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SOME POINTS ABOUT THE GUIDANCE OF PARENTS OF MENTALLY SUBNORMAL CHILDREN

R. S. ILLINGWORTH, M.D., F.R.C.P., D.P.H., D.C.H.

Professor of Child Health, The University of Sheffield

It is difficult and almost impossible in the busy out-patient department to give parents all the help which they need with regard to the problems of their mentally subnormal child. It is difficult not only because of the considerable amount of time necessary to help each parent, but also because the problems are so deep and complex, and often so individual in each family, that it is easy for the doctor to think that he has dealt with the matter in full, when in fact he has only touched the fringe of the problem, and he has totally failed to understand the real feelings of the parents.

In order to provide the greatest possible help to parents, the doctor must have a thorough knowledge of the disease, its natural history and prognosis: he must have a basic knowledge of genetics: he must know something of the devious workings of the human mind, so that from apparently irrelevant remarks, he can pick up clues as to what the mother really feels or fears: he must sincerely want to help the parents and feel real sympathy for them: and he must be prepared to give time, not just in one interview but sometimes in several interviews. Parents should be given every opportunity to ask all the questions they wish in order that they can resolve their anxieties and doubts. In this connection it is always my practice to speak fairly briefly to the mother in the first interview, breaking the news of the child's backwardness, if she does not know already (as she usually does), discussing the prognosis briefly with her and answering her questions: but then to offer another appointment in a month or two in order that she can ask further questions which have occurred to her. It is easy to try to pack far too much into the first interview when the mother is distraught at finding that her worst fears were justified, and when she is not in a fit state to discuss the outlook and management intelligently. It is essential that the parents' initial reactions of disappointment, frustration, shock, depression and failure should be resolved, before a rational discussion of the future can be commenced.

It is very difficult for the physician in an outpatient department to appreciate the magnitude of the task of attempting to give the parents the help which they need. There is comparatively little in the literature which will help him — largely because it is so difficult to write about it. He has to try to understand their difficulties and help them to find the solution. As Blodgett says (1957) it is unrealistic in counselling to expect complete success. It is important that every doctor should know that the worst, the most harmful and the most incorrect thing which the doctor can say is that nothing can be done for the child. A doctor who says this, on his first interview, and never sees the child again, is seriously failing the parents.

In this paper I will attempt to pick out some of the points of importance in trying to help the parents of subnormal children.

(1) When should the parents be told that their child is abnormal? I would say that the mother should not normally be told during the puerperium, but that after that she should be told *as soon as one is certain of the diagnosis*. Before one is certain one should not give the slightest hint or suspicion that the child is abnormal: it would

cause a great deal of unnecessary worry. It is a great mistake to be overconfident in the diagnosis of mental subnormality and other handicaps in infancy. I have seen several examples of erroneous diagnoses — including several of hydrocephalus, when in fact the head was normal, and several of cerebral palsy and of mongolism, when in fact there was no abnormality. The diagnosis of mongolism in the newborn can be easy and obvious, but it can be difficult and uncertain. When in doubt, one should wait and see, or supplement one's clinical opinion by chromosome studies. In the case of cerebral palsy, one *must* remember that neurological signs found in the newborn period may disappear as the child grows older. With regard to mental subnormality, one must remember that backwardness in infancy is not necessarily permanent. Delayed maturation may involve all fields of development (Illingworth 1961, A), so that the child is uniformly retarded, with the result that mental subnormality is the obvious but incorrect diagnosis. Delayed maturation in motor development is not infrequent, and the doctor who makes the mistake of placing much reliance on motor development in assessing a child may diagnose mental subnormality when in fact the child is normal.

