have special educational needs. Children aged over two must then be formally assessed. (Those under two may be assessed with the consent of the parents but the education authority has no remit to provide services for them). Education authorities do, however, often provide the services of an advisory teacher. Apart from the educational assessment, in most cases a medical assessment is carried out by the school doctor and nurse, the community physician usually having overall responsibility for advising the local education authority on the appropriate action.

Nursery schools in this country still cater for only 50% of 2-5 year olds. Local education authorities have been urged by government to give priority to those of this age group who have learning difficulty.

The movement away from special schools towards integration into normal schools is proceeding. In some schools special care units provide for the needs of the most severely handicapped children, whilst in many areas the severely handicapped are integrated with the less handicapped. Parents benefit from the social contact with other families which they gain from attending parents' associations and similar organizations.

Progress at school will be monitored by regular annual medical examinations. These are reported to the general practitioner, through whom access can be gained to the specialist hospital services where necessary. School nurses likewise can work with health visitors and practice nurses. Co-ordination between the education authorities and the medical authorities is usually very good, and for many families the care given to their handicapped child during the school years is of a very high standard.

The problems of the school-leaver are still unresolved in many areas. Liaison between schools and the social education or adult training centres, between children's services and adult services, and between schools and further or adult education centres is difficult and requires careful forward planning by all parties based on an assessment of the student's ability and future needs (DHSS, 1977).

Social services

The social services departments are represented by their appropriate field workers on the district handicap teams. They are made aware of the presence of a handicapped child in their area at an early stage and will be involved in planning services such as effective arrangements for short-term and respite care.

Most social services departments are promoting fostering and befriending schemes. Foster parents and family befrienders are carefully selected and given basic training before being introduced to a family with a handicapped child. The idea is for the families to pair up so that the handicapped child regards the foster home as a 'second home' and looks forward to the change. Care may be for a few weeks in the holiday season, or for just half a day a week to allow the mother to go shopping. Crisis care could also be made available in this way.

Not all handicapped children can be cared for in this way; some may require the more specialized care which is available in a hostel or hospital. This may be the case with the more severely handicapped children. Some families find the concept of foster care difficult to accept and they may prefer respite care to be offered in the more formal setting of hostel or hospital.

Voluntary care

The voluntary sector has much to offer families and over the years has been instrumental in producing a favourable shift in public attitudes towards the mentally handicapped. Many self-help groups have been established and in some cases are being effectively co-ordinated by national bodies such as MENCAP. Sensitive help from voluntary bodies in bringing together families facing similar problems can be very helpful.

Voluntary organizations also make representation on behalf of the mentally handicapped and their families when the planning and management of public sector services are discussed.

For many years the voluntary sector has responded to the wishes of parents, involving itself in the provision of long-term care in imaginative settings such as the Home Farm Trust and in the setting up of long-term and short-term places in suitable housing.

Care in hospital

Only 14 children (1989 figures) now remain in long-term hospital accommodation thanks to improved provision in education and in local authority care. The role of the hospital service in relation to the mentally handicapped is contracting and traditional long-stay hospitals contain fewer and fewer children. The medical care of children will continue to be shared between primary care teams, district handicap teams and paediatric departments of local hospitals, with the school medical services shouldering most of the burden of routine medical assessment. Ideally, paediatric wards should only be used for sick children or those in severe social crisis, with respite care being provided in the community. Hospital admission of children should be kept to a minimum.

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CHAPTER 7

Down's syndrome and the general practitioner

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Introduction

DOWN'S syndrome is the most frequently observed chromosomal abnormality and the commonest identifiable cause of mental handicap. All primary care teams are faced with the challenges of the condition. Nothing can be done about the underlying impairment but the associated disabilities require active management if serious handicaps are to be minimized. In a condition which often requires the intervention of many specialists the role of the general practitioner is crucial — we must be aware of the common hazards of the condition if we are to prevent unnecessary morbidity. The same model of care should be applied to all mentally handicapped patients.

Incidence and aetiology

Down's syndrome is found in all races and all levels of society. About 95% of those affected have an extra chromosome 21. The incidence of Down's syndrome is strongly influenced by maternal age — for mothers under the age of 30 years the incidence is 1 in 2500, for those aged 29–34 years it rises to 1 in 1200 and in those aged 35–39 years it reaches 1 in 200. There is a peak incidence of 1 in 35 in mothers aged 39–47 years but the incidence falls for those who conceive above the age of 47 years (Ferguson-Smith, 1983). Contrasting with this is an increased frequency of affected babies in the very youngest mothers (Erickson, 1978). Although maternal age is of paramount importance, 20% of all Down's syndrome births are independent of maternal age and chromosomal banding shows that 30% of all meiotic errors responsible for trisomy 21 are of paternal origin (Stene et al., 1977). Although the differences between male and female meiosis would suggest that paternal non-dysjunction is not age dependent, in reality a significant paternal age effect does occur (Stene and Stene, 1977; Stene et al., 1981).

Translocations, usually with the additional chromosome attached to chromosome 14, occur in 4% of cases with Down's syndrome, with mosaicism occurring in 1% of cases (Zellweger and Simpson, 1977). In half of the translocations this is a *de novo* event in the embryo with the parents having normal karyotypes. In the other half one parent, almost always the mother, will have only 45 chromosomes with a balanced translocation, that is 45XX, −14, −21 +t(14q 21q). The theoretical risk that an affected mother will have a Down's syndrome child is 1 in 3, but in practice the risk is 1 in 10. If the father carries the translocation the practical risk is only 1 in 20 (Davidson, 1982).

Mosaicism is the result of non-dysjunction in the fertilized zygote: a few cells have two cell lines, one normal and the other with 47 chromosomes. There is a marked variation in the relative proportion of each cell line within organs and tissues and if there is a relatively low number of cells with trisomy 21 in the brain then intelligence may be within the normal range. Some people with mosaicism may be difficult to identify as having Down's syndrome.

Clinical presentation and management

Occasionally, at birth there may be some uncertainty about the diagnosis of Down's syndrome and in this event the karyotype should be determined. The diagnosis is usually made by the paediatrician who would normally reveal his findings only when both parents are present. Down's syndrome is instantly recognizable to health care professionals and many of the features, for example abnormalities of the ears, saddle nose, macroglossia, strabismus and pasty dry skin represent therapeutic opportunities.

Mental impairment is virtually a constant feature among people with Down's syndrome. They score badly when subjected to formal intelligence testing and are often labelled as severely mentally handicapped. However, a low intelligence quotient is insufficient to substantiate the diagnosis of mental handicap; social functioning must also be impaired. Furthermore, when assessing social function the doctor should not only consider existing social skills but also whether the person has had appropriate opportunities for acquiring them. The majority of people with Down's syndrome will, if they are provided with good health care, emotional security and early education, fall into the mild or moderate categories of mental handicap (Cunningham, 1982). There is considerable variation in ability and the acceptance of a low upper limit should be discouraged as this plays into the hands of those education authorities who wish to exclude children with Down's syndrome from mainstream education.

Aesthetics of Down's syndrome

> *Beauty is a greater recommendation than any letter of introduction.* Aristotle.

Although mental handicap is the most critical of all the disabilities in Down's syndrome it is often the facial appearance which prevents acceptance by society (Olbrisch, 1982). The plastic surgeon can help to overcome this problem, first by reducing or removing the aesthetic and functional handicaps caused by macroglossia and secondly, by correction of the distorted facial appearance. The main stigmatizing features are a habitually open mouth, a drooping lower lip, an ugly large furrowed tongue protruding from the mouth, a flat nasal bridge which results in epicanthal folds, hypoplastic ears, a flat facial profile and a fat neck.

Olbrisch (1982) advocates five procedures: partial resection of the over-sized tongue; correction of the drooping lower lip; lifting of the flat nasal bridge; correction of the hypoplastic ears; and correction of the fat neck. No plastic material is used; the flat nose is built up with homograft cartilage. All the procedures can be carried out in one operation under general anaesthesia and require only a few days in hospital. Following surgery, complete closing of the mouth is possible in the majority of cases, the likelihood of respiratory tract infection is substantially reduced and articulation is usually improved. Not all children with Down's syndrome require plastic surgery but the procedures outlined are relatively risk free and simple, so no child should be deprived of them (Lemperle and Radu, 1980).

The problems of achieving progress in the medical management of Down's syndrome were neatly illustrated in the *Lancet* in 1983 when Rozner, a plastic surgeon, presented an enthusiastic case for the benefits of surgery. However, a leading article in the same issue commented that the main problem of Down's syndrome is severe mental handicap, that most of those affected have an intelligence quotient of 25–50 and that surgeons can implant chins but not intelligence. These remarks were made even though Rozner had quite rightly pointed out that the procedures which he advocated were all standard; the only novelty was their use for the relief of the stigmata of Down's syndrome. Many doctors believe that because nothing can be done for the biological impairment it is not worthwhile doing anything for the associated disabilities.

Most authors emphasize the preschool years as the most favourable time for surgical repair. Parental satisfaction is important, and 95% of parents whose children have undergone surgery would recommend the operation to other parents of children with Down's syndrome. However, the improvement in speech secondary to the correction of the macroglossia may be more immediately gratifying to the child (Belfer, 1980). Some parents will say that they do not wish an improved facial appearance as people will then expect their children to be more competent than they are. Perhaps the answer to this is that their children will indeed be more socially competent.

Dermatological problems

The skin of those with Down's syndrome is frequently responsible for much aesthetic handicap and functional disability. Although in infancy the skin is usually soft it soon becomes dry, thick and rough with patchy lichenification. Circumscribed sore redness of the cheeks, cutis marmorata and xerosis are frequent problems, and acne is often persistent. Recurrent furunculosis of the thighs, especially of the inner surfaces, is often troublesome and cheilitis and blepharitis are sources of discomfort and unsightliness. Periocular syringoma, small dermal papules, usually flesh, yellow or mauve in colour, are frequent in adolescents. There is a high incidence of alopecia areata and vitiligo while alopecia totalis is common. These three conditions are the result of immunological deficiency in thymus dependent (T cell) function which exists in Down's syndrome. A chronic dark red, follicular dermatosis involving the presternal and interscapular skin has been found in almost half of male Down's syndrome patients (Howells G, personal observation) but the condition is rare in females (Finn et al., 1978). Elastosis perforans serpiginosa is said to be common in Down's syndrome but in a series of 115 cases the condition was found only once (Howells G, personal observation). Hyperkeratotic patches of scaly thickened skin, greyish in colour on the limbs, are common as are keratosis palmaris and plantaris. There is also a high incidence of fungal infections of the skin.

Dry skin can be helped by the regular application of emollients and the emollient effect can also be achieved by bath oils and the regular use of soapless soaps. A dry centrally heated home environment can be improved by some form of humidification.

Sensory impairment

Impairment of hearing and/or vision can lead to an erroneous diagnosis of mental handicap even in normal children. It is not surprising then that in Down's syndrome such impairments, which occur with alarming frequency, can lead to a gross distortion in the perceived potential of an affected individual. Furthermore, unrecognized deafness may result in behavioural disorders or even apparent psychotic features, especially among those with a poor level of communication.

Hearing problems

In 1968 Fulton and Lloyd found that 58% of a group of Down's children had a significant hearing loss. Among those affected 55% had conductive loss, 23% sensorineural loss and 22% a loss of mixed type. With increasing age the ratio between conductive and sensorineural loss in Down's syndrome reverses — among those aged 21 years or over 55% may have sensorineural loss. Clearly people with Down's syndrome need careful audiological supervision throughout their lives and all those involved in caring for these people must be aware of the extent of the problem and oppose the notion that a reduced hearing level may be adequate for someone with Down's syndrome. Routine testing, appropriate to the level of understanding of the individual, can be carried out in hospital audiology departments or in the case of children, at assessment centres.

Among children, the most commonly encountered problem is middle ear effusion associated with a flat tympanogram and conductive hearing loss. The tympanogram does not usually revert to normal during remissions, unlike the tympanogram of normal children. Owing to the chronic nature of the middle ear effusion, antibiotic therapy is not usually helpful. In the short term, surgery may be useful but in the long term the results are discouraging — the fluid in the middle ear is so tenacious that grommets and T-tubes become blocked and their repeated removal results in an unacceptable scarring of the tympanic membrane. As the auditory canal is stenosed the surgeon often has difficulty placing the tube but even so Strome (1981) in his extensive study of the problems advocates conservative treatment only when absolute certainty exists as to the ability to follow the pathology and accurately assess its resolution. In Strome's study factors relating to intelligence were explored with the conclusion that a direct relationship exists between improved hearing and improved intellect.

The indications for tonsillectomy in Down's syndrome are limited. Should the size of the tonsils become a consideration for removal, significant obstruction of the oropharynx must be present (Strome, 1981). Tonsillectomy is one of the commonest procedures requested by parents and in general should be resisted. It may, however, be necessary in the management of sleep apnoea which will be discussed later.

Fortunately postaural hearing aids can be effectively worn by children with Down's syndrome. Associated abnormalities of the external ear may present difficulties in the preparation of a suitable mould, but these can usually be overcome.

Common eye problems

Virtually all adults and children with Down's syndrome suffer problems relating to the eyes but fortunately many of these are amenable to treatment. Blepharitis occurs frequently and may be the result of an abnormality of the tears (Allerhand et al., 1963). Constant rubbing of the eyes often produces ectropion, entropion and trichiasis. Frequent gentle cleansing of the eyelids using warm water is helpful and acute flare-ups can be controlled by topical antibiotic eye ointments.

Most authors state that by the age of 12 or 13 years, 50% of children with Down's syndrome have cataracts but these are usually flake-like opacities which do not affect vision significantly until later life (Lowe, 1949). Congenital cataracts are uncommon in the general population but affect 1%–5% of babies with Down's syndrome (Lowe, 1949). Because of their extent and density they often require early removal.

