

# Dealing with the Disadvantaged

## Helping families with a mentally handicapped member

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The incidence of mental handicap has been estimated, using criteria based on an intelligence quotient of below 50 in children of school age, as between 3 and 4 per 1000 in most developed countries. It is reasonable to assume the same incidence, worldwide, in countries from which statistical data are unobtainable. Down's syndrome accounts for almost one-third of these figures.

Many parents will first be told of their child's handicap by the medical or nursing staff in the obstetric unit. In some cases, genetic screening may have identified a potentially handicapped infant before delivery, and the parents may have been offered termination; this is sometimes refused. Cases still occur where, in spite of screening, a handicapped baby has been born to parents who have previously been advised that the infant would be normal. Some infants suffer damage during birth or in the immediate postnatal period, which is considered by the parents to have been avoidable.

Medical practitioners are likely, therefore, to be dealing from the start with a family under great stress and to find the distress and anger directed at them personally, though this may not be openly expressed. This calls for immense skill; compassion and the shared sense of acute disappointment on the part of the doctor must not be allowed to obscure the immediate practical help which alone will alleviate some of the suffering. Comfort is usually derived from positive information—in other words, what can be done by the parents to make the most of their child in spite of the handicap—rather than an attitude of “wait and see.” The doctor who *has* information about the particular handicap should put his knowledge into simple unambiguous language that is not inherently hurtful; if he has no precise knowledge of the particular condition he should have the courage to say so and be willing to refer the parents to others who may be able to help. Of particular value is the specialist group of parents with a similar condition to cope with. Medicine has a part to play in the management of mental handicap, but best results are obtained from co-operation with a multidisciplinary team.

It is not always realised that the mother of a handicapped baby experiences grief comparable with that of the mother of a stillborn child. In a real sense she has lost the healthy baby she awaited with joy and has now to come to terms with a tragedy—not finite as a stillbirth, but destined to continue for the whole life of the child. We can make a few practical points that may help practitioners, and list them in the order in which they most frequently arise.

### Antenatal counselling

(1) The doctor may be asked to advise on the possibility of a mentally handicapped child being born to a mother who knows herself to be at risk. Some hereditary conditions can be predicted with reasonable accuracy. What cannot be predicted is the individual response to scientifically estimated data. Given the infinite variability of the human condition, it probably never will be. Thus the doctor faced with any prediction based on scientific data needs to take into account the possibility of error or of modification of the prognosis by factors at present unknown.

(2) Parents constantly repeat statements, allegedly made at the time they were told of their child's handicap, which state the child's future in terms such as “He will never be able to look after himself,” or “He would be better placed in care.” It is important that the doctor makes it clear that his predictions on the future of the child are a matter of opinion not of fact, but that the diagnosis of the handicap is a matter of fact, if in truth it is.

(3) The duty of the doctor who is asked by parents for information is to give it, wherever possible, to both parents at the same time in privacy; to differentiate clearly between factual information and opinion; to say clearly what is not known; and to allow time for the parents to understand what is being conveyed and to ask questions if they wish.

(4) It may be necessary to repeat essential information several times, and it is helpful to arrange a further consultation at a not too distant date so that parents may have the chance to ask questions arising from the earlier consultation. If it is possible to give some essential information, in simple concise terms, as a printed note, it may help the parents to read it quietly at home.

### At the birth

(5) If the handicap has been expected, there will have been time to organise a support procedure. Such a procedure should be standard practice, so that the traumatic effect on the mother and immediate family is minimised.

(6) The child should be given to the mother in the usual way, wrapped if necessary, so that she may have an immediate contact with the infant. She should not be denied this moment by any clinical examination. If the child is breathing and there are no grossly apparent signs of birth defects—and sometimes even if there are—it is the right of the mother to be first to greet her child.

(7) The support procedure should begin at once. Staff should act unanimously on a previously agreed programme, designed by the consultant in charge. It is his responsibility to ensure that the best is done for his patient, and this involves his personal instructions to all concerned in the care of mother and child.

(8) The mentally handicapped baby without physical defects

needs exactly the same care and attention as other infants—only more of it. He may need longer periods with his mother at feeding times, longer time for stimulation by nursing and cuddling, time to ensure that his feeds are properly digested, and probably more time for bathing and exercise. The establishment of confidence in the mother of a handicapped infant is of primary concern; she should realise even in the first hours and days after birth that there is much that she alone can do, will have the time and the incentive to do, and which cannot be done by nursing and medical staff. If her baby is constantly being removed for tests or treatment, conditions are being created for rejection.