In my opinion it is absolutely wrong to leave the mother to find out the truth herself. I have asked the opinion of innumerable mothers of handicapped children about this, and all without exception have said that they feel that a mother should be told the truth as soon as possible. A mother of a mongol said to me "I think that I have known from the day he was born. I have bottled it up all this time and never dared to tell even the doctor." Tizard and Grad (1962) found that only three per cent of 218 mothers of defective children said that they should be left to find out for themselves. Mothers like to know the truth, so that they can face the problem and plan and adjust accordingly. It is most unfair to allow them to develop lingering, gnawing doubts, which they do not like to mention even to the husband or family doctor. Very many mothers suspect that the child is abnormal very soon indeed after his birth. A mother readily senses that we are trying to hold something back: but if in doubt we have to try our best not to give any hint that the child is abnormal. It is another matter altogether if we know that the child is subnormal. I agree with Waskowitz (1959) that failure to tell the parents about the child's handicap leads to resentment against the doctor, and to disturbing and even expensive "shopping around" for opinions.

I am not sure whether the father should be told before the mother. There are arguments for and against this. If a father is told that his child is a mongol, a day or two after birth, it may save his wife the unpleasant task of breaking the news to him.

(2) How should the parents be told? Above all things, they should be told with deep sympathy. Unfortunately doctors and nurses tend to become hardened to human suffering. I heard a doctor refer to his ward round with students in the following words: "By sheer good luck there was a beautiful newborn mongol to teach about." I felt that this indicated a complete lack of feeling for the parents in their tragedy. Zwerling (1959) and others have described various ways in which parents have been told that their child is abnormal. A lady doctor told a mother that "Mongols make nice pets about the house." Another doctor told a mother to "put her away and forget you ever had her, unless you want to lead a dog's life." Killilea (1953) was given similar advice with regard to her spastic daughter Karen, who in fact was highly intelligent. When mongolism is diagnosed in some American obstetrical units, it is the practice to tell the father that the child is a mongol and should be placed in an institution, while the doctor and father tell the mother that the child is dead.

Certain words should never be used when counselling parents. These words include 'Idiot,' 'Mongolian idiot,' 'Imbecile,' 'Mental defective,' 'It's his brain,'

'Ineducable,' 'Hopeless.' I always avoid the term 'Birth Injury,' because it implies that the defect is due to injury at birth. This is a very difficult thing to prove, and in general unlikely to be true, for maldevelopment in utero is a far more likely cause. Several mothers have said to me "I did hope that you would not use the words 'Birth injury'." The expression implies blame on the obstetrician or midwife, which is quite unjustifiable. If a tragedy occurs in one's life, it is far better to feel that it was unavoidable, than to feel that it could have been prevented. The term 'brain injury' carries the same connotation. A mother told me that a doctor was 'brutal' for using those words. Mothers have told me of their extreme resentment at being told that their child is "a hopeless idiot." A mother told me how angry she was when a doctor told her that her hydrocephalic boy's siblings would "grow up to be terribly ashamed of him." She refused ever to see that doctor again.

I prefer to use the words 'retarded' or 'backward,' making it clear, however, that the child will always be backward. It is wrong to leave the parents with the impression that the child is backward but will soon become normal. Some doctors wrongly tell the mother that the child is 'just lazy,' or that 'there is nothing to worry about.'

It is my practice, after I have made my diagnosis, to let the mother say what she thinks of the child, and when she says that he is backward, I then agree with her. I often find it useful to ask her how far she thinks that the child has developed. It is surprising how accurate mothers often are in assessing the child's developmental age. It helps them to know what his level is, so that he can be managed accordingly.

(3) What parental attitudes can we expect to meet?

The first is refusal to accept the verdict that the child is severely retarded. This attitude concerns the older child, and not the infant. Innumerable mothers have told me that "He's very intelligent," or that "He has a fantastic memory." The paediatrician should try to understand the reason for this attitude. One reason is related to the normal development of the child. For example, an average 18 month old child knows where items are kept for the table, and where his daddy's slippers are, and can be shown to have a memory span of up to 6 months. In the same way a three year old, with a developmental quotient of 50, might well have the same extent of knowledge and of memory span, with the result that the parents cannot accept the verdict that he is considerably retarded. There are deeper reasons for parents' unwillingness to accept the verdict, but as these are individual to each case, they cannot be discussed here.