Myopia, hypermetropia and astigmatism are very common in those with Down's syndrome. Vision can usually be tested using standard charts but when this is not possible retinoscopy using homatropine can detect myopia. The pupil in Down's syndrome appears to be sensitive to atropine, dilating quickly and remaining dilated for longer than normal. In addition, nystagmus is common and can make sight testing difficult. It often occurs only when one eye is closed so the patient should keep both eyes open during examination.

Squints, almost invariably of the convergent type, are common among those with Down's syndrome and are usually managed by correction of the refractive error. When this is not possible surgical correction is necessary. Improved vision is relatively easy to achieve but binocular function and a satisfactory cosmetic result are more difficult.

Keratoconus occurs in 5% of people with Down's syndrome (Cullen and Butler, 1963). The incidence is higher than in any other condition and it often appears at puberty when it may be associated with cataract and glaucoma. The acute type is painful and requires admission to hospital. The chronic form presents in a less dramatic way as increasing astigmatism.

The possibility of a visual problem should always be considered when a child or adult with Down's syndrome loses interest or becomes frustrated with daily activities which require a reasonable level of visual acuity. Ideally all babies with Down's syndrome should be seen by the ophthalmologist within the first year of life and again before they start school.

Cardiac problems

The incidence of congenital heart disease in the population as a whole is less than 1% (Keith et al., 1978) but the incidence in those with Down's syndrome is at least 50% (Greenwood and Nadas, 1976). In addition, there is a high frequency of serious abnormalities which account for 30%–35% of deaths (Thase, 1982). In the general population atrioventricular canal defect represents only 2% of all congenital cardiac defects but in Down's syndrome it is the commonest anomaly accounting for 60% of the cardiac findings at autopsy (Tandon and Edwards, 1983). In people with Down's syndrome the common heart defects differ in expression and in frequency from those in the general population — in only two of a series of 300 Down's syndrome children with ventricular septal defects were the defects considered small and only one of these closed spontaneously (Hallidie-Smith, 1985). Interestingly, pulmonary and aortic stenosis and coarctation of the aorta, which are relatively common in the general population, are infrequently met in Down's syndrome (Keith et al., 1978).

The diagnosis of heart disease in Down's syndrome is often unnecessarily delayed. The diagnosis should be considered in the absence of a murmur as an atrioventricular canal defect may be murmur free. Often the symptoms of heart failure in Down's syndrome are erroneously attributed to developmental delay and hypotonia which is commonly found in this syndrome. It is good practice to consider the possibility of a cardiac defect in all cases of Down's syndrome; and in all cases where there is a doubt a cardiological opinion should be sought.

Those caring for people with Down's syndrome should be aware of the importance of antibiotic prophylaxis for endocarditis before dental work is carried out. While recognizing that virtually any dental procedure can produce transient bacteraemia the report of a working party of the British Society for Antimicrobial Chemotherapy (1982) recommended prophylactic antibiotics only for extractions, scaling or surgery involving the gingival tissues. The problem in Down's syndrome is compounded by the extent of periodontal disease, which has been reported to begin before the age of five years and to affect nearly all adults (Brown and Cunningham, 1961). The report also draws attention to the need for prophylaxis during endoscopy or in surgery of the genitourinary or upper respiratory tract.

Respiratory problems

Children with Down's syndrome are predisposed to frequent infections of the respiratory tract, probably as a result of a poor immunological defence mechanism (de la Nuez et al., 1981). The lungs of those with Down's syndrome are hypoplastic, irrespective of whether heart disease is present and there is a persistence of the double capillary network in the alveolar wall which is found in the normal fetus with a diminished number of alveoli and a small alveolar surface area (Cooney and Thurlbeck, 1982). These anatomical changes predispose the child not only to infection but also to the development of pulmonary hypertension. Pulmonary hypertension may also result from chronic upper airway obstruction (Rowland et al., 1981).

In Down's syndrome there are two major factors which can cause obstructive sleep apnoea: first the pharynx may be crowded by lymphoid hyperplasia and the large tongue, and secondly the pharyngeal muscles are frequently hypotonic. Children who are overweight or catarrhal are particularly vulnerable. Direct effects during sleep include restlessness, unusual postures and snoring, and apnoeic pauses often result in bed wetting. Common daytime symptoms include difficulty in waking, somnolence and difficult behaviour (Silverman, 1988). Sleep-related upper airway obstruction is an often undetected complication of Down's syndrome and all necessary measures should be taken to overcome the obstruction before it reaches the stage of producing hypoxaemia (Southall et al., 1987).

Alzheimer's disease

It is said that for those with Down's syndrome the reward for survival beyond the age of 40 years is presenile dementia (Ellis et al., 1974). The incidence of Alzheimer's disease is high (Burger and Vogel, 1973; Cutler et al., 1985; Wisniewski et al., 1985), but fortunately most people with Down's syndrome do not show the clinical features of Alzheimer's disease. To what extent this is related to the difficulty of recognizing subtle changes in memory and performance in individuals who have few demands placed on them is difficult to know. Among 35 people with Down's syndrome over the age of 40 years only two cases of clinical Alzheimer's disease could be identified (Howells G, personal observation). They may all have had the neuropathological changes of Alzheimer's disease, but dementia is essentially a symptomatological diagnosis in which there is loss of intellectual functioning severe enough to interfere with occupational or social skills. Wisniewski and Hill (1985) have developed a useful questionnaire for assessing dementia in mentally handicapped people. It consists of a series of questions which assess items related to cognitive functioning.

It is important that dementia should be considered in any middle-aged person with Down's syndrome who has developed behavioural problems, memory loss, mental inflexibility or a general slowing in activity, not only because of the possibility of Alzheimer's disease but also because of the chance of a remediable medical cause. It is often taught that delirium is common among infants and the elderly; it would be useful to add patients with Down's syndrome to the list. If a previously competent patient with Down's syndrome becomes confused a sedative is often prescribed, whereas it would be much more sensible to take the patient's temperature and carry out a proper physical examination.

Depression

Not surprisingly depression can remain undiagnosed in patients with Down's syndrome. They will have difficulty in describing the usual symptoms of depression such as lowered mood or feelings of worthlessness, and the hypochondriacal delusions they describe will often sound highly improbable. Depression should always be considered when Down's syndrome patients who have been reasonably active become withdrawn, sit alone or do not involve themselves in their usual activities. The common physical accompaniments of depression will be present, for example, poor sleep, poor appetite and loss of weight. The diagnosis is important as the condition will usually respond to conventional methods of treatment.

Bereavement

Bereavement poses many problems for patients with Down's syndrome. Many live with elderly parents and the degree of attachment and dependence may be strong. McLoughlin argues that the mentally handicapped, because of their reduced social horizons restricting the development of peer group relationships, may have a great investment in a few highly significant relationships; the breaking of these close bonds may be catastrophic (McLoughlin, 1986). Often, people with Down's syndrome are unable to understand death or to negotiate the normal mourning process. Bicknell (1983) in her sensitive account of the psychopathology of handicap describes how a handicapped person is often sent on a fortnight's holiday when there is a death in the family while the rest of the family grieve the loss. The handicapped person is assumed not to notice the loss but exclusion from the grieving process often results in overlooked depression and behavioural difficulties.

As people with Down's syndrome are now living longer, this problem will increase. When the carers are aged or in poor health the handicapped person should be introduced into alternative accommodation, perhaps on a regular short-term basis so that new relationships can develop. Not unexpectedly carers may be reluctant to agree to these changes as so often they are emotionally dependent on the attachment themselves. It is a situation that requires sensitivity and understanding on the part of the general practitioner.

Epilepsy

Epilepsy is less common among people with Down's syndrome than in the mentally handicapped population as a whole (Smith and Berg, 1976). The frequency of fits is less than 2% in Down's syndrome patients under the age of 20 years but it rises to 12% in those aged over 55 years suggesting neurological degeneration (Veale, 1974). There are special problems in treating epilepsy in patients with Down's syndrome. For example, the clinical signs of toxicity from anticonvulsant drugs are difficult to elicit and so the monitoring of blood levels is particularly important (Pond, 1979). Anti-epileptic drugs can cause serious degradation of cognitive function leading to a syndrome resembling dementia — phenytoin is more likely to do this than other anti-epileptic drugs causing 'phenytoin encephalopathy' (Trimble, 1982). Of the anti-epileptic drugs phenytoin has also been shown to have the greatest effect on attention and memory with sodium valproate and carbamazepine having the least effect (Thompson et al., 1981). In contrast with normal adults who will readily complain when drugs are causing unpleasant symptoms, people with Down's syndrome are often unable to complain and are obliged to continue with medication.

Thyroid disease

Several studies have shown that there is an increased prevalence of hypothyroidism among people with Down's syndrome compared with the general population (Baxter et al., 1975). In a series of 52 adults with Down's syndrome attending adult training centres seven were found to have biochemical evidence of hypothyroidism (Howells G, personal observation). Interestingly 18 of the total were found to have a T4 level in the lower normal range. In only one case was a diagnosis of hypothyroidism made on clinical grounds. Part of the difficulty is that in general those with Down's syndrome are slower and less active than normal people, have thickening of the skin, have difficulties with articulation, which masks any hoarseness, and are less alert. Murdoch and colleagues (1977) initiated a study on the basis of an observation that the electrocardiograms in adults with Down's syndrome commonly show abnormalities which are consistent with hypothyroidism. In a study of 82 adults with Down's syndrome they found that 40% had abnormalities of one or more thyroid functions suggesting underactivity: hypothyroidism had been suspected in only one case. In contrast, 50% of a group of 55 adults with Down's syndrome resident in a hospital for the mentally handicapped were thought to have clinical features suggesting hypothyroidism (Mani, 1988). Clearly people with Down's syndrome must be screened for hypothyroidism at least every five years and thyroid antibodies should also be checked. A positive antibody test indicates that hypothyroidism will almost certainly develop (Murdoch, 1984).

Hyperthyroidism is rare in patients with Down's syndrome but is important because it can present as a behavioural problem (McCulloch et al., 1983). With the increasing life span of people with Down's syndrome general practitioners must become more aware of the possibility of an organic brain disorder such as hyperthyroidism and the need for specific treatment.

Joint and muscle problems

Atlanto-axial instability was first described in 1830 by Bell. Recently because of the greater involvement of people with Down's syndrome in sporting activities, potential dangers of the condition have been highlighted (Collacott, 1987). The abnormality consists of a misalignment of the first two cervical vertebrae and during hyperextension or flexion of the neck this presents a neurological hazard. The condition affects between 12% and 22% of all people with Down's syndrome. It might appear reasonable to screen for atlanto-axial instability when patients are five or six years old but the clinical significance of this radiographic sign is not fully understood and thus it is not justifiable to ban affected patients from activities which are socially rewarding and physically beneficial. Perhaps of greater clinical importance is the high incidence of degenerative cervical arthritis in young people with Down's syndrome, often associated with the clinical signs of myelopathy. Because of the inherent problems of communication, people with Down's syndrome are in general unable to describe the resulting symptoms (Howells, 1984).

Obesity

Obesity is common in patients with Down's syndrome and the problem appears to be more marked from early childhood to adolescence. Not only is the motor development of the child hampered but also the social development as a result of restricted recreational activities with other children. The parents of infants with Down's syndrome should be warned of the potential problems ahead so that they can form appropriate eating patterns. Established obesity in Down's syndrome is difficult to manage and requires persistence over a long period.

Nutritional supplements

General practitioners will frequently be asked about the value of mineral and vitamin supplements for patients with Down's syndrome. A well organized clinical trial was carried out in Chicago to determine whether supplements improve the level of intellectual functioning. The results demonstrated that the use of a combination of nutritional supplements in school-age children with Down's syndrome did not lead to improvements in intellectual test performance (Smith et al., 1983, 1984). Although there is no specific evidence that megavitamin therapy (doses vastly exceeding the amount recommended for nutritional balance) has a place in the management of Down's syndrome there is a great deal of anecdotal evidence that the general health of this group is often dependent on vitamin and mineral supplementation. It would seem reasonable to provide vitamins A, B, C and D together with a zinc supplement.

Screening for Down's syndrome

The present policy on antenatal screening for Down's syndrome is to offer amniocentesis to all women who will be aged 36 years or over at their expected date of delivery. Screening is also offered to couples who have already had a child with a chromosomal abnormality or who are known to be carrying a balanced translocation. Unfortunately, screening based on age alone is unsatisfactory and has had no significant influence on the incidence of Down's syndrome at birth. Amniocentesis in the 5% of expectant mothers who are over 36 years of age will detect only 30% of all Down's syndrome pregnancies. Moreover in practice fewer than 15% of affected pregnancies are detected because fewer than half of the older women take up amniocentesis (Wald and Cuckle, 1987). The general practitioner has a role to play in trying to improve this figure. Sometimes a history of threatened abortion is given as a reason for omitting amniocentesis despite the fact that bleeding in the first trimester occurs in 26% of women carrying a Down's fetus compared with 1% of mothers carrying a normal fetus (Boué et al., 1975).

Pregnancies resulting in babies with Down's syndrome are associated with reduced maternal alpha-fetoprotein concentration (Cuckle et al., 1984). More recently a method of detecting Down's syndrome, measuring human chorionic gonadotrophin, unconjugated oestriol and alpha-fetoprotein in the maternal serum at 16 weeks has been found to be reliable (Wald et al., 1988). Taking into consideration maternal age, this method of screening could detect over 60% of affected pregnancies. Such a programme could reduce the number of children born with Down's syndrome in the United Kingdom from about 900 a year to about 350. It is likely that this cost-effective method of screening will gradually become standard. Some patients who are recognized to be at high risk may still prefer to have chorionic villi biopsy or amniocentesis early in pregnancy because of the more certain diagnosis which these techniques offer (Donnai and Andrews, 1988; Harris and Andrews, 1988). The difficulty for general practitioners is to balance the wishes of an individual woman and her personal risk against the benefits of population screening programmes with high rates of detection. It has been suggested that the new screening strategy should apply for all women aged under 38 years and efforts made to provide chorionic villi biopsy for women above that age (Simoni et al., 1983). Naturally the decision to have amniocentesis or chorionic villi biopsy has to be made by the couple and the responsibility of the general practitioner is to provide them with up-to-date information free from any personal prejudice.

