Ten-year-old Rachel lives with her mother, Mrs. Peggy Burke, in a flat in Chiswick. She attends a junior training centre in Isleworth during the day. *Photo: NSMHC*

A place in the family

A mentally handicapped child can add something positive and cohesive to many family units. Dr. Joan Bicknell, a child psychiatrist, wants us and the adoption societies to re-think our attitude towards these children and the parents who keep them at home.

A YOUNG couple wanted to have a family. They were happily married, with a stable financial background and no history of serious illness in either themselves or their relatives. There had been four pregnancies and from these only one child was alive and she was a mongol: two of the pregnancies resulted in miscarriages and the other in the stillbirth of a seriously malformed child.

One can hardly imagine the despair of such a family, and yet they fully accepted their only surviving child, Susan, recognising the degree of her handicap and the prospects for her future. Fortunately she has developed into a sturdy, happy, affectionate child who started at the local junior training school when she was 3½, and is now doing well within her expected limitations. These parents have not indulged in self-pity but have been involved in providing for the mentally handicapped and in the promotion of mental health. Susan's mother is training as a teacher which enables her to keep the world of childhood in perspective and serve the needs of normal children.

These parents would like a normal child and, rather than attempt a fifth pregnancy, they tried to adopt a baby. All their applications to adoption societies were unsuccessful. In the majority of cases they were not interviewed but received a letter telling them they were not considered suitable

or that there were insufficient babies for adoption. Some societies admitted that they may be considered if they put Susan into residential care.

Surely we all need to think again on this whole problem of couples who wish to adopt a child and already have a handicapped child of their own to prevent further heartbreak in such families.

It is felt by some that a handicapped child inevitably creates insoluble difficulties within the home. A recent article stated that any family, no matter how altruistic, suffered severely when a seriously handicapped child was introduced into it. I would suggest that this nihilistic view is perpetuated by those workers who see handicapped children only when a problem has arisen. They may rarely see a handicapped child who is not at the centre of some crisis.

While I am not minimising the problems a handicapped child may create in the home, it is my view that there are some families where the presence of such a child adds something positive and cohesive to the family unit. Overall surveys, that were not 'problem orientated' have confirmed that this is so. These are the children who are not taken frequently to the hospital out-patient department and do not visit the Child Guidance Clinic. They may attend the local junior training school and are essentially part of a normal family. Some families admit that their handicapped child has caused less upheaval than their other children have done in learning to cope with the stresses and competition inherent in the modern world.

Why should it be assumed that stress, conflict and the handicapped child are inseparable? There are two aspects to this problem, the emotional and the practical or material. No one would deny that the handicapped child who, perhaps, is in nappies for three or four years, always falling over once he is walking and messy with his food, fills the wash tub more quickly than the normal child. More supervision is needed, probably he has more minor physical ailments and there may be additional behaviour problems.

However, it is the emotional aspects that are often at the source of conflict, should this be present, but the initial distress, when the parents become aware of their child's handicap and the meaning of this for future development, may be modified with skilled help to become a positive attitude of acceptance.

The first reaction to the knowledge of handicap can be understood as mourning for the child they had awaited, for whom their fantasies of future attainments were limitless; in his place they are being asked to embrace a child who is an imperfect reflection of the one for whom they hoped and prepared. Some parents find this acceptance impossible, in others the acceptance is only partial and mourning leads to chronic sorrow of unfulfilled longing. With help, a few parents overcome their feelings of rejection and the period of mourning ends. These parents are few, *but they do exist.*

Acceptance and rejection are, of course, dynamic concepts and not mutally exclusive. Parental attitudes may well change as the child grows and problems arise. Love and trust between parents and child are vital emotions that must be nourished by the mutual giving and receiving of affection.

Many a handicapped child is well equipped to play his part in establishing a firm relationship of affection, thus dimming the image of the child who never came. All parents know of the delight when their child takes his first faltering steps but is the delight any less when these steps are taken in the third year or even later? One little patient of mine learned to finger feed himself at the age of ten years. His six brothers were so delighted that they fed him immediately with a whole packet of biscuits, taking it in turns to hand him one. *Of course* progress in the child's development gives satisfaction—at whatever age it occurs.

For those parents then, who find themselves able to include their handicapped child as an equal member of the family, and who can cope with the additional everyday problems, the child need not cause undue stress and certainly need not be an intolerable emotional burden.