(9) The support team should include the general practitioner, midwife, health visitor, father, grandparents or other relatives, social workers, and representatives of appropriate local voluntary groups. The team must have the information they will need to help the mother, *but* the request for help must come from her. Nevertheless, before she can ask for help she may have a primary need for counselling from a qualified psychiatrist, later from a clinical psychologist, to help her come to terms with her own grief and bewilderment. The close relatives need to be given accurate information and to be told how they can help and where they can get further information and advice. Well-informed family support will often prevent the fruitless round of “second opinions,” “experts,” and unproved fashionable therapeutic programmes.

#### At the clinic

(10) Sometimes a doctor seeing infants at a routine examination may be presented with a baby with an undiagnosed mental handicap. If this arises the doctor needs to be aware of all the factors already described. Both parents should be present when any information is given and this may well be best done by the family physician, who, if forewarned, will have time to call up the supporting team to help the family. Health visitors may be the first professionals to notice that an infant may be handicapped. They should always warn the doctor quietly of their suspicions, before his consultation.

(11) At the routine health checks the parents may ask about the advisability of protective immunisation for their child. Discussions on advice given will certainly take place among the waiting mothers, and the coverage by the media will ensure that parents will be aware of any statements made on existing programmes or proposed new protective techniques. The doctor needs to be fully aware not only of the medical implications of the question but also of the current climate of popular opinion, especially if it is influenced by a particular local tragedy. Again, the doctor should give the facts, as distinct from his opinion, then give his advice, but accept that ultimately the decision rests with the parents.

#### Management of the handicapped child

(12) Though the number of mentally handicapped infants in any general practice may be small, the family doctor may be consulted more often for advice by the parents. They will need reassurance that they are coping with the infant, and their successes should be remarked upon and praised. While accepting that, for example, respiratory infections, skin conditions, and feeding difficulties may occur more often in mentally handicapped babies, these should not be seen as inevitable, and when they occur, the parents should be assured that the doctor will help them to manage the child at home and that his skill and their patience may be as effective as hospital care.

(13) A mentally handicapped young child is no less affected emotionally, or damaged psychologically, by separation from the parents in sickness simply because he appears less able to

communicate his distress; he may in fact suffer more since he comprehends less.

(14) *At school*—Many mentally handicapped children now attend ordinary schools and are under the same surveillance as other school children. The school nurse should be aware of any special problems and bring them to the attention of the doctor during school inspections, but it will always be necessary to check that the child's sight and hearing are normal and that, if needed, he is receiving proper speech therapy. If regular treatment is being given, the effectiveness of the regimen can be estimated by classroom performance and the opinions of teachers. Poor posture and gait need to be identified early to avoid future disablement; simple corrective orthopaedic measures may prevent much additional discomfort in later life.

(15) *Dental care*—Because of feeding and dietary problems, the teeth of some mentally handicapped children need intensive dental care. Some children present severe management problems in dental care sessions and the doctor may need to advise how distress may be minimised.

(16) *Adolescence*—Mentally handicapped adolescents are subject to the same stresses and emotional strains provoked by physiological changes as other young people. Their awakening sexuality often causes great anxiety to their parents, who may seek medical advice on contraception, the management of menstruation, and masturbation; they may fear sexual exploitation. Though it may be self-evident that the problem exists for the parents rather than the mentally handicapped young person, the doctor can give advice only if he is fully aware of the family background. Adequate supervision is needed to ensure that prescriptive advice is actually carried out. Frequent revision of all drug treatment—contraceptives, tranquillisers, sedatives—is needed at this time to avoid the “repeat prescription” syndrome.

#### Mentally handicapped adults

(17) More mentally handicapped adults now live in the community. Few children now stay in hospitals, and no new admissions are planned. Families who have always cared for their mentally handicapped members at home will already have given instructions in the simple skills of shopping and using public transport and of personal hygiene and self-care. Difficulties arise when the parents die and the mentally handicapped person is alone. Some will be accustomed to spending part of their time in hostels, perhaps returning home at weekends, and medical supervision for this group is probably adequate.

(18) Once the mentally handicapped person is alone, or in a group home or hostel, he must rely on the ability of those nominally responsible—that is, visitors, social workers—to recognise a need for medical attention. There is often a communication problem, owing to imperfect speech. A general practitioner may visit regularly, without relying on the crisis call, if proper medical surveillance and care are to be given. The doctor needs to be aware of the degree of support and surveillance the mentally handicapped person on his list are receiving, and to see that those responsible are properly informed of the signs and symptoms that require medical aid. Visits to a mentally handicapped person who is ill should always include a full medical examination to discover the real extent of the problem. Neglected simple ailments can add greatly to daily discomfort and these are sometimes disclosed only when a more serious condition supervenes.