It is essential to know the chromosomal type in every child with Down's syndrome not only to assess the risks to siblings but also the risk to other close relatives. When the chromosomal type of someone with Down's syndrome is unknown then a patient who is a relative of that person must have his or her chromosomes checked to exclude a translocation carrier state.

Prognosis for Down's syndrome

The social prognosis for Down's syndrome has improved dramatically over the past few years. Until recently society considered children with Down's syndrome to be ineducable and incapable of a meaningful life but now they can learn to read and to care for themselves and can acquire skills in some trades; many can live semi-independently with minimal supervision. However, the medical prognosis is not as optimistic. The high incidence of congenital heart disease and immunodeficiency result in a high mortality in infancy and childhood and in those aged 40 years and over. Øster (1975) found that the mortality rate for respiratory disease was very high, especially for the age group 5 to 14 years. In those aged over 40 years there is a high incidence of neurological disorders and the mortality rate from premature ageing and strokes is five times higher than in the general population. Although there is evidence that Down's syndrome confers a greater than 10-fold increased risk of leukaemias in children, it is not known if adults have comparable increased risks (Rosner and Lee, 1972). One prospective study did, however, show that the mortality rate from miscellaneous cancers was five times higher among men with Down's syndrome than among men in the general population (Holland et al., 1962).

Care in the community

This review has suggested ways in which the general practitioner can respond to some of the medical challenges of Down's syndrome. We must ensure that the medical needs of Down's syndrome patients are not overlooked and that referrals to the specialist services are appropriate. At the same time the adoption of the clinical perspective must not isolate people with Down's syndrome from other professional and voluntary agencies. Although the management of disability and the prevention of handicap remains the primary role of the general practitioner it is essential that a therapeutic relationship is established with the families of Down's syndrome patients. People with Down's syndrome and their families experience the same life events as everyone else and often these are periods of intense emotional turmoil. The birth of a sibling, starting school, the onset of puberty and leaving school are times when regression, frustration or maladaptive behaviour may appear. The out-of-home placement is probably the most important psychosocial event and those with Down's syndrome usually have little say in where they are placed. Whereas the non-handicapped adult may experience a new freedom from parental demands, the handicapped person leaving home may, paradoxically, experience new and greater restrictions. Thus, the grief at leaving home may be greater than anticipated because it is not tempered by any gains (Gilson and Levitas, 1987). Now that community-based services are established with a greater variety of out-of-home placements, separation from the family can, if carefully planned, become a positive growth experience. Residential care should be accepted as a normal life event and not seen as rejection by the family. The general practitioner, if he is to participate in these processes must see himself as part of a larger network of services providing care for people with Down's syndrome and their families. Studies of the clinical aspects of Down's syndrome reveal large discrepancies between those living in institutions and in the community. For example, studies show that institutionalized people with Down's syndrome have a much higher incidence of hepatitis carrier status than other mentally handicapped people (Boughton et al., 1976; Madden et al., 1976). However, a study carried out on a group of people with Down's syndrome living in the community showed that they do not have a higher incidence of positive hepatitis B antigen than the general population (Dicks and Dennis, 1987). Thus, patients with Down's syndrome who have never been institutionalized should be treated no differently from any other person in the general population who is not suspected of being a transmitter of infectious disease.

In this paper it has not been possible to review the hundreds of recent articles on Down's syndrome and so attention has been focused on those topics of greatest practical importance. We have created many of the images of Down's syndrome patients ourselves; we must now reverse the negative images of this intriguing condition.

Acknowledgement

This paper was first published in the *Journal of the Royal College of General Practitioners* (1989, **39**, 470-75) and is reproduced with permission of the Editor.

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CHAPTER 8

The management of epilepsy

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EPILEPSY is a common additional handicap for people with a mental handicap. Corbett et al. (1975) studied the prevalence of epilepsy in all the known severely mentally handicapped children in a London suburb with a population of about 175 000. They showed that of children with severe mental handicap (with an IQ below 50), one third had a history of seizures at some stage during life; 19% had had at least one seizure during the previous year. Similar findings were made by Tizard and Grad (1961). Additionally, Corbett (1981) showed that the prevalence of epilepsy increased directly with the severity of the mental handicap.

Frequent seizures

Frequent seizures occurring in people with a mental handicap are often associated with irritability and drowsiness, which may seriously interfere with the social aspects of the person's life. Trends towards community care have increased the risk of injury to these people at the time of the seizure. Dynamic factors undoubtedly operate amongst the mentally handicapped as amongst the general population. Having a condition which suddenly and without warning prostrates one, which is associated with incontinence and damage to bodily integrity and amnesia for the actual seizure, and which is often watched by frightened onlookers during the recovery phase, will inevitably damage psychological well-being. Temporal lobe epilepsy has long been associated with psychosis (Slater et al., 1963; Flor-Henry, 1976).

A number of mentally handicapped people with a history of infantile seizures associated with EEG changes of hypsarrythmia or slow spike-and-wave activity suffer from either West's or Lennox-Gastaut syndromes. For these people seizures may be very frequent indeed, and may be quite refractive to conventional therapies (Brown and Livingstone, 1985).

Medication

The medical management of epilepsy amongst mentally handicapped people follows the principle of using single anticonvulsant therapy whenever possible, using adequate dosage whilst avoiding unwanted side effects.

Mentally handicapped patients are particularly vulnerable to the side effects of medication; they may be unable to conceptualize their experiences or communicate them to their carers. It is important to consider the regular use of serum anticonvulsant monitoring, which will ensure that undertreatment on the one hand, and the toxic effects of over-dosage on the other, are more readily revealed. This is particularly important when phenytoin is used, since the exponential relationship between drug dose and plasma drug concentration may result in inordinate increases in drug concentration (with associated toxicity) after only minimal increases in dose. Facilities for monitoring the blood levels of carbamazepine, sodium valproate, phenobarbitone and phenytoin are now widely available.

It is now generally believed that the use of all anticonvulsants, possibly with the exception of carbamazepine and sodium valproate, lead to cognitive impairment (Dodrill and Troupin, 1977; Thompson et al., 1981; Thompson and Trimble, 1982; Hirtz and Nelson, 1985). Whilst it is recognized that these unwanted side effects occur when the serum concentration of the drug lies within the toxic range, such changes may also occur within the therapeutic range. Phenobarbitone has been shown to have adverse behavioural effects in children (Reynolds and Travers, 1974; Reynolds, 1975; Stores, 1975; Trimble and Reynolds, 1976; Trimble and Corbett, 1980). The use of the benzodiazepine group of anticonvulsants (clonazepam, clobazam, nitrazepam) may be limited in mentally handicapped people by the induction of disinhibited behaviours.

Anticonvulsant polypharmacy has been considered inappropriate for several reasons: it is believed that the incidence of side effects from medication is compounded, unnecessary medication may be given, and it may be difficult to monitor adjustments made to only one of the drugs; behaviour difficulties and cognitive impairment are compounded (Reynolds, 1975; Shorvon et al., 1978; Shorvon, 1980).

Studies based on institutional populations have shown that it should be possible to maintain up to 80% of mentally handicapped epileptics on monotherapy (Fischbacher, 1982; Sheppard et al., 1987; Collacott et al., 1989).

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CHAPTER 9

Drug therapy of mental disorders

Gwyn Howells, RD, MRCGP and Richard Collacott, DM, PhD, MRCGP, MRCPsych

PEOPLE with a mental handicap appear to be at greater risk than the general population of developing mental disorders — whether mental illness or behaviour disorder. For example, amongst 9-11 year old children, Rutter and his colleagues (1970) discovered that 50% of those with severe mental handicap had a significant psychiatric disorder, compared with only 7% of children of normal intelligence. Similar findings were confirmed by Richardson et al. (1979) in Aberdeen, and by Corbett (1979) in the Camberwell study.

Types of mental disorder

Children

Among the mental disorders exhibited by mentally handicapped children, autism (now known as pervasive developmental disorder) is the most common. Stereotypes (repetitive, rhythmic and non-purposive movements) such as rocking, head-banging, self-stimulation and complex twisting movements of the hands and arms occur in about 10% of severely mentally handicapped children. Other mental disorders include pica (the ingestion of non-food items), hyperkinetic behaviour (now known as attention deficit disorder), conduct disorder and neuroses.

Adults

Nearly half of all adults with mental handicap demonstrate mental disorders (Corbett, 1979), whether they reside within the community or within an institution. Amongst adults, the commonest mental disorder is behaviour or personality disorder. However, the whole spectrum of mental disorders found in the general population — acute confusional states, dementia, affective disorder, schizophrenia, neuroses, and so on — may also affect those with a mental handicap.

The aetiology of mental disorders amongst the mentally handicapped is complex, but is determined both by features intrinsic to the individual, as well as extrinsic factors in his/her environment or life experience. The relative effects of these features will vary in any individual.

Some uncommon syndromes which give rise to mental handicap appear to be directly related to a behaviour disorder. For example the Lesch-Nyhan syndrome of mental handicap, hyperuricaemia and choreoathetoid movements, appears to be associated with self-injurious behaviour — particularly that of biting oneself, often inflicting considerable damage. Down's syndrome, the commonest cause of mental handicap, is associated with a presenile dementia, indistinguishable on pathological grounds from Alzheimer's disease. People with Down's syndrome are also particularly vulnerable to psychiatric sequelae — regression, depression and paranoid psychosis — associated with autoimmune thyroiditis. The fragile-X syndrome appears to be associated with autistic traits. Klinefelter's syndrome is associated with additional specific learning defects and behaviour disorders.

Rutter (1981) has suggested that brain damage itself may account for the psychiatric disorder seen in some individuals in the same way that brain damage can give rise to mental disorders in those of normal intelligence. However, the role of epilepsy remains controversial. Brain-damaged individuals may additionally suffer from the psychological stress of associated handicaps such as motor or sensory disorders, or from the stigma attached to them and their families.

Effect of the environment

In people with a mental handicap who develop a mental disorder, it is important to consider the role of the environment. The effects of parental attitudes and parenting skills are of obvious importance in determining a handicapped person's self-image. Behaviour disorders are in general considered to have been learned and rewarded over a period of time. They may respond to changes in the environment which permit the child to obtain attention more readily, and without recourse to demonstrating abnormal behaviour. Parents are frequently stressed and school or training centre attendance, respite care and organized recreational activities (such as Gateway clubs) may go a long way to remove the stress under which the parents may find themselves.

Handicapped people are particularly susceptible to changes going on around them, which their peers of normal intelligence would not remark upon.

Diagnosis

The diagnosis of mental disorders in those with a mental handicap is often difficult. These difficulties arise as much from the poor communication skills of the mentally handicapped as from the different presentation of these disorders when the more florid symptoms or signs are absent.

The diagnosis of mental disorders in the mentally handicapped is based largely on history taking and the observance of behaviour. Whilst a history may be obtained from the handicapped person, it is imperative to obtain a history from at least one other informant — such as parents, hostel staff, or training centre keyworkers. The most important point to elicit is that of change. A handicapped individual may have become increasingly aggressive, subdued, socially withdrawn, restless or agitated. The loss of self-care skills, particularly those of washing, toileting, feeding and ability to use money is usually highly significant.

The history must also enquire into biological systems suggestive of affective disorder, for example, loss of appetite and weight, constipation, sleeplessness, diurnal variation and loss of energy. Unhappiness, tearfulness, and morbid thoughts, which are so common in the depressed general population, are usually absent in the mentally handicapped.

Drug treatments

Drug treatments are useful in the management of the majority of mental disorders but should seldom be seen as the only treatment to be employed, since changes in the person's life circumstances are often required. The management of most behaviour disorders will properly entail the use of behavioural techniques.

In depressive disorders drug treatments follow conventional lines, using antidepressant medication in full dosage for an adequate duration. The drug of first choice is usually one of the tricyclic antidepressants. Consideration should be given to those with a low side-effect profile, since the mentally handicapped may be unable to recognize or express the adverse effects that may be experienced.

People with a mental handicap may sustain hypomanic illness: however the symptomatology usually excludes excessive happiness, euphoria, grandiosity or expansiveness, whilst the quantity, volume and speed of speech may be increased. Restlessness may be marked and aggressive or disinhibited behaviour may occur. In hypomania, lithium, phenothiazines (such as thioridazine or chlorpromazine) or butyrophenones (such as haloperidol) may be effective in the acute stage. Thereafter the prescription of lithium or carbamazepine may be useful as a prophylactic against further recurrences. In view of its toxicity, and the need for an initial assessment of thyroid and renal function, it is probable that lithium should be prescribed only after referral to a consultant. The prescription of carbamazepine should be accompanied by regular monitoring of serum levels to minimize the risk of toxicity occurring.

The full spectrum of neurotic disorders, including anxiety neuroses, phobic disorders and hysterical neurosis, may be encountered in the mentally handicapped. The management of such disorders is best achieved through a psychotherapeutic, educational or behavioural approach. The long-term risks to the mentally handicapped of the use of benzodiazepines is probably similar to that of the general population. However, the mentally handicapped are particularly liable to become disinhibited through the use of these drugs, with the release of aggression or sexually maladaptive behaviours.

For many mentally handicapped people where a complete diagnostic formulation may not be possible, mental disorders require to be treated on a symptomatic basis.