This attitude frequently leads to conflict between the parents and the medical and school authorities. It is because of this that wherever possible a retarded child should be given a trial in an E.S.N. School. If he manifestly cannot manage at such a school, the parents are much more likely to accept the verdict that he is unsuitable for education at school than if they are told this without the child being given such a trial.

The second attitude is a feeling of hurt pride. The birth of an abnormal child puts them back in their efforts to keep up with their neighbours.

The third attitude is a feeling of guilt. There are several possible reasons for this. The parents may feel that they have conceived too soon after the previous pregnancy. A mother who has attempted to terminate a pregnancy may feel serious guilt if her child is abnormal. An hour after I had told a mother that her child was retarded I found her waiting for me in a state of anxiety. She asked me whether I thought she had 'murdered' her child. When I asked her to explain this, she said that she feared that the child was abnormal because she had had intercourse with her

husband when seven months pregnant. A mother may fear that the tragedy was due to over-exertion during pregnancy, or to carrying on with her work when pregnant.

A feeling of guilt and also of blame of the marriage partner can readily be engendered by over-enthusiastic efforts to obtain a detailed family history. It is a mistake to delve too deeply into the family graveyard, and to ask, for instance, whether the parents are absolutely sure that there has been no one, not even a distant cousin, who was handicapped. Except in the case of certain specific deficiencies like phenylketonuria, such a family history doesn't help in the diagnosis or genetic counselling. It is very apt to cause strained family relationships, for it invites one marriage partner to blame the other for the tragedy, usually quite unjustifiably. The fact that a cousin on the father's side was mentally defective provides no evidence that the defect in the child being examined emanates from the father's side of the family.

Another attitude is a pathological attachment to the child. It is altogether desirable that parents should show great affection to a handicapped child: but affection can go too far. We saw a notable example of this at the Children's Hospital, Sheffield. A mongol patient of ours, called Jane, had a normal baby sister. This baby was sent up to the Casualty Department with bronchopneumonia, and on arrival was found to be dead. When we told the mother that it was too late, for the baby was dead, she immediately said with relief "Well thank God it was not our Jane."

We have twice seen mothers have their own normal children adopted so that they could give their whole time to the severely mentally defective child (Holt, 1957). Ounsted (1955) wrote about the pathological attachment of mothers to mentally defective epileptic children. He found that as the child's behaviour deteriorated, the parental devotion increased. One mother stayed indoors for two years, without a break night and day, in order to give her whole time to the child. He described the complete withdrawal of parents from society and normal pleasures. Some of the children showed considerable improvement in behaviour when their mothers gave them less attention.

When talking to a mother about her severely defective child, I always tell her that we can take her child or arrange accommodation for him for short periods in order to give her a break or a holiday without him. In my experience not more than one in thirty mothers takes advantage of this. Mothers commonly say "I would not dream of such a thing. I give my whole life to the child and I would never let anyone else look after him."

It should be remembered that this pathological attachment to a child may have a disruptive effect on the marriage. It may also have a serious psychological effect on the other children.

In my experience frank rejection of a handicapped child is rare, though I have seen it.

(4) The Prognosis

An essential part of guiding the parents consists of a discussion of the prognosis. A woman rang me up late one night to say that an obstetrician had told her that her newborn mongol would never learn to sit, walk or talk. She wanted to know whether this was correct, and was greatly relieved when I told her that it was quite wrong. She was also helped by being told the average age at which mongols learn to sit, walk, talk and acquire clean toilet habits. All parents want to know whether their child will achieve these simple skills. They also want to know whether the child will be able to go to school, and later on whether he will be able to earn his living. It is the duty of the paediatrician to equip himself with the necessary knowledge