(19) Mentally handicapped adults make relationships with the opposite sex, and they may wish to live together or to marry. Some of these partnerships, properly supported, have survived several years. The family doctor can do much to help these couples, and to advise and counsel the parents of mentally handicapped people who wish to leave the family home to live in the community.

Mental handicap cannot be cured but the ability and skill of

the doctor to provide comfort and to alleviate distress are essential to the handicapped person, child or adult, and the family who accept his care.

The Secretary-General of Mencap writes: The suggestions given are based on the most commonly expressed anxieties and problems received by this Society over the past 25 years and are written from the point of view of parents. The Society

provides a selection of literature giving practical advice to parents and is grateful to the Royal College of General Practitioners for maintaining reference samples of these publications during the past 10 years.

On 24 June 1981 our Annual Mental Handicap Week Conference will deal with the theme "Right from the Start," an interdisciplinary forum which hopes to explore current practice and make recommendations for the future. BRIAN RIX CBE.

## Compensation for Drug Injury

### Two solutions to an insoluble problem

RICHARD SMITH

During the early 1970s in the United States manufacturers began to complain loudly about product liability problems. They claimed that the number of cases was increasing dramatically, that an increasing percentage were successful, that insurance to cover product liability was becoming much more expensive, and that some companies were being forced into bankruptcy. This was the "product liability crisis."

Consequently in April 1976 the President's Economic Policy Board set up a task force to look into the problem. The task force commissioned a legal study, an insurance study, and an industry study, and reported in December 1976.<sup>1</sup> I met Dr Edward Barrett, the task force's project director, in Washington. He explained that the task force members had started their job thinking that they were dealing with a problem of the law of tort. Two things became apparent, however: firstly, that the "product liability crisis" had been exaggerated; and, secondly, that the problem was more one of insurance than of tort law.

#### Findings of the task force

The task force had only limited data on which to base its conclusions. Product liability was not easy to study: most cases were settled out of court, and most insurance companies did not keep separate accounts of their product liability experience.

The task force did find that the number of product injury claims had increased "substantially." Lawyers who acted for injured people claimed that the average size of awards had not increased, and the task force could not find many data to oppose that claim. One survey in Cook County, Illinois, did show, however, a "substantial" increase in the size of the awards. There was also an increase in the number of "blockbuster awards" (\$1m or more). The study also suggested that the number of "wins" in appellate and jury cases was approaching 50%, though the number of injuries did not seem to have increased. This suggested that a higher percentage of injuries were leading to legal cases.

The task force was sure that insurance premiums had risen considerably in most industries; the drug industry was included among those most severely affected. Smaller firms suffered

particularly badly, but the task force found no evidence that any companies had been forced out of business because of product liability problems. Some companies had been unable to obtain product liability insurance, but this was more a problem of "affordability than availability." Nevertheless, for most companies, even those with severe increases, premiums were hardly more than 1% of sales. Disturbingly, some companies—even large ones—had chosen to trade without insurance.

Another finding was that in some industries—particularly the drug industry—manufacturers forwent and delayed the introduction of new products because of product liability problems. The task force was not sure whether this was a good thing or a bad thing. The drugs not introduced might have been potentially dangerous or they might not have provided much advantage over old drugs. Alternatively, they might have been drugs such as vaccines that offered little profit and yet provided considerable potential for injury—simply because of their wide use in healthy people. One encouraging finding of the task force was that manufacturers were devoting more time and money to avoiding producing defective products. Finally, although some injured people were receiving full compensation from the tort-litigation system, many were not.

The table shows data extracted from the report on the experience of some drug companies with product liability. Claims, damages sought, and damages paid did not increase at all between 1971 and 1976. In that time, however, total sales and product liability insurance premiums did increase. These limited

*Impact of product liability on a sample of American drug companies (information extracted from the report of the Interagency Task Force on Product Liability)*

	1971	1972	1973	1974	1975	1976
Average total sales (\$m) (31 to 38 companies)	164	188	207	234	292	329
Average general liability premium (\$m) (14 to 23 companies)	0.11	0.09	0.10	0.13	0.16	0.23
Average product liability premium (\$m) (11 to 21 companies)	0.08	0.08	0.09	0.10	0.13	0.21
Average pending claims (32 to 33 companies)	10	9	10	11	12	14
Average new claims (33 to 35 companies)	2	32	34	33	33	31
Average damages sought in new claims (\$m) (29 to 31 companies)	0.44	0.57	0.42	0.13	0.11	0.45
Average total amount paid out in settlements in and out of courts (\$m) (33 to 36 companies)	0.03	0.03	0.04	0.04	0.02	0.02

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