Aggression, whether verbal or physical, may quickly lead to a breakdown in care and requires speedy resolution. Behavioural techniques and/or medication may be extremely valuable. Neuroleptic drugs are capable of suppressing or controlling aggressive behaviour through a reduction in the level of arousal.

Self-injurious behaviour in the mentally handicapped can be severe and mutilating involving self-biting, eye or ear poking, head slapping, and so on. Such symptoms are frequently difficult to control, particularly since the cause of such behaviour often remains elusive. However, structured behavioural therapy and/or medication with phenothiazines and/or haloperidol can help to reduce the severity of such behaviour. The recent arrival of orally administered antagonists to endogenous opiates is arousing interest as a possible therapeutic tool.

The hyperkinetic syndrome (attention deficit disorder) is marked by a reduced attention span, impulsiveness and restlessness. Again, behavioural therapy may be of value. Drug approaches to management include the use of neuroleptic medication, including the phenothiazines or haloperidol and also carbamazepine. The use of amphetamine derivatives for hyperkinetic syndromes remains unclear in the mentally handicapped, unlike in those of normal intelligence.

Conclusion

Mental disorders occur commonly amongst the mentally handicapped, both as a result of endogenous and environmental factors. It is important to develop a high index of suspicion of the presence of a mental disorder when a change in someone's behaviour or level of functioning has been demonstrated. Diagnosis may be difficult because of the patient's poor communication skills, but observation of his/her behaviour and good history taking, not only from the patient but from those who know him well, is essential. If the diagnosis remains elusive, referral to the consultant psychiatrist in mental handicap may be appropriate.

The drug management of mental disorders in the mentally handicapped should not be considered in isolation. Drugs are often used best as an adjunct either to behavioural treatments or to the introduction of changes in that person's environment.

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CHAPTER 10

Behaviour approaches

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THE study of learning in the mentally handicapped developed in the 1950s and applications of this early work included the development of industrial workshops in hospitals. The work established that whilst severely mentally handicapped people did have considerable difficulty in learning new skills, once learned, the skills were retained as well by them as by anyone else.

In the mid-1960s a series of clinical studies on behaviour therapy was published in the world literature. With these new techniques mentally handicapped people could be taught much more than many people had thought possible. At the same time it was recognized that there was no need for the techniques to be used solely by psychologists. Almost any carer of a mentally handicapped person could be taught to carry out these therapies and, with suitable supervision and regular review, much could be achieved. By the mid-1970s behaviour modification was established as a therapeutic tool. Its applications have been in the teaching of new skills and in reducing or eliminating 'problem' or 'challenging' behaviours.

The basic premise of behavioural therapy is that certain actions will be learned and repeated if rewarded appropriately, as occurs daily in all our lives. Such rewards may be tangible, as when a gift is given, or intangible as when somebody gives praise for something.

Similarly, in learning theory, bad behaviours are 'learned' and 'rewarded'. For example, someone with a mental handicap might work in an overcrowded and understaffed training centre. Whilst everyone needs attention from others, that particular person might find vicariously that by behaving badly — perhaps with a show of aggression, or a temper tantrum — that he receives attention from the staff. Repeated acts of aggression or tantrums are similarly rewarded, and a pattern of maladaptive behaviour becomes established. Additionally, other trainees at the centre may 'model' their behaviour on their colleague, whose deviant behaviour has been rewarded by attention.

Recording behaviour

In order to undertake a therapeutic approach using behavioural methods, accurate recordings of the deviant behaviour need to be established. These are usually recorded by using a diary, which is kept by all those in close contact with the patient, such as parents, carer, school teachers, or training centre keyworker. The diary is divided into three columns headed 'A' for 'Antecedents', 'B' for 'Behaviour', and 'C' for 'Consequences' (ABC charts). The number of entries in the diary gives an indication of the frequency with which the behaviour occurs, and acts as a baseline on which to assess the effectiveness of the therapy.

The 'A' or 'Antecedents' column consists of a description of events surrounding and leading up to the behaviour. The 'B' or 'Behaviour' column is a description of the behaviour itself; for example, "John pinched Mary hard on the arm, so that she cried, whilst John stood and laughed." The 'C' or 'Consequences' column refers to the effect that the behaviour had on others and on the individual concerned. "Raymond, John's keyworker, came up to John and told him firmly to stop. John pinched Mary several more times, but then stopped pinching her for about an hour."

Repeated observations such as these can give information about the cause of the behaviour, a description of its range of specificity, its frequency and severity, and in addition, give indications for management.

The therapist will then decide whether changes in the person's environment would reduce the frequency or severity of the behaviour, or whether a behavioural programme might be instituted.

A behavioural programme

Instituting a behavioural programme requires problem behaviours, such as tantrums, physical aggression and verbal aggression, to be targeted individually. The identification of a suitable reward system is also required. Rewards may be given for periods of good behaviour, or for the achievement of success in other areas, or in undertaking activities which are incompatible with the bad behaviour.

Historically, bad behaviour has been treated with 'aversive' stimuli, that is painful experiences when the bad behaviour occurs. At its simplest level this may include spanking a disobedient child, electric shock treatment in sexual deviation, or the administration of drugs such as disulfiram in alcohol abuse. Punishments and other aversive treatments have no place in the care of those with a mental handicap for ethical and moral reasons. Additionally, they are less effective than reward systems.

Other behavioural methods rely on the removal of the reward that the bad behaviour is intended to elicit. All doctors and parents are familiar with the young child whose temper tantrums are designed to attract undivided attention. The attention given to such tantrums rewards the child and the behaviour continues or escalates. Tantrums are managed by depriving the person of the attention sought, by not responding to them. If such a response is continued consistently, the tantrums will disappear. Before they disappear totally, however, they may become more severe or prolonged, as the child or adult is forced to 'raise the stakes' in an attempt to elicit the sought-for response.

Behavioural therapy can also be used effectively in the teaching of new skills. A system of prompts or cues is used to focus the attention of the student. The new skill is clearly demonstrated and on completion of the task, success is rewarded. Praise, attention, sweets, can all be used to motivate effort and compliance, and success often adds to the reinforcing effect.

General practitioners can be of great help to parents and carers in coming to an understanding of behavioural problems, and they and the community mental handicap nurse can help to reinforce learning programmes.

Changing one's own behaviour continues throughout life, and for the most part people are not aware of it. In the clinical setting the therapist uses this day-to-day phenomenon consciously to influence the student's lifestyle. The introduction of moral issues has sometimes confused discussion of the effectiveness of this therapy — is it morally right to influence lifestyle or attempt to control behaviour? Each case should be approached on an individual basis and these questions should not detract from the value of the technique as a therapeutic approach.

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CHAPTER 11

The carers

David Sutcliffe, *BA, MA, PGCE*

ALL carers pay for their caring responsibilities: financially, socially, emotionally and mentally. A number of issues relate particularly to the mentally handicapped, but in practice the problems that arise cross all boundaries of age and type of illness or disability.

Relationship problems

Carers are often very restricted in their social activity. There are few opportunities for social life because of their responsibility to the handicapped person. Visitors are likely to be few, and invitations infrequent. When the carer accompanies the dependent person out, there may be either real or supposed embarrassment because of unusual or bizarre behaviour. In the case of the parents of a mentally handicapped child, the isolation is reinforced if the child cannot attend the same nursery or playgroup as other local children; when a child has to attend a specialist school, social contact with other parents at the school gate is lost, and with it much knowledge of community activity. Even where there are other 'normal' children in the family, patterns of social interaction are restricted and those children may also experience isolation. Carers may begin to lose the social skills they once had. Their caring involvement may lead to a situation where they are unable to enjoy themselves even when given the opportunity to do so. They may develop difficulty in making relationships and may discourage people by too frequent reference to their problems.

Not only are relationships with friends outside the home under threat, but there are similar dangers within it. The carer's preoccupation may be perceived by other members of the family as neglect of them. This causes tensions to arise. Commonly a husband will feel aggrieved that so much of his wife's love and attention is directed elsewhere. Children may resent the fact that they feel unable to bring friends home, or that they are unable to have the same kind of holidays as other families. In cases where an ailing grandparent is in need of care, these problems may be seen as temporary, but with a disabled sibling, in the time-scale of a childhood, they are permanent.

Damage to social life leads naturally to a damaged emotional life. A marriage may die because one of the partners is too heavily committed to the caring task. Wearying anxieties can take their toll: fears of not knowing enough about the condition they are coping with; fears of being held in ignorance by the authorities; and fears for the future — how will they cope when the child becomes adult?

Supporting the carers

All carers are likely to come to a stage when they are angry, angry with their situation, with the person they are caring for, and with those who provide the social and health services. This anger is sometimes expressed in inappropriate ways: a social worker may be shouted at on the doorstep, a child may be roughly handled, an old person verbally or physically abused. There are better ways of working through anger: joining a carers' group enables people to say what they think within a supportive framework; together, members may be able to make improvements to their lot.

Many carers feel undervalued by professionals supposedly there to serve them. For example, a district nurse may call and minister to the patient but forget that the *carer* could have needs which are not being met. Barely to acknowledge the carer during the visit is to give the message that he or she is not thought important. To say, "You're doing a good job" on leaving could be thought patronizing and not to address the real problems. Many carers develop considerable expertise in dealing with a particular condition or circumstance and will have a thorough knowledge of the patient. A professional who forgets this can harm his relationship with the family: he may appear to be a threat to their established ways of coping and cause them to adopt a defensive attitude.

However, one should not follow the "Does he take sugar?" line, forgetting to take account of the handicapped person's feelings as an individual. The disabled person should always be greeted and acknowledged however limited his ability to respond may be.

Carers are often exhausted. Their task may be heavy and non-stop, with no weekends off duty, no holidays, and with disturbed nights. In addition they often have to do battle to obtain any help. In far too many areas the service for such families remains minimal and information is piecemeal. It may be necessary to negotiate with the social services department, the Department of Social Security, local community nurses, the general practitioner and the education authority — sometimes all at the same time and at different offices, which may be, in the case of some county councils, as much as fifty miles away! Even when some help is arranged, it may not be when or where it is wanted: it is no good sending home support at 6 o'clock in the evening if an adolescent does not want to go to bed until 9 o'clock, and respite care needs to be in surroundings good enough to avoid feelings of guilt in the carer. It is essential to get away from the idea that a handicapped person should be fitted into an existing scheme of things.

The concept of a multidisciplinary 'keyworker' to smooth the way for carers is a good and useful one and it is to be hoped that more will be appointed.

Financial help

Financial problems may not be immediately obvious. One hears of Department of Social Security allowances for attendance, invalid care, and mobility; pensions or benefits are paid where appropriate, but it should be borne in mind that all these are available only when information is available about how to get them, and in the face of changes in the qualifying rules; this can be difficult. A long-term commitment can cause considerable extra expense to carers and their families. Apart from the increased wear and tear on clothing, bed-linen and furniture, there will be increased laundry costs, bigger heating bills, 'sitting-in' expenses, and increased transport costs. On a larger scale, the home may need to be adapted to provide such aids as a groundfloor lavatory, a shower, widening of doorways, and the installation of hoists or lifts. Family income may be affected by the need for the carer to give up work, or forego plans to return to work, when the child reaches school age.

Carers' organizations point out that vast sums of money are saved by the state when people care for their relatives at home. In an ideal world they might expect to be paid for their work; instead they are constantly struggling to get any financial help at all.

Rewards of care

The parents of mentally handicapped children are afforded a wide range of experience, both negative and positive. Many handicapped children are extremely affectionate and bring joy to their families. Their progress, slow though it may be, can make parents, brothers and sisters very proud. Growing independence can be a source of real pleasure. There is a fellowship of shared experience to be found in parent or self-help groups, and although the distances that some children must travel by bus or taxi to school make it difficult for their parents to take an active interest, the school can provide expertise, support and a meeting place for families.

CHAPTER 12

Counselling the families: a general practitioner's view

Martin Barker, FRCGP

HAVING to face up to parents following the birth of a handicapped child can be a harrowing experience for a general practitioner. He meets mourning relatives following a bereavement perhaps once every few weeks in a practice and tries to help them. This is never an easy situation, and no two families are the same, but in time he becomes more comfortable with that type of contact and develops tactics for coping with it.

The birth of a handicapped child into the practice is a much less common situation and yet it is the general practitioner's job to be involved at an early stage. Several studies made of parents' views show that most couples would have preferred that they had been told together, and with sensitivity, about their baby's condition on about the second day after its birth (Hannam, 1980).

Early reactions

The reaction which usually follows is very similar to that after a sudden bereavement. The parents, grandparents and siblings will grieve for the loss of a normal baby. All phases of mourning can occur and there may be an added emotion — the feeling that this abnormal baby must be rejected. At this stage it is no help if the general practitioner too conveys attitudes of rejection or hopelessness, as this will only increase the parents' despair. A positive attitude which yet recognizes the parents' need is all important.

Shock, anger, isolation and embarrassment will all be present. Questions will be asked and the answers misunderstood again and again. Comprehension is often limited; misinformation and misapprehension abound. Longstanding trust can be lost if a parent is misled by an over optimistic or too pessimistic prognosis. A general practitioner's position makes him a most powerful therapist even when he feels no confidence at all.

Throughout this period of psychological and physical adjustment the general practitioner should be able to assume the role of counsellor and friend. He is often the first person to whom the parents turn; a positive response is then required — the approach may not be made again. Friendship and support are paramount. Direct questions may be needed to find out how grandparents and siblings are getting on and whether they need support. It is important to know the way that contacts such as neighbours and schoolteachers are responding to the crisis, and the way that the parents are reacting to each other. Bringing up a child with a disability makes enormous practical and emotional demands on parents; unsupported families often fail badly.

