Workshop Report

FAMILY PLACEMENTS
for
mentally handicapped children

a collection of scene-setting papers with a summary of the content of a residential workshop organised by BIMH and ABAFA and held at King's Fund College

bimh

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Report of a residential workshop

FAMILY PLACEMENTS
for mentally handicapped children

King's Fund College, Bayswater, 14th - 16th May, 1979
organised jointly by the
British Institute of Mental Handicap
and the
Association of British Adoption and Fostering Agencies

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Acknowledgements

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PART I. WORKSHOP REPORT

WORKSHOP REPORT

by MARGARET MAWER, Assistant Director, Association of British Adoption and Fostering Agencies, 11 Southwark Street, London.

1. Background to the workshop

During the past decade there has been much public discussion about the care of mentally handicapped people while the quality of services provided at both national and local level by statutory and voluntary agencies has come under close scrutiny. In looking at the network of care — whether hospital or community-based — the public at large, as well as the professionals, has begun to question some firmly-entrenched attitudes.

A central issue which emerges in almost every discussion of the strategies for the mentally handicapped is: WHERE IS THE IDEAL PLACE FOR MENTALLY HANDICAPPED PEOPLE TO LIVE ? Although it is widely accepted that most children, including children with handicaps, are more likely to thrive and reach their full potential in a family setting, what options are open to mentally handicapped children who, for some reason, cannot be cared for by their own parents, yet do not require the range of specialist services provided in hospital? Is a small residential or group home appropriate? What happens in those parts of the country where such facilities are sparse? Are there any families willing to take on the care of someone else's handicapped child through adoption or fostering? If so, how are these substitute parents to be located? What support services do they need and are they widely available? Are some children so handicapped that placement in a family is unthinkable? Or is there a family somewhere for every child, no matter what the degree of handicap?

These questions, amongst others, were first explored by the British Institute of Mental Handicap (then the Institute of Mental Subnormality) and the Association of British Adoption and Fostering Agencies (ABAFA) at a one-day conference in July 1977. So great was the interest in the topic that the event was heavily over-subscribed. Clearly, there was a need for a workshop where the issues could be explored at a deeper level by representatives of two bodies of knowledge: those experienced in adoption and fostering, but who know little about mental handicap; and those involved in the care of the mentally handicapped, either professionally or as parents, who wish to extend their knowledge of substitute family care.

As a result, the Institute and ABAFA, with the help of a small working group, jointly planned a residential workshop for 30 people from the respective fields of interest. King Edward's Hospital Fund for London generously provided residential facilities and administrative back-up services at the King's Fund College in Bayswater. The specially invited participants (see Appendix 5) came together there under the leadership of James Elliott, formerly Associate Director of the King's Fund Centre, for some intensive work between 14th and 16th May, 1979.

This book provides a summary of the workshop discussions and the major issues raised, as well as the invited papers upon which the initial discussions were based.

2. Resource material

Scene-setting papers on the following key themes had been circulated to participants before the workshop and were introduced by their authors:

1. *Bringing up disabled children,* by Derek Ricks
2. *The handicapped child in the family,* by Mary McCormack
3. *Behavioural aspects and behaviour problems,* by John Hattersley
4. *Special needs of the multiply-handicapped child,* by Janet Round
5. *Service needs and availability,* by Philippa Russell
6. *Finding parents for severely handicapped children,* by Hedi Argent and Phillida Sawbridge
7. *Recruitment methods — making the need known,* by Christine Hammond.

The papers are published in Appendix I. Details of other publications available throughout the workshop and the audio-visual aids used are given in Appendix 2.

3. The four main issues

During the opening session of the workshop, participants discussed the issues which they wished to explore in depth.

Four main themes predominated:

1. *Which children*? The nature of mental handicap; developmental patterns; prognosis.
2. *Finding families*: recruitment methods; handling the response; helping applicants to understand what they might be taking on.
3. *The support network*: availability of specialist services, such as psychiatric and psychological assessment and treatment, physiotherapy and speech therapy; links with parents' support groups; short-term relief schemes; allowances.
4. *Family relationships*: effect on the new family of taking on the care of a handicapped child; need for adequate preparation for the task; links with natural parents; reactions of natural parents.

Before further discussion took place on these issues Dr. Derek Ricks gave an overview of the types of handicap, causes (where known) and different approaches to handling which is summarised as follows:

> "While it is desirable to provide handicapped children with consistent relationships within a family or small group, it must be remembered that the day-to-day care of severely handicapped children can bring about a high degree of trauma and stress in the care-givers. It is important to consider each child as an individual within the broad categories of handicap and dilemmas can arise when deciding upon appropriate care for any one individual.
>
> Problems of providing mentally handicapped children with appropriate care divide them into two broad categories:
>
> 1. SYNDROME GROUP.
>
> Children in this group are born with their handicap, having had either very early illness before birth or some abnormal brain development. For some, such as Down's syndrome children, the aetiology is known. They have recognisable characteristics and advance evenly on all fronts, but at a slower pace than other children. It is important to realise that children with other handicaps are not like Down's syndrome