and experience to attempt to answer these questions. The first essential towards this is a thorough understanding of the principles of developmental assessment and its difficulties. I have discussed these principles in detail elsewhere (1960). One has to determine the developmental quotient, and try to assess the developmental potential. The greatest difficulty lies in the care of a mentally subnormal child with a severe form of cerebral palsy. It is a sobering thought that the well known neurologist Earl Carlson could not walk unaided until the age of 18 years, on account of athetosis. It must have been extremely easy to give a hopeless prognosis in his early months or years (Carlson 1941). Karen, the intelligent spastic child, was thought to be a hopeless idiot (Killilea, 1953). One must always remember that delayed maturation is not uncommon in physically or mentally handicapped children (Illingworth, 1961, a, b,), so that it is very easy to underestimate their potential. On the other hand one must always bear in mind the possibility that deterioration rather than improvement may occur. This applies particularly to children suffering from uncontrolled epilepsy. Emotional deprivation, due to placement in an institution or other factors, will cause deterioration in performance. Except in the case of conditions which may be associated with deterioration, one should make it clear that the child will go on learning.

With regard to the question of whether the child will be able to go to school, a developmental quotient over 50 should mean that school attendance will be possible, provided that there is not a very severe physical handicap. If the D.Q. is above 50 but below 75 he is likely to have to go to a special school, unless unexpected improvement occurs—and improvement frequently does occur, because of delayed maturation.

It is a great help to a parent to be told that the child is likely to be able to earn his own living. In general if the developmental quotient suggests that his I.Q. is likely to be over 50, he is likely to be able to earn his living provided that he is not physically handicapped (as with cerebral palsy) (Ferguson and Kerr, 1959). An important guide to the prognosis lies in serial measurements of head circumference. It is obvious that a serious degree of microcephaly must signify a very poor prognosis.

Zwerling (1959) rightly made the point that one should try to emphasise the child's assets rather than his limitations, and the possibility of living a more or less normal life, instead of concentrating on the difficulties which have to be faced. I liked the suggestion that after giving one's views as to the prognosis in a severely affected child one should say that one hopes that they will be wrong. Not infrequently it is impossible to give a confident prognosis without further observation. Mothers respect sincerity, and I have never felt that any parent has been critical when I made it clear that only further observation will determine the outlook for the child.

(5) Genetic advice.

Genetic advice is an essential part of parent guidance. Once more the paediatrician has to equip himself with the necessary knowledge. I have seen several tragedies from an incorrectly optimistic genetic prognosis. Parents may ask whether their normal children will become feeble minded. The answer to this must depend on a knowledge of the natural history and genetics of the disease in question. The parents must have advice about the desirability of having another child. If they decide that they dare not risk having another abnormal one, the question of adoption should be raised. It must be remembered, however, that they cannot adopt if they have a mentally defective child in the house: he would have to be placed in an institution. If the parents decide not to have further pregnancies because they dare not risk having another abnormal child, they should be given full advice about family limitations, by methods appropriate to their religious principles.

(6) The management of the child. Parental guidance must include advice about the management of the child. The child must, if possible, learn independence. It is the natural reaction of the parents of any handicapped child to over-protect him and to do everything for him, instead of slowly and laboriously teaching him to feed himself, dress himself, and attend to his own toilet needs. As far as possible he must be taught acceptable behaviour. Much of the bad behaviour of mentally subnormal children may well be due to lack of discipline at home. Parents have to be reminded that the teaching of acceptable behaviour must be related to his mental age and not to his actual age. It is common to see determined efforts to teach good behaviour when the mental age is such that the child is too young to learn.

The child needs love and security, for insecurity and emotional deprivation will greatly reduce his developmental level. He must not be pushed too hard, in futile efforts to make him learn. Mentally subnormal children cannot concentrate for long, and excessive efforts to make them concentrate merely add psychological problems of insecurity to the intellectual problem. One must demand neither too much nor too little of the child.

In the case of the child with cerebral palsy, advice has to be given with regard to equipment. This may make all the difference to the happiness of the child and his parents. Holt (1960) discussed this in useful detail. He suggested that attention to clothing detail is well worth while. The provision of zips instead of buttons, or of elastic tops to the trousers instead of braces, might make the difference between the child being able to dress himself and having to have the help of his mother.

The parents need advice about the management of sleeping, eating, and boredom. For instance, it is particularly important to prevent obesity in a bed-ridden child: it adds greatly to the mother's difficulties.