Counselling is really about allowing people to express their feelings freely in a non-judgemental atmosphere. The general practitioner is well placed to add the next dimension, which is to help to clarify and assess the present and possible future situation. The relationship must favour listening, within the privacy of the home or the surgery. The aim will be to try to influence the attitude and outlook of the parents. It is hard for doctors not to advise or prescribe all the time; a general practitioner may be afraid to become involved in interpersonal relationships or family dynamics. What is wanted is a sympathetic listener who will give the family the chance to develop positive attitudes towards the handicapped child.

Gradual adjustment

Usually, as the initial shock diminishes, parents will adapt to the situation, but their ability to do this and the speed with which it happens depends on their own personalities and the marital and family strengths and weaknesses.

A family doctor in regular contact will spot those parents where the expectation was not to have a child for the sake of the child, but as a boost for their own confidence, or a defence against marital break-up. The birth of a handicapped child against this background needs understanding. The adjustment required may be beyond the scope of existing family relationships.

If counselling can allow the parents to express their feelings in a joint consultation, so much the better, for a common development is for the husband to isolate himself both from the problem and from his wife and the child. He may be apprehensive and unable to look at his own feelings; he will need just as much help as his wife in these circumstances.

In due time, and as the particular needs of both the child and his parents become apparent, the counselling general practitioner will be able to introduce help from appropriate more specialized sources, such as social services, voluntary organizations and self-help groups.

Needs of the carer

The general practitioner should never lose sight of the fact that very often carers too are patients whose health should be of as much concern to him as that of any other. A patient who is also a carer will make frequent calls on the services of the doctor, resulting in a relationship with the family which could give rise to a division of the doctor's loyalty — between handicapped patient and carer patient. The general practitioner's sensitivity to the needs of both, as well as his overview of the family as a unit, will be important when decisions must be made.

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CHAPTER 13

Social services provision

Georgiana Robertson, *B.Soc.Sci, CQSW, DASS*

THE social services departments have much they can offer to people who have a mental handicap and to their families and carers. Provision ranges from support in the community and social work counselling to day care and short-term and long-term residential care, as well as financial support to voluntary agencies.

Background

Local authority provision for people with a mental handicap is built on two foundation stones, legislation and philosophy.

Legislation

Some legislation is mandatory (that is, it is a duty upon the local authority), and some is permissive (it allows the authority to act on it if they so wish). There is very little mandatory legislation concerning people with mental handicap compared, for example, to the weight of that affecting social services departments regarding children.

Social work for the mentally handicapped and their families can be traced back to the 1913 Mental Deficiency Act, but it is from the 1948 National Assistance Act that the present shape of services was formed. This Act has been added to and amended by various subsequent Acts, for example the 1959 Mental Health Act, the 1970 Chronically Sick and Disabled Persons Act, and the 1986 Disabled Persons (Services Consultation and Representation) Act, as well as numerous social security circulars from the Department of Health, as it is now. The most important of these circulars are LAC 13/74 and LAC 19/74.

Together, these Acts and circulars mean that local authorities, via their social services departments, have responsibilities to people with a mental handicap for:

(a) day care provision

(b) residential provision

(c) social work services for the identification, diagnosis, assessment and support of individuals

(d) related services for practical assistance, for example home helps and home care facilities.

The legislation also sets out a clear expectation of cooperation between health authorities and the local authorities through their social services, housing, and education departments in pursuing preventive and proactive work for the welfare of people with a mental handicap.

Philosophy

The second foundation stone of social services provision has been service philosophy. In times gone by when people with a mental handicap were judged to be wicked, sinful, dangerous or contagious, the response was to put them into 'asylums' to protect society. Now, the prevailing philosophy is that of 'normalization' or 'social role valorization' based on the work of Wolf Wolfensburger in the USA. In this country the standard definition of these unwieldy terms is:

> "The use of means that are valued in our society in order to develop and support personal behaviour, experiences and characteristics which are likewise valued."

This means emphasizing dignity, autonomy, personal choice, age appropriateness, social integration, individual rights and responsibilities for people with a mental handicap. These principles have had a significant influence on the way in which services for people with a mental handicap have developed over the last two decades.

Provision

Social services responsibility covers people of all ages who have a mental handicap. Nowadays there is probably less specialized provision for children with a mental handicap than for adults. This reflects the philosophical base that 'a child is a child first and handicapped second' and therefore the full range of social services resources available to children in general are equally available to those with a handicap.

Social services structure comprises residential care, day care and area offices.

Day services

In the last decade a revolution has taken place in day care provision for adults. The traditional adult training centre (ATC) where trainees were engaged in assembly work has largely disappeared and been replaced by a day centre or social education centre (SEC), where the emphasis is on social skills training, for example community living skills, personal awareness and relationships and advocacy skills, artistic work, computer-aided learning and work preparation. The term 'trainee' has been dropped in favour of 'client', 'student' or 'service user'.

Day centres cater for adults with differing needs ranging from those who have a severe or profound handicap to those with a moderate or mild handicap. Actual arrangements vary across the country but it is usual for access to be via the social work office.

Consumer choice and self-advocacy are becoming the tenets of the new service and it is rare for a day service not to have an elected client committee or council which has an influence on how the centre operates. Some members from these councils have gone on to become members of the national 'People first' movement, whose credo is: "We are people first and handicapped second".

Some day services are organized on a 'core and satellite' basis; that is, through a central large unit known as the core which the majority of people attend and from which the administration is organized, with smaller satellite units located geographically closer to where the clients live. These satellites offer opportunities for community integration, such as using local facilities, shopping and road safety awareness, as well as the more individualized attention that working in small groups can provide.

More handicapped people are now taking part in activities in their local community and using ordinary local facilities such as the sports centre, art college and adult education groups rather than attending specialized social services facilities. Linked with this, day centre staff are increasingly involved in supporting people in activities outside the day centre building. Voluntary organizations such as MENCAP's employment agency, 'Pathway' and the Shaw Trust are important in enabling people to move into full-time or part-time employment.

Residential services

Eighty per cent of people with a mental handicap live at home with their parents; for those who do not, social services are now one of the major providers of residential care, alongside voluntary organizations and, increasingly, private agencies.

Social services hostels offer residential care to a broad spectrum of adults with differing needs. This is mainly provided in hostels for 20-25 people. There is a move towards the smaller, more homely accommodation which is now generally preferred. Weekend, holiday, short-term, and respite and emergency care is offered, as well as long-term residential places. Most people continue to live at home until their parents are no longer able to care for them, but residential establishments have become more proactive in helping people and their parents to consider the choice of leaving home at an earlier stage, as is done by the majority of the population.

For children, respite care with link families, foster or adoptive families is increasingly provided in preference to admission to children's homes, for example in the school holidays. Access to respite care is usually via a social worker at the area office.

Some clients move into a hostel as part of an assessment period and then move quickly on to a staffed small group home for, say, three to six people, or perhaps to an unstaffed group home. In the latter instance, care workers might still offer some form of regular support such as assistance in sorting out finances.

Other clients may opt for an adult placement, which is similar to a supported lodgings scheme, where a maximum of three clients can live with an adult placement carer and the carer's own family.

Two other options exist: to live independently in a privately owned flat with regular support as required, for example from an outreach worker, social worker or home help; or to move to a voluntary or privately run establishment. Social services departments may assist with financial sponsorship for a person at this type of establishment. Application for such sponsorship is via a social worker.

Area offices

There are a multitude of different workers based at an area social work office. Social workers can offer to an individual with learning difficulty and his family assistance in:

- counselling, therapy and support in looking at the present situation and exploring their feelings about it
- help for individuals in working out their needs
- co-ordinating the services they may be receiving already via review meetings and liaison
- helping people to gain access to resources
- supplying information about mental handicap and the resources available and acting as advocate
- future planning.

Social services departments are also involved in the inspection and registration of a wide range of services including childminding, playgroups, foster families and private and voluntarily run establishments and homes.

The home care section of the department can offer practical assistance to people in their own homes, and occupational therapists are involved in the assessment for and provision of domestic appliances, aids and adaptations.

Community mental handicap teams

One of the most positive developments of the past five years is the appointment of specialist social workers for this group of clients. The precise nature of their jobs varies up and down the country but it is not unusual to find them working in the community mental handicap team. These teams have become the keystone of services for people with a mental handicap. A core team often comprises a minimum of community mental handicap nurses and specialist social workers, but the full team may include a psychiatrist, psychologist, speech therapist and art therapist, with representatives of the day and residential care services, the education department and the voluntary sector. Sometimes the team will have its own offices where all the members work at least part time, but more often it will have regular meetings but retain separate offices and line managers.

Records

Records are kept on all clients receiving a service from social services. Since 1988 clients have had a right to open access to these records with the exception of information given by a third party, which is filed in a confidential module. This exemption would include information given, for example, by general practitioners and health visitors, unless they had specifically agreed that it was not confidential. There is a clear procedure for clients requesting access to their records but take-up has been low across all client groups.

Individual programme plans and reviews

It is good practice that every person receiving day or residential care has at least an annual review. The client and all relevant people should be involved in the procedure. Part of the process will be to draw up an individual programme plan (IPP) with the client, based on an assessment of needs. Key workers are nominated to pursue aspects of this.

Joint planning

Many developments in the area of mental handicap services reflect joint planning between district health authorities and social services departments. Similar joint planning exists involving the education and housing departments and the voluntary agencies.

The future

Social services departments are trying to make the services they offer as relevant as possible to the individual client. In the future this may lead to the development of far more flexible packages of care.

Further reading

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CHAPTER 14

The voluntary organizations

Mary Holland and Carol Youngs, RGN

VOLUNTARY organizations in the field of both mental and multiple handicaps are many and range from large national organizations such as MENCAP, Invalid Children's Aid Nationwide, and Contact a Family to small local parent/mutual support groups.

MENCAP

Forty years ago little was being done to support families with a mentally handicapped son or daughter, and there was a lack of service in education, housing, training, employment, life skills and opportunities. Judy Fryd was a parent who not only challenged but took action, and in 1946 founded the Association of Parents of Backward Children.

In 1955 this became the National Society for Mentally Handicapped Children, and in 1980 the title changed to include adults. In 1981 MENCAP was granted its Royal title.

Today, MENCAP is the largest national parent movement in Britain for people with a mental handicap. It has 550 local societies and is supported by a staff of over 700 in its national headquarters, divisional offices, and in educational and residential establishments and advisory centres.

The Royal Society's primary objective is to create a sympathetic climate of public opinion towards people with mental handicap, to increase public awareness and understanding of their problems, and to secure the provision that they and their families need. At the same time MENCAP aims to ensure that people with mental handicap are able to develop their full potential to live in the community 'like other people'.

One of the main reasons for the success of the parent movement is its insistence on challenging the established order. Its effectiveness was, and still is, due in large part to the diverse talents available from parents themselves — people from all walks of life who are united as parents, and whose skills and knowledge offer an unrivalled resource of expertise with which to educate professional opinion.

Today, there is a wide spectrum of both voluntary and statutory provision. There has been progress, but much more could be done — not the least being to ensure that services across the board, from before birth through schooling into adulthood and old age, are available to all who need them, and not dependent on geographical luck.

A number of roles have been prescribed for the voluntary sector, most recently by Sir Roy Griffiths in his report *Community Care: Agenda for Action* (1988). Griffiths sees the voluntary sector as being service providers, educators, innovators, campaigners, advocates/befrienders and constructive critics. MENCAP would agree. These roles are central to its policies and are reflected in a diverse range of services.

MENCAP provides expert information, support and advice on education, training, housing, benefits and rights, holidays, recreation and leisure facilities through its national and regional staff, and through its real professionals — the parents.

One of the greatest strengths of a voluntary organization is its freedom to initiate and develop new ways of responding to the needs of its client group. MENCAP is, and has been, at the forefront of the development of services for people with mental handicap. The following projects are examples of this pioneering work.

MENCAP Homes Foundation

The MENCAP Homes Foundation provides a range of accommodation in the community, from flats for two people to group homes for up to 10. The average size of a group home is six. Residents will get as much help as they need to live safely, happily and comfortably. If they need constant care, they can live in a house which has full-time staff. Even if they are very independent and can live in an unstaffed house, they will have someone to turn to in case of problems.

New Era Housing Association works with the Foundation on projects, New Era producing new housing by building or conversion and the Homes Foundation taking responsibility for management of the completed houses.

Holiday services

Advice and information are provided on family and group holidays. In addition there is an annual programme of special care, adventure and guest house holidays throughout the UK for unaccompanied people of all ages with a wide variety of handicaps.

Profound Retardation and Multiple Handicap Project

This project has undertaken a survey of the needs of parents and carers of children and adults with profound retardation and multiple handicap. Building on findings, the project will provide workshops to help parents and professionals to understand and meet the special needs of this group.

MENCAP Open University Course

"Mental Handicap: Patterns for Living" was launched in 1986. It is based on experiences of people's lives. Its aims are to broaden understanding, increase opportunities and improve the lives of people with a mental handicap, their families, and those working for them. The course has attracted a multidisciplinary attendance, and more than 17 000 student packets have been sold. Work is under way to transform the course to be accessible to people with a mental handicap. Phase two of the course is being developed.

GATEWAY

MENCAP's National Federation of GATEWAY Clubs, founded in 1966, has over 700 clubs throughout England, Wales and Northern Ireland. GATEWAY gives some 40 000 people a chance to take part in leisure activities which encourage movement towards independence, self-awareness and self-esteem, through participation, the exercise of choice, and decision-making. The success of this national voluntary youth and community organization is largely dependent on the skills and interests of 20 000 volunteers.

Voluntary welfare visitors

Voluntary welfare visitors provide a lifeline of help, advice and practical support. The trained visitors help families and individuals to obtain the benefits and statutory services to which they are entitled.