A few months ago I was two hours late to an out-patient session and, somewhat apprehensively, I asked the mother of a 2 year old mongol baby to come in. I expected annoyance at the delay, but not a bit of it—mother and child were perfectly happy and mother explained that she had never before had time away from her other four older children to sit down and enjoy the company of her handicapped child, without thinking of the household chores she should be doing. She pointed out that he was the least of her worries—he was affectionate, friendly, able to amuse himself and always had a smile. Alas, she could not always say the same for the other children.

Let me quote from a parent's letter to me. 'We adopted a baby but when he was about a year old, we learned that he was mentally handicapped and he is now $3\frac{1}{2}$ years old. He is a very happy gentle little boy, fits happily into our family life and we treat him as a normal member of the family'. The same adoption society placed a second child in that home, who was since developed normally. 'We have no problems between the two children, and in fact they appear to think the world of each other. We honestly feel that the little girl has not suffered in any way because of our son's mental handicap, and although we appreciate that problems will arise as he gets older we are sure we shall all cope with them calmly as they come along'. This couple

have applied to adopt a third child and I feel that, if this child is granted to them and the parents have the support they will need, he or she will grow up with a richer understanding of life than many another child.

This brings me to another aspect of this problem —the effect of a handicapped child on his brothers and sisters. While workers in the field, including myself, can readily think of many children who have been deprived of love and attention because of the needs of the handicapped brother or sister, experience has shown that not all brothers and sisters are adversely affected, as far as we can tell. Some parents feel that behavioural problems in the 'normal' child have diminished as he has learned to help care for his less fortunate brother or sister.

In many cases the reactions of brothers and sisters reflect the feelings of the parents. If the parents have unresolved conflicts of guilt and possibly resentment, the 'why should this have happened to us, our life will never be the same' attitude, then their other children will react with behaviour that is unacceptable or causes concern at home or at school. However, if the parents have mastered their own resentment, then the brothers and sisters usually overcome the minor difficulties and become helpful, protective and often proud of the one for whom their help is needed.

A comment from an outsider who was in close contact with such a family illustrates my point. 'We were particularly impressed by the change in one brother from being a rather pestilential small boy to becoming a pleasant teenager. . . . We think the older children have positively benefited from having a disabled child to help.'

And now to the advice to place the child in residential care before being accepted as adoptive parents. This advice is as unthinking as it is unkind and presupposes that there are no good feelings for the handicapped one. In essence this is exchanging a handicapped child for a normal child and is bound to arouse feelings of guilt and anxiety for the future of the one who is to be displaced and denied his home and family. Parents may rationalise their feelings and agree to residential placement but, at a later date, retribution and conflict over this decision may act to the detriment of the adopted child. We can surely imagine the thoughts of this adopted child when he learns about, and probably meets, the child he has replaced.

Another story to illustrate my meaning, 'We have Jane, a microcephalic child [with an abnormally small head] and we had two other stillborn children. Following medical advice we decided to try and adopt a baby. Most societies refused to consider our application unless Jane went into a home. After much heart searching we eventually agreed, but the doctor at the appropriate hospital refused to take Jane, saying that she would be better off at home. We had even been turned down as foster parents. Eventually we were accepted by . . . and we now have a lovely little boy. *I did wonder if we would be able to manage after all the doubts and fears that had been sown in our minds* . . . but we are a very happy family.'

My main concern is that we should rethink our attitude on the mentally handicapped child within the family and encourage adoption societies to do the same—let us try to see the 'good' through the quagmire of 'bad'. Few families with a handicapped child would wish to adopt but there are a small number of these for whom this would seem to be a mutually beneficial arrangement. Parents who have a handicapped child and wish to adopt, should be interviewed and their problems discussed in the light of knowledge of the facilities available for the handicapped child. There may be a psychiatrist supervising the family and his opinion should be sought.

No one is suggesting that this is a prescription of an adopted child to salvage an unhappy family situation, indeed the trials successfully overcome by some of these parents could indicate that their marriage is inherently stable and that the joys of parenthood will not be easily extinguished. Let us in future handle these requests in such a way that we do not add to the idea that mental handicap is a social stigma or that parents who have an afflicted child are in some way unworthy of the role they wish to assume. Such policies which allow no compromise or exceptions can only be regarded as cruel and indefensible.

Please, if you have not returned the readership survey in the Autumn issue of 'Mental Health', do so now.