The parents should be told in simple language about the nature of the handicap. They need to know about the value or lack of value of drugs, the rôle of surgery, and the place of speech therapy. When a mentally defective child or a child with cerebral palsy has convulsions, the parents should be warned that prevention of convulsions in such children is a matter of great difficulty. This helps to avoid disappointment later. The question of whether an operation on the brain will help is one frequently asked. The rôle of speech therapy is very commonly misunderstood. The child who cannot speak is unlikely to benefit from speech therapy unless he is deaf. Speech therapy will only help those developmentally ready for speech. It certainly helps those who have dyslalia and difficulties of articulation. Parents need advice about the choice of toys and books for the child, because it is important yet difficult to keep him occupied, and to give him the opportunity to learn from the use of his hands.

Blodgett (1957) discussed a variety of items on which counselling is needed. Blodgett wrote as follows:—

“Some things which can be suggested in the course of several discussions with the parents include the child's need for constructive things to do; his need for close supervision; his need to acquire physical independence; good basic habits, and good social habits; the possibility that later on he might be unhappy at home or in the community because of his inability to complete or find a niche for himself; the need of the family to consider other children and themselves; ways in which others have been mutually helpful; ways of handling specific problems of behaviour, and all through the processes of counselling, the fact that there is no one ‘right’ solution; that each family faces different constellations of problems.”

(7) Institutional care.

Finally, one has to discuss the vital question of institutional care. The matter should be raised by the doctor with great circumspection. I have seen considerable resentment in parents because they felt, not necessarily with justification, that the matter should not have been mentioned, or that it was discussed tactlessly and cruelly. Amongst other things, they are apt to feel that the doctor is trying to take the child away from them. The doctor has to sense the right time to raise the matter—and the right time to say nothing about it. He must certainly not raise the question unless the child is seriously defective or at least has such seriously deranged behaviour in the presence of moderate subnormality that institutional care is definitely advisable. It is the doctor's responsibility to know the pros and cons and to be able to present them to the parents; but he should remember that the decision must be theirs, and that he should not attempt to make the decision and try to force them to agree with it. He should also know what accommodation is available, the likely waiting period for it, and should be informed about the cost of private care if the parents disapprove of a public institution, or feel that they cannot wait until a vacancy arises.

The doctor has to consider the degree of retardation and the type of child. He may well advise institutional care for a destructive, hyperkinetic child, who is apt to commit sex crimes, and who is aggressive toward his siblings, committing actual bodily harm on them (Holt, 1957).

It is commonly said that mongols are docile and easy to manage at home (Schipper, 1959). It has been shown, however, that mongols do not differ in their behaviour from other defective children of a similar level of intelligence (Blacketer-Simmonds 1953, Tizard and Grad 1961). I have certainly seen aggressive, destructive mongols who had worn their parents out.

The doctor must know about the likely or possible effect of a mentally subnormal child on his siblings. Holt (1957) found that some younger children were terrified of their older mentally defective brothers, who inflicted physical violence on them. Schipper (1959) found that siblings were likely to suffer more when a younger child was retarded, while the parents tend to suffer more when the retarded child is older. On the other hand an older retarded child may take so much of his mother's time that she has not the necessary time to devote to her younger children, at a time when they most need her love and attention.

It is extremely common for parents to show favouritism to the affected child at the cost of the normal children, who feel jealous of the handicapped sibling. The normal children may feel ashamed of an abnormal sibling, be unwilling to have friends into the house, and be loth to take him out with them. It is largely true to say that the attitude of the siblings usually reflects the attitudes of the parents. Apart from this, however, there are many ways in which they are affected by the presence of a mentally subnormal child. For instance, the nature of their holidays is likely to be altered by the presence of the abnormal child. They are apt to be forced to take an unduly large share in helping in the work of the house. One has to balance the psychological needs of the abnormal child against the psychological needs of the normal siblings. There is no doubt at all that there are families in which the mentally subnormal child is greatly loved by the normal siblings, and there is no sign of emotional disturbance as a result of the presence of the handicapped child; but one must be aware of the frequency with which problems do arise in the normal children.