Trustee Visitors Service

This scheme provides a visitor for people after their parents have died. Real friendships develop between visitors and beneficiaries and great care is taken in choosing people to do this important work.

Pathway Employment Scheme

Set up as a pilot project in South Wales to meet concerns over the lack of employment opportunities for people with a mental handicap, the Pathway Employment Scheme now has 27 employment officers providing services in 31 cities, boroughs or counties. To date, 1500 people with mental handicap have been placed in employment, with a success rate of about 80%. In addition, 1541 people have been placed in work experience programmes, which are stepping stones to paid employment.

Volunteers

Volunteers are the backbone of MENCAP's work. Local societies throughout England, Wales and Northern Ireland provide many varied services. Some have their own premises where parents, carers and professionals meet in partnership to plan and provide opportunities for children, young people and adults with mental handicap. Services include early intervention groups, opportunity groups, playgroups, hostels for children, and flats for single parents.

Most local societies arrange sitting facilities, respite care, and help with transport. All local societies provide friendship, understanding and support. Local societies and their honorary officers, many of whom are parents themselves, liaise with statutory authorities within their own areas to ensure that their problems and priorities are under constant review.

Local societies are supported by MENCAP's divisional offices and through their elected representatives on the Royal Society's National Council.

Contact a Family

Contact a Family was set up 10 years ago to encourage the creation of self-help groups and the sharing of advice, information and emotional support among parents. The service can be summarized as follows.

Multi-handicap support services

These services provide development support, training and information to parents' groups which are organized on a wide range of handicaps basis, usually within a defined geographical area.

Rare handicap support groups

These provide similar services to parents' groups which are organized on a rare handicap basis. The groups vary in size from Ehlers-Danlos syndrome, with eight families across the country, to the Multipolysaccharide Group, which has more than 350 members nationally. These rare handicap groups number 200 at present; a record is kept of any enquiry concerning a rare handicap where no group has formed, in order to link up any new parents who may ring in about that particular diagnosis.

These two types of groups are each supported by a full-time development officer who can advise, support and guide leaders and professionals as required. This support includes training/support days for parent group leaders.

Contact Line

A vital component in the service is the Information Service, which includes a telephone help-line, Contact Line.

Using specialized directories which are stored in a microcomputer and continuously updated, it is possible for Contact a Family to link callers with other parents who are willing to listen and lend support.

Through Contact Line parents and professionals are also put in touch with the appropriate self-help support group, multi-handicap and/or rare handicap, and advised on sources of support for parents all over the country.

Contact Line may be of particular use in locating a parent contact or national group for general practitioners whose patient may have a child diagnosed with a rare handicap where it is obviously less likely that there would be a local contact. Equally, Contact Line could also advise on available support groups and services at a local level by referring to the directory.

Useful addresses

A list of useful addresses can be found at the end of the book (Appendix 2).

References

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CHAPTER 15

Occupational therapy, physiotherapy, and speech therapy

The Therapists of Brighton Health Authority

Occupational therapy

THE occupational therapy service aims to provide people with mental handicap with opportunities, stimulation and direction to develop their maximum potential in personal activities for daily living, social skills, work, leisure and hobbies; to prevent regression, and to give them the opportunity as individuals to have some control over their own lives.

Assessment and therapy

The occupational therapist, as part of a multidisciplinary team, will assess the client in both a structured and informal setting in the following areas:

- Assessment of motor, sensory, cognitive, intrapersonal and interpersonal skills — progressing where appropriate to the provision of a specific treatment programme
- Evaluation of skills in the personal activities of daily living and the introduction of programmes to enable optimum independence
- Identification of the need for specialist aids, equipment and environmental adaptations, e.g. seating, hoists, microtechnology
- Assessment and provision of treatment programmes to develop work skills and productivity where appropriate
- Assistance to the client in developing vocational interests and to plan leisure activities based on need, ability and individual choice.

Following assessment, a client's needs can be put in order of priority according to his own requirements and those of people closely involved with him, for example parents, carers or teachers.

Advice, liaison and instruction

Occupational therapists can advise carers and professionals about someone's functional ability at home and in his everyday and leisure environments. They can also support the carers by closely monitoring the client's progress, and can support and monitor the use of specialist equipment.

There may be liaison with any member of the multidisciplinary team, with any voluntary organization, or with other individuals involved with carers and appropriate professionals. For example, architects and environmental health officers can advise on the suitability or possibility of adapting private houses or local authority and public buildings for use by people who have a mental handicap.

The occupational therapist has a role to play in the identification of appropriate residential or day care facilities for mentally handicapped people, and in the training of staff and provision of information to other professional and voluntary colleagues.

Referrals and access to the service

Referrals are usually accepted from anyone involved with a person with a mental handicap or his/her family. Access is variable depending on the locality, but contact can be made through the hospital occupational therapy department, social services department, community mental handicap teams, residential services and special schools.

Physiotherapy

The physiotherapist's aims are to maximize and maintain the physical potential of a person with a mental handicap, to encourage all aspects of independence and, with other professionals, to ensure that he or she receives a high standard of health care. A physiotherapist can increase the understanding of those working with the mentally handicapped about the effects of physical and neurological disability on their achievement levels.

Assessment

A physiotherapist, as part of the multidisciplinary team, will be involved in a specific physical assessment of the client. In children this assessment will be concerned with achieving physical milestones, encouraging function, mobility and balance, and the maintenance of body position during the growth years. In adult life the assessment will be broader, looking towards both physical and non-physical needs, and helping with an overall view of lifestyle, achievable aims and future requirements.

Assessment will involve:

- initial examination made at a venue and time suitable to the client/carer/parent/referee, for example at home, or in a hostel, day care establishment, hospital or school
- diagnosis, assessment and treatment of conditions both acute and chronic
- recommending the most suitable treatment, and whether this is best administered by the physiotherapist or a carer.
- treatments using any of the numerous techniques available to the physiotherapist, including specialized physiotherapy according to specific needs
- monitoring of all work undertaken by carers.

Advice

Advice given by the physiotherapy service to people who have a mental handicap may include guidance on the management of deteriorating conditions, advice on managing chest conditions, help regarding the provision, repair and adaptation of wheelchairs, specialized footwear, walking aids and appliances; advice and practical help with leisure and recreational activities (by liaison with other professionals working in those fields) and arranging access to swimming, hydrotherapy and relaxation programmes. Physiotherapists can help the client to achieve a positive self-image, in the management of challenging or aggressive behaviour, through programmes of activity and exercise.

Instruction and liaison

Instruction of and liaison with other professionals, care workers and parents is an important part of the physiotherapy service. This could include such subjects as the causes and recognition of physical and neurological disability and its relevance to achievement levels, lifting techniques and back care.

Referrals and access to the service

Referrals are usually accepted from anyone involved with the client, but this may vary from area to area. Means of access to the therapist is also variable, but contact can be made through the district physiotherapy service, hospital physiotherapy departments, community mental handicap teams, social services patch offices, specialized day centres and special schools.

Speech therapy

The aims of a speech therapist working with people with a mental handicap are to facilitate a functional communication system which enables them to communicate with others in a variety of settings and allows them some control or influence over their own lives.

Assessment

Both formal and informal assessment is designed to give an overall picture of the client's communication skills in both structured and 'normal' situations. The following areas are considered:

- — verbal expression
- — non-verbal comprehension
- — articulation
- — language use
- — social skills
- — functional communication
- — sensory impairment (hearing, vision)
- — physical disability
- — feeding/swallowing.

The needs of the individual are then considered in liaison with key individuals in the client's life. Relevant aspects are:

- — relationships
- — environmental factors
- — physical state and general health
- — medication
- — psychological factors (personality, emotional state).

Therapy

Therapy can be offered in several different ways: either through training staff and carers so that a programme can be implemented, or by direct input to the client by means of structured teaching. Indirect therapy, using guidelines for staff and carers to carry out communication programmes in different situations, may also be used.

Communication aids such as computers, electronic aids, signing or symbols can be used as an alternative to or as a supplement to communication programmes where this is appropriate to the physical and other abilities of the client.

Access

Referrals are usually accepted from anyone involved with the client, but these may vary according to the system in any one district. Therapists can usually be contacted through the district health authority speech therapy service, or through the preschool, education and social services, community mental handicap teams, day centres and residential services.

Conclusion

In occupational therapy, physiotherapy and speech therapy, there have recently been moves towards ensuring a flexible, client-oriented and holistic approach to care of people with a mental handicap.

CHAPTER 16

Sexuality and sex education

David Beckitt, MRCGP

WITH the increasing move towards care in the community and the development of 'normalization' the subject of sexuality of people with a mental handicap has swung towards the rights of the individual. It is now widely acknowledged that people with a mental handicap should have the same rights and opportunities as others to form personal and sexual relationships, and to express their sexuality. To avoid the many pitfalls which confront anyone who is sexually active in present day society, they will need counselling, education and support. They may need to learn what is appropriate behaviour, and where and when it can take place. An important area for counselling is that of contraception; but sex education is not just about contraception, it must also emphasize the importance of care in developing an emotional and physical relationship (Craft et al., 1985; Cooke, 1990).

Many people believe the myth that children are not sexual beings and that people with a mental handicap remain children forever. They conclude erroneously that individuals with a mental handicap have no sexual needs or feelings, or that such needs and feelings are totally inappropriate because they are 'children'. Many people have difficulty in talking to their children about sex, and for parents of children with mental handicap the problems can be doubled.

The reason for sex education for people with a mental handicap have been well discussed and can be summarized as follows:

> "The vast majority of those with a mental handicap will develop normal secondary sexual characteristics. They need more help, not less, in making sense of these changes and the accompanying strong emotional feelings.
>
> They need knowledge which will protect them from exploitation and from unwittingly offending others" (Cooke, 1990).

Many people have expressed fears that providing sex education for young people with mental handicap will open Pandora's box; in other words, without it they would not be aware of their own sexuality. However, in an evaluation of 31 courses which taught 430 young people with a mental handicap by means of specially devised teaching slides, it was found: "There were no reports that the staff were aware of serious inappropriate behaviour that could be attributed to the programmes." Instead, teachers commented on improved social behaviour, increased self-respect, more openness and fewer feelings of guilt.

The Warnock Committee (1978) on special education commented:

> "At present, sex education and counselling on sexual relationships tend to be handled generally. This is unfortunate for all young people, but it is particularly serious in the case of young people with disabilities, whose opportunities for personal development through self-education are so limited compared to those of other young people, and for whom the problems of adolescence are likely to be increased by their disability."

The Warnock Report recommended that sexual and genetic counselling and advice on contraception should be readily available to young people with special needs and their parents. It also suggested that reference to sexual counselling should be made in all training courses for professionals who would be working with adolescents with special needs.

In 1980, the National Development Group for the Mentally Handicapped produced a checklist of standards called "Improving the Quality of Services for Mentally Handicapped People". Standards 92-94 are concerned with sexual counselling for staff, people with a mental handicap and their families.

Most counsellors would not consider the 5-15 minute consultation in the surgery as the most appropriate setting for the task, but the practitioner should:

- try to identify the need
- identify the authority best suited to respond to that need and, if appropriate, refer
- establish good communication and follow-up
- ensure that the carer understands the needs and responsibilities involved.

The sexuality of the adolescent with learning difficulty is just as powerful, and the feelings just as intense as in other members of society. He or she is just as embarrassed to initiate discussion with parents/carers or teachers as other children. In common with parents or carers of children without learning difficulty his or her parent/carer may fail to recognize and respond to the needs of the maturing child.

What to teach

A change of feelings, an increased need for privacy, an altered awareness, a subtle change in sensation as well as developmental physiology, with menstruation in one sex and wet dreams in the other, must be recognized as normal and shown as such.

Learning to cope with moods or sudden arousal, the responsibilities involved in building up and continuing relationships, acceptable behaviour and reasonable expectations of the opposite sex should all be covered.

Society's secret, the role of the father in conception, the mysteries of pregnancy and childbirth must all be explained. The needs and rights of the newborn child for total care and protection in secure surroundings must be understood. The prevention of pregnancy if coping skills are inadequate should be discussed, since it is to be hoped that the proper use of contraception will prevent the tragedy of abortion and sterilization. To fail to provide basic information on this topic is to fail at a basic level of need.

How to teach

The Family Planning Association's Social Education Department's 'Design for Living' programme increasingly provides sex education to clients. It is often undertaken in small groups with a fixed membership of roughly the same age and ability. With open (supervised) discussion, the group sets its own limits and its own vocabulary. Provided all contribute, the use of visual aids, models and role play with the added spice of spontaneous humour is a potent learning form. It allows the members to talk about hitherto secret aspects of their lives and how growing up has changed them. Gaps in comprehension are identified and best dealt with on a one-to-one teacher-learner basis.

The person with mental handicap may then be in a better position to make an informed choice on the need for contraception, and can be shown the appropriate methods. Brook Street Centre's pamphlet "How to Use the Condom" was developed to meet the needs of an increasing number of young people with learning difficulty attending the Centre, and they are pleased to show young people their consultation centre simply to familiarize them with and demystify the setting, procedures and equipment.

The problems associated with the AIDs epidemic also need sensitive handling. The British Institute of Mental Handicap have produced some helpful leaflets about this.

Mentally handicapped people demand remarkably little of their doctors in proportion to their disabilities; there are excellent agencies to help in the field of sex education and it is important to ensure that these are made accessible to them.

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CHAPTER 17

Genetic counselling

Martin Barker, FRCGP and David Livingstone, MRCGP

THE general practitioner and the primary care team are already deeply involved in antenatal and postpartum care. In time general practitioners will become involved in prepregnancy counselling.

Prepregnancy counselling would involve general health education, dietary advice, advice on sensible handling of alcohol and tobacco, and the routine enquiry into the patient's immune status, especially with regard to rubella. A family history of diabetes, epilepsy, handicap or other chronic illness would trigger off further appropriate advice, perhaps with referral for specialist advice. Increasingly this will include referral for genetic counselling.

Needs and aims

There are 160 000 severely mentally handicapped people in England and Wales. In Great Britain there could be over one million people with mental handicap. Thus many families are affected and increasingly will be looking for genetic counselling.

A genetic counsellor must first meet the family and construct the family tree. This in itself may be difficult as diagnostic information can be weak and it is important that a proper diagnosis is confirmed.

In this country, because accurate diagnosis is seen as important, genetic counselling is the province of medically trained geneticists. The geneticist's aim is to quantify the risk and offer factual advice. During the initial consultation he will, if possible, confirm the diagnosis and construct the family tree while also getting to know the family. Understanding of the family's attitude will be important when the doctor comes to offer the advice on which they will make decisions. The situation is never straightforward; advice cannot be clear cut: some families can face up to a 50-50 chance of having a handicapped child, others cannot live with a 200-1 risk. A sensitive assessment of the circumstances is required and in many cases long-term support will be necessary.

Mental handicap is a feature of many genetic disorders, which fall into three main categories.

1. Mendelian inheritance

Autosomal dominant type

The risk to the offspring of affected members of these families is one half, regardless of sex and regardless of whether or not the disease is fully developed. The risk to unaffected members of the family is the same as that for the general population, but in some conditions, such as Huntingdon's chorea, where the disease may not be manifest until late in life, affected family members may not be readily identified. Tuberous sclerosis and neurofibromatosis are other examples of autosomal dominant inheritance.

Predominantly, patients with autosomal conditions will be heterozygote; that is, they will have inherited their condition from one parent only or will themselves be a new mutation.

Homozygosity means that both parents have transmitted the gene; this is most unusual but may become more common if more among the affected handicapped individuals decide to marry. Unfortunately homozygote autosomal dominant children are usually severely damaged and do not survive.

Autosomal recessive inheritance

If the diagnosis is clear, prediction is relatively simple, but this is not commonly the case. Usually only isolated cases are seen, and the risk to offspring is very low. Included in this group are many of the inborn errors of metabolism.

The numbers of families at risk are small compared to those with chromosomal disorders. The risk to offspring of affected patients is 1:4. Porphyria, cystic fibrosis, Tay-Sach's disease and the mucopolysaccharoidoses are in this group.

In x-linked inheritance women act as carriers, affecting half their sons whilst half their daughters will be carriers. Many sex-linked disorders are now known but only a few are dominant. Of increasing importance is the fragile X syndrome.

Fragile X syndrome: this is a mutation associated with a fragile site on the long arm of the X chromosome at xq 27.3. It is a common abnormality affecting 1 in 100 school children (Thake et al., 1987). It is second only to Down's syndrome as a common cause of mental handicap. The xq fragile site, an unstainable 'gap', is only visible in karyotypes by special cell culture conditions (Sutherland and Hecht, 1985).

The fragile X syndrome should be considered as a diagnosis in any child who in the absence of neurological signs shows developmental delay. At least 1 in 10 of such children are affected. For those children in this group whose head circumferences are over the 50th centile, 1 in 8 will have a positive result (Thake et al., 1985). It is vital to recognize the fragile X syndrome early because the mother is always a carrier and there are many relatives at risk of having mentally handicapped children (Sherman et al., 1984). It is particularly important to recognize the syndrome in mildly handicapped girls because they are likely to have children of their own.

Perhaps the most intriguing feature of the fragile X syndrome is its pattern of inheritance. A grandfather may be clinically unaffected, yet transmit the fragile X chromosome to all his daughters who all have normal intelligence. They in turn may have sons affected with the fragile X syndrome, and carrier daughters, of whom one third will be mentally handicapped. It thus appears as though the fragile X mental retardation undergoes a change after transmission through a female; in other words, during oogenesis (Bundey, 1980). The syndrome is not inherited in a regular X-linked way so that in some families affected cousins will have inherited the condition from a symptomless fragile-site-negative grandfather rather than the grandmother (*Lancet,* 1986).

The clinical picture of adult males with the fragile X syndrome is that of a moderate degree of mental handicap associated with short stocky build, large head, prominent lower jaw and ears and large testes. Approximately one third of female carriers are mentally handicapped and are of normal appearance. Furthermore, even in the best cytogenic laboratories fragile sites at xq 27.3 can be demonstrated in only half of the normal carriers. It is hoped that the development of closely linked DNA probes will lead to the reliable detection of these carriers (Brown, 1989).

The general practitioner is ideally placed to identify the fragile X syndrome from his knowledge of families. The problem is that, having identified his patient at risk, he does not have a definitive test available to determine who is and who is not affected. Many will be shown to be carriers and can be offered prenatal diagnosis. Some of his patients will however be left in a state of uncertainty. However, the situation is changing in that highly accurate DNA molecular techniques allow one to track fragile X mutation in a large number of families. These techniques are not as accurate as one would like but they are now of clinical use and are much more reliable than the cytogenic, chromosomal techniques for carrier detection and prenatal diagnosis.

2. Chromosomal disorders

Chromosomal abnormalities are found in 6.6 per 1000 babies born. In spontaneous abortion 50% show chromosomal abnormalities. The most common chromosome disorder is Down's syndrome (trisonomy 21); the overall population incidence of Down's syndrome is 1:650 live births. There are about 40 000 people with Down's syndrome in England and Wales. The risk of another affected child being born to a couple who already have one child with Down's syndrome is increased to 1:200 under the age of 35, rising with maternal age to 5:100 at the age of 45.

3. Multifactorial genetic disorders

The third category of genetic disorders is multifactorial. The mildly mentally handicapped present a good example of this group. Environmental factors as well as genetic factors may be important. As yet counselling can only be based on an analysis of population studies for these disorders.

People with mental handicap

The dividing line between the normal population and those with mild mental handicap is usually set at 70 on the IQ scale, but in fact those with mild mental handicap (IQ 50-70) merge imperceptibly into the normal population and their levels of IQ are greatly influenced by those of their parents. By contrast, in those with severe mental handicap, parental intelligence is usually normal.

In the severe group it is more likely that a specific cause for the mental handicap may be found. The number of possible disorders is large and includes abnormalities which may be biochemical, chromosomal or environmental. Despite this, for the majority of severely mentally handicapped people there will not be a satisfactory diagnosis.

The risk of similar severe mental handicap to siblings is ten times greater than that for the normal population; even so, this represents an overall recurrence risk to siblings of only about 3%. Where two affected children exist the risk increases to 1:4 for future siblings.

The risk to the offspring of a healthy individual who has a severely handicapped sibling is often a cause of concern. Where a severely handicapped brother is concerned, the possibility of x-linked inheritance must be considered. Where the affected individual is female, the risks will be small, and more distant relatives (third degree) are unlikely to be at any significant risk.

Professor Peter F Harper, in his excellent book *Practical Genetic Counselling* (1984) concludes that:

> "At a time when small families are the rule, it seems essential for those having children to take every possible measure to ensure that they will be healthy, and to do so beforehand. At present public awareness of the subject, perhaps because of television programmes, is focused on problems and diagnostic techniques *during* pregnancy. As a result there is a danger of increasing the level of anxiety without increasing people's knowledge. It is to be hoped that in the next decade there will be a shift of emphasis to health care before conception, with genetic counselling as a part of overall health education prior to reproduction. Should this occur it would increase demand for counselling services from general practitioners and specialists" (Harper, 1984).

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CHAPTER 18

The law and mental handicap

(England and Wales)

Andy Newland, BSc(Soc), CQSW, DASS

A CHILD or an adult with a mental handicap has the same rights in law as any other citizen, except where he or she is detained in hospital or made subject to guardianship under the Mental Health Act. In addition he or she has rights to education and local authority services where a need has been established.

People with mild to moderate mental handicap will, with varying degrees of help, be quite able to express an opinion and make judgements about their own medical treatment. That is to say, they will be able to give real consent to treatment, provided adequate information is given and successfully communicated.

Capacity to give consent

However, a problem of capacity to give consent to medical treatment may arise with some people with severe to profound forms of mental handicap. Statute law is generally unhelpful on this question, and case law confusing and contradictory. Common law does give some general guidelines which should inform medical practice. It should be remembered that in law no person may make a substitute judgement for another except:

- a parent or guardian, in relation to a minor (under 18 years)
- a local authority, in relation to a child in care
- the High Court, in relation to a ward of court
- the High Court (in effect) in connection with the sterilization of an adult woman with a mental handicap.

In respect of the last of these, the House of Lords, in the case of 'F', have ruled that the High Court should, by way of a declaration, confirm (or not) that a proposed sterilization of an adult woman with a mental handicap is in her best interests, having regard to what would be accepted as the proper practice at the time of a responsible body of medical opinion. This is a controversial decision which goes against the grain of much other thinking on individuals' rights (MENCAP, 1989). This decision may eventually be reviewed in the light of the need for a statutory and comprehensive legal framework within which to consider a wide range of competency and substitute judgement issues.

While it may be good practice to seek the views of close relatives when the question of consent has to be addressed, it is not sufficient in law.

Children with mental handicap

Children with mental handicap are treated no differently in law except:

- Under the Education Act they are entitled to needs assessment ('statementing'), and services to meet needs
- They may be accommodated in local authority children's homes without necessarily being received into care
- Ordinarily a minor of 16 years or over can give a fully effective consent for any surgical, medical or dental treatment. Some young people with a mental handicap may lack capacity to give this consent however. If this is so, and he or she is between 16 and 18 years, it may be necessary to seek the consent of the parents to any treatment.

Social services departments have extensive responsibilities for the care and protection of children and this is no different for those with mental handicap.

Unless treatment is required urgently and of necessity (the usual common law rule for treatment without consent) the basic common law rules apply to mentally handicapped children and adults as to anyone:

- Any form of physical treatment without the patient/parent's consent is an assault unless consent can be dispensed with (urgency and necessity)
- The patient/parent's consent must be real. It must be genuine, uninfluenced by fraud or misconception and must be based on sufficient information
- Anyone treating a patient has a duty to use reasonable care and skill.

There may, however, be a conflict between the principle of consent and a doctor's duty of care. Such conflicts must be resolved taking into account the person's individual circumstances and the degree of risk he or she would otherwise be exposed to.

Detention in hospital

People with mental disorder as defined in the Mental Health Act (a very wide category including mental illness and mental handicap) may be detained for up to 28 days in hospital for assessment on the application of an approved social worker or the nearest relative (based on medical recommendations) if the degree of disorder and the health or safety of the patient justifies it.

Mentally handicapped people may not be detained in hospital on a six-month treatment order or made subject of a guardianship order unless they are mentally impaired within the meaning of the Act. To come within this definition the person will need to have a mental handicap which is associated with abnormally aggressive or seriously irresponsible conduct (by his own part).

For hospital detention, unless the person is seriously impaired, it is necessary also to demonstrate that the order is likely to alleviate or prevent a deterioration of his or her condition. This means that under the current law, it is difficult, if not impossible, to protect a mentally handicapped adult from exploitation by others in circumstances where he or she is 'willing' to be exploited.

Powers to enter premises

An approved social worker has powers under the Mental Health Act to enter and inspect premises where he or she believes that someone with a mental handicap/mental illness is not under proper care. Approved social workers also have powers under this Act to apply to a Magistrates Court for a warrant to enable the police to enter (if need be, forcibly) premises where it is believed a mentally disordered person is being neglected or ill-treated, or is being kept otherwise than under proper control.

After entry, the person concerned may be taken to a place of safety for up to 72 hours, during which arrangements may be made for the use of the longer term powers of the Mental Health Act. A police officer has powers, again for up to 72 hours, to remove someone from a public place to a place of safety who appears to him to be suffering from mental disorder for the purposes of being examined by a doctor and interviewed by an approved social worker.

The Mental Health Act consent to treatment provisions set out the rules under which consent may be dispensed with for the treatment of mental disorder. These rules also apply to those few people with mental handicap and impairment detained under the Act.

Guardianship

The guardianship of a mentally impaired person may be accepted by the local authority social services on the application of an approved social worker or nearest relative based on two medical recommendations if this is thought to be in the interests of the welfare of the patient. Once accepted, this order gives the guardian (who may be the local authority or an individual) the following powers — and these only:

- To require the patient to reside at a specific place
- To require the patient to attend at places and times specified for the purposes of medical treatment, occupation, education or training (does not give power to dispense with consent to treatment)
- To require access to be given where the patient is residing to doctor, approved social worker or other person specified by the guardian.

A doctor may produce evidence of mental disorder for the Public Trustee Office (Protection Division) also known as the Court of Protection. This body has extensive powers to administer funds and property on behalf of mentally disordered persons.

Sexual activity

The only restrictions in law on sexual activity with mentally handicapped persons are that it is an offence for a man to have sexual intercourse with a woman he knows to have a severe mental handicap and for a man to commit homosexual acts with a man he knows to have a severe mental handicap. It is also an offence for those employed in hospitals and social services establishments to have intercourse with women suffering from mental disorder in certain circumstances. Otherwise, sexual activity for people with a mental handicap is outside the ambit of the law except insofar as it may lead to decisions such as in the case of 'F' and sterilization.

Provided a person is able to give a valid consent there is no bar to mentally handicapped persons marrying. A person must understand the nature and purport of the marriage and freely give consent. A doctor or other person who does not believe that the person is capable of giving a valid consent may enter a caveat before the ceremony with the Superintendent Registrar. The person concerned will be notified of this and will have an opportunity to answer any objections.