The doctor must also consider the effect of the mentally handicapped child on the marriage. Farber (1959) thought that as the subnormal child grew older, the dis-

ruptive effect on the marriage increases. Placement in an institution improved the relationships not only between the mother and father, but between the other children and their parents. Holt (1958) discussed the frequency with which the presence of the retarded child in the home prevents further pregnancies. This may well lead to domestic disharmony. The mother may become worn out physically and emotionally, so that family relationships suffer. The frequent impossibility of the parents to go out together, because of the presence of the defective child in the home, and the difficulty of obtaining a 'baby-sitter,' is very apt to lead to dis-harmony. The effect of pathological attachment to the abnormal child in relation to the rest of the family has already been discussed. It is essential that the doctor should consider the age of the parents, their ability to cope with the child, and the effect of the child on the whole family.

The financial repercussion of the handicapped child should not be forgotten. The parents may have quite considerable expenditure on account of the cost of bus fares to get the child to a special school; they may spend money on obtaining medical opinions; they may spend extra money on account of unduly rapid wearing out of clothes, damage done by the defective child, or the extra cost of 'sitters.' Some parents, moreover, prefer to send their child to a private institution instead of a public one, at considerable expense. This may cause more difficulty in the home than the presence of the defective child did. I have seen several families in which the normal siblings were considerably affected by the heavy financial outlay for private education for mongols who were most unlikely to benefit in the least.

In considering institutional care the question of the type of institution has to be considered. Parents tend to dislike the idea of their child being sent to a large institution; they tend to prefer a smaller, 'more homely' one. In addition, they are apt to be disturbed at the distressing cases which they see in an institution, and fear that their child will learn undesirable things from them. They are usually certain that their child is not nearly as badly retarded as others which they see.

The question of when the child should be placed in an institution is a vital one. Immediate placement of a mongol at birth into an institution might implant a feeling of guilt in the minds of the parents, and of doubt as to the correctness of the diagnosis. In many ways it is better for parents to try the effect of loving home care, and place him in an institution only if home care fails, or if they find that they cannot manage any longer. They are much less likely to have a feeling of guilt if they do this. The parents themselves usually plan for the care of the child after their death. The patient's siblings should certainly not be saddled with the responsibility of looking after him: they have their own life to live, and usually their own families to consider. The book by Pearl Buck (1951) discussed this problem, and other questions of institutional care, and I have found it a useful one to lend to parents.

It must always be remembered that the affected child does not benefit from being placed in an institution: it is only his family which benefits. I have been impressed repeatedly by the rapid and severe deterioration undergone by a defective child when placed in an institution for a short time, such as a month, when the parents are away or have some domestic crisis. Farrell (1956) wrote about the adverse effect of early institutional care. Lind and Kirman (1958) described the high death rate of defective children in the immediate post-admission period.

(8) Parents' Association.

Parents of defective children should be advised to join the National Society for Mentally Handicapped Children. They gain a great deal by meeting others with similar problems, and they can contribute their own help to the Society.

(9) Books.

Books which can profitably be read by intelligent parents, include the following :

- "*The Subnormal Child at Home*," F. J. Schonell, J. A. Richardson and T. S. McConnel. Macmillan & Co. Ltd., London, 1958. Price 5/-.
- "*Caring for Intellectually Handicapped Children*," Ralph Winterbourn. New Zealand Council for Educational Research, Wellington. Price 4/6d.
- "*Mentally Handicapped Children*," National Association for Mental Health, 39 Queen Anne Street, London, W.1. Price 6/-.
- "*Children who can never go to School*," National Association for Mental Health, 39 Queen Anne Street, London, W.1. Price 9d.
- "*Simple beginnings in the training of mentally defective children*," Margaret McDowell. National Association for Mental Health, 39 Queen Anne Street, London, W.1. Price 3/10d.
- "*The Retarded Child*," Herta Loewy. Staples Press Limited, Staples House, Mandeville Place, London, W.1. Price 3/6d.
- "*You and Your Retarded Child*," Samuel Kirk. The Macmillan Company, New York, 1955. Price 28/-.

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