The right to vote

In common law there is an assumption that severely mentally handicapped people may not appear on the electoral register. Electoral officials are entitled to ask permitted questions which if answered in an intelligible manner would enable him or her to vote. Informal (that is, not detained) patients may be invited to vote on nominating the hospital or elsewhere as their address for electoral purposes. Apart from assistance with making a declaration as a result of blindness or physical disability, it is a requirement that persons completing the voting declaration form do it themselves. This is to test whether the patient is able to understand the information required to make a declaration.

Residential and other facilities

Private or voluntary homes for mentally handicapped people must be registered with the social services department if they care for more than three people, board is provided and personal care is required. If nursing care is required, homes must be registered with the district health authority. Both statutory agencies have extensive powers to control the standards of and supervise private and voluntary homes.

Local authority education and social services departments have a duty to assess the needs of mentally handicapped and other disabled people and to provide resources to meet identified needs including special education, day activities, residential care and aids to daily living.

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CHAPTER 19

Information unbound

David Sutcliffe, *BA, MA, PGCE*

THERE are common strategies which doctors use to meet the needs of patients:

> "I'll prescribe you these pills."
>
> "I'll get the nurse to come and visit your husband."
>
> "I'll write to the specialist at the hospital."

But there are other initiatives which could be equally effective:

> "I'll ring the social services department and see if they can provide..."
>
> "There is a carers' support group that meets at the church hall. Here's the phone number of the person who runs it."
>
> "I think you should apply for the attendance allowance."
>
> "If you ask the receptionist she has all the information about local voluntary societies."

Finding out

Unfortunately 'end of consultation' phrases tend to depend on the information that general practitioners have either in their head or easily accessible. Every general practitioner has a copy of the *British National Formulary.* Other information about the latest drugs is also easily available; it comes in the post in copious quantities. The prescription pad is close at hand and may offer both the doctor and patient an apparently simple remedy for problems which at root may be social in nature. Although general practitioners are expected to assess the needs of their patients in social as well as physical and psychological terms, problem solving in the social dimension is impeded by a lack of information. Patients may not be aware of this lack of information and imagine that the general practitioner is the gateway to all services, social as well as medical. They may then find it difficult to understand why they have been left in ignorance for years about a benefit such as the attendance allowance.

From the doctor's point of view it is not as easy as the patient might think. There is the problem of raised expectations. For instance, a doctor may feel that a patient or a carer should have a home help, but it would be very unwise to say that he will provide one; that is the job of the home help organizer, who may not think that the referral is appropriate. Mentioning a self-help group to a patient is likely to be understood as an endorsement of the activities of the group. It may seem safer to keep quiet, but important issues should not be avoided just because they are difficult.

A new formulary?

What is needed is a 'social' version of the *British National Formulary* which could be available to every general practitioner and to other workers who deal with the public. It would need to be in two sections, national and local. National information would include:

- benefits available from the Department of Social Security, and grants available from charitable sources
- names, addresses and phone numbers of voluntary organizations and an indication of the services which they can offer
- specialist hospitals and homes able to cope with unusual conditions and disabilities.

Local information would include:

- addresses and phone numbers of social services officers and the facilities available locally, for example, homes for the elderly, day centres, home help services, respite care facilities, carers' support groups and transport services for the disabled
- addresses and phone numbers of local voluntary organizations and facilities that they can offer, for example, Crossroads care attendants schemes, Alzheimer's Disease Society sitter service
- addresses and phone numbers of nursing homes and rest homes
- names and addresses of special schools for children with learning difficulties
- address and telephone number of the local office of the Department of Social Security.

Some of this information is already available. Local councils of voluntary service, health education units and social services departments all have useful lists, but there is no single reliable source of information for doctors and their patients. Looking through sheets of paper, booklets and brochures is hardly possible in the course of a five-minute consultation.

Making use of the computer

The arrival of the computer in the surgery provides one answer to the difficulty and one which has already been proved to be worthwhile and an asset to both patients and professionals. Jarman (1985) has described how to set up a computer program for use at a health centre to deal with the problems of patients who have financial difficulties. The program was started in 1980 and dealt with a wide range of benefits including attendance allowance, invalidity pensions and so on. At the time of writing Jarman could claim a 100% record of accuracy with the information provided by the computer being checked by the DHSS social security officer. With two or three enquiries a day the service was clearly meeting a need and, in addition, it provided doctors at the health centre with greater knowledge and confidence when talking to people in their own homes on matters to do with benefits. So successful was the project that in 1983 the DHSS provided one of their officers to work with the program at the health centre and run an advice centre there for the patients.

It would not be too difficult to extend this service to include the range of information outlined earlier so that patients, carers and also the primary health care team could have at their fingertips the answer to the information needs of everyone. What is much more difficult is finding the right person or organization to provide and maintain the up-to-date information. Some general practices and health centres regard the work of the practice manager as including the gathering of information, but it would be very wasteful of time and energy for every practice to have to do its own research. As local information is vital to meet people's needs, it is necessary to find a local organization which could undertake the task. There are at least five organizations which have the expertise and/or the interest to develop such a programme on behalf of all surgeries in their area: family practitioner committees, community health councils, councils of voluntary service, social services departments and colleges of arts and technology.

Taking the initiative

Social services departments will have much greater responsibilities for the care of the frail and disabled now that the Government has accepted the main recommendations of the Griffiths Report (1988). From 1991 they are to be responsible for ensuring that an adequate level of care is available to help people to stay in their own homes rather than be forced to go into residential care. To do this social services departments will need to develop efficient information systems which could be made available to the public not only through their own officers but also through every general practitioner's surgery.

Alternatively the health authorities could take the lead in providing this service. Wessex Health Authority has already taken steps in this direction with a computer-based information service 'Help for health' (Gann, 1988), which supports a telephone enquiry service. It enables enquirers to find out just the sort of information that carers and their general practitioners need to know. For example, what is the new address of the Hyperactive Children's Support Group? Is there a self-help group for post-viral fatigue? It is now available to other health authorities, libraries and advice centres, and has so far been bought by 20 different organizations. This system is of particular value for national information; local organization is required for local information.

These schemes are just stepping stones to further developments. All professionals should have access to information at their place of work and the general public should have the same ease of access. In the future we are likely to see a computerized information system in every living room. At that point there should be no more difficulty in finding out about the local carers' group or the address of the Parkinson's Disease Society than in getting up-to-date information about the latest traffic jam on the M25 or the weather in the Mediterranean. That might give the doctor and his team rather less work to do; it would certainly allow patients to be more independent.

Acknowledgement

This paper was first published in the *Journal of the Royal College of General Practitioners* (1989, **39**, 397-8) and is reproduced with permission of the Editor.

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APPENDIX 1

A short protocol for the care of people with mental handicap in general practice

THE regular medical assessment of vulnerable groups of patients is becoming a normal feature of general practice. It is recommended that a regular medical assessment is carried out on this group of patients, who are known to have a large hidden morbidity together with a low consultation rate. There are 30 to 40 people with a mild mental handicap, and from 6 to 8 people with a severe mental handicap for every 2000 patients, and these form a large group; however, annual assessment should be possible.

Social services departments are now charged with the responsibility of organizing a register of people with a mental handicap: data from the register could be made available to general practitioners. The increasing use of computers in general practices enables an accurate age-sex register with a diagnostic index to be maintained. This will make the follow-up of mentally handicapped patients routine.

The mentally handicapped cannot be viewed as a homogeneous group: they are all individuals, with individual needs and aspirations, requiring special attention. There are however guidelines which could help the general practitioner to get a picture of his patients and their problems.

Guidelines for assessment

Regular medical examinations should give time for the practitioner to talk with the patient (alone if possible) and then with the principal carer. The assessment could include the following:

Social assessment

- Establish who are the primary and secondary carers and what their relationship is to the patient, noting relevant addresses and telephone numbers.
- Establish a family tree, possibly using a simplified version of Zander's charts.
- Establish what services are being provided for the patient such as day care, schooling, respite care, holiday relief, and recreational facilities.
- Establish what allowances are being claimed (such as mobility, severe disablement benefit or attendance allowance).
- Establish what the long-term aspirations are for the carers and for the handicapped patient.
- Other social factors, including employment, housing and family circumstances should be noted.

In addition:

- The potential strain of constantly caring for a mentally handicapped person must be assessed, and available support (or lack of it) noted in the record.
- Genetic counselling may or may not have been offered; if positive advice has been given it should be noted.
- Contact with the social worker, community mental handicap nurse, key worker or case manager needs to be documented.
- The availability of aids to independent living needs to be assessed in some cases.
- An assessment of the patient's lifestyle should include enquiring into diet, exercise, use of tobacco, consumption of alcohol and contraceptive practice. Sexual counselling may be appropriate.

Medical assessment

A detailed medical and family history is required, especially at the initial assessment. This should include a note of illnesses, allergies and medication. Special attention should be paid to:

- immunizations (correcting previous deficiencies in administration if appropriate)
- drug therapy
- dental treatment
- speech therapy.

Direct questioning may be required to clarify problems resulting from epilepsy, incontinence and behavioural problems. These are under reported by carers and a sympathetic general practitioner is excellently placed to assess these problems and make appropriate referrals. Psychiatric illness, communication difficulties and challenging behaviours need to be evaluated carefully, as referral can be valuable.

Ongoing medical problems must be defined and a note made of the patient's attendance at special clinics. A full physical examination should be offered.

In people with a mental handicap, problems may occur in any system of the body. Special attention should be paid to: obesity, visual and hearing impairment, mobility, undescended testicles and hernias. An assessment of social and mental attainments, including use of language and comprehension, will be made during the examination.

Investigations, including a midstream specimen of urine and a full blood count, may be helpful. In patients with Down's syndrome thyroid function tests should be undertaken every two years.

Similarly, in patients with Down's syndrome, an x-ray of the cervical spine should be undertaken. In women, cervical smear and breast examination should be undertaken as a routine, with appropriate arrangements being made to facilitate these examinations where necessary.

The needs of the carer

Simultaneous assessment of a person with a mental handicap and his carers is a valuable undertaking. Carers are often the doctor's patients also. Their needs are of vital importance not only to their own well-being, but also to that of the handicapped person.

APPENDIX 2

Useful addresses

British Dyslexia Association
98 London Road
Reading
Berkshire RG1 5AU
Tel: 0734 668271/2

British Heart Foundation
102 Gloucester Place
London W1H 4DH
Tel: 071 935 0185

British Institute of Mental Health
Wolverhampton Road
Kidderminster DY10 3PP

Carers National Association
29 Chilworth Mews
London W2 3RG
Tel: 071 724 7776

Contact a Family
16 Strutton Ground
London SW1P 2HP
Tel: 071 222 2695

Cystic Fibrosis Research Trust
Alexandra House
5 Blyth Road
Bromley
Kent BR1 3RS
Tel: 081 464 7211/2

Disability Alliance
25 Denmark Street
London WC2H 8NJ
Tel: 071 240 0806

Disabled Living Foundation
380-384 Harrow Road
London W9 2HU
Tel: 071 289 6111

Down's Syndrome Association
12-13 Clapham Common Southside
London SW4 7AA
Tel: 071 720 0008

Eating Disorders Association
(formerly Anorexic Aid & Anorexic Family Aid National Information Centre)
Sackville Place
44-48 Magdalen Street
Norwich
Norfolk NR3 1JE
Tel: 0603 621414

Family Welfare Association
501-505 Kingsland Road
London E8 4AU
Tel: 071 254 6251

Holiday Care Service
2 Old Bank Chambers
Station Road
Horley
Surrey RH6 9HW
Tel: 0293 774535

MIND
22 Harley Street
London W1N 2ED
Tel: 071 637 0741
Public Enq: 071 387 9126

National Autistic Society
276 Willesden Lane
London NW2 5RB
Tel: 081 451 1114

National Association for the Welfare of Children in Hospital (NAWCH)
Argyle House
29-31 Euston Road
London NW1 2SD
Tel: 071 833 2041

National Library for the Handicapped Child
Institute of Education
20 Bedford Way
London WC1M 0AL
Tel: 071 636 1500

National Society for Mentally Handicapped People in Residential Care (RESCARE)
Raynor House
23 Higher Hillgate
Stockport
Cheshire SK1 3ER

Network 81
52 Magnaville Road
Bishops Stortford
Hertfordshire CM23 4DW
Tel: 0279 503244

PHAB (Physically Handicapped & Able-Bodied)
Tavistock House North (2nd Floor)
Tavistock Square
London WC1H 9HX
Tel: 071 388 1963

Rathbone Society
1st Floor Princess House
105-107 Princess Street
Manchester M1 6DD
Tel: 061 236 5358

Research Trust for Metabolic Diseases in Children
53 Beam Street
Nantwich
Cheshire CW5 5NF
Tel: 0270 629782

Riding for the Disabled Association
Avenue R
National Agriculture Centre
Kenilworth
Warwickshire CV8 2LY
Tel: 0203 696510

Royal Association for Disability and Rehabilitation (RADAR)
25 Mortimer Street
London W1N 8AB
Tel: 071 637 5400

Royal National Institute for the Blind (RNIB)
224 Great Portland Street
London W1N 6AA
Tel: 071 388 1266

Royal National Institute for the Deaf (RNID)
105 Gower Street
Camden
London WC1E 6AH
Tel: 071 387 8033

Royal Society for Mentally Handicapped Children and Adults (MENCAP)
MENCAP National Centre
123 Golden Lane
London EC1Y 0RT
Tel: 071 454 0454

Sense (National Deaf-Blind & Rubella Association)
311 Grays Inn Road
London WC1X 8PT
Tel: 081 550 8822

Spastics Society
12 Park Crescent
London W1N 4EQ
Tel: 071 636 5020 Ext. 241

SPOD (Association to Aid Sexual & Personal Relationships of People with a Disability)
286 Camden Road
London N7 0BJ
Tel: 071 607 8851/2

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Typeset and printed by Hillprint Ltd, Bishop Auckland, Co. Durham
ISBN 0 850 841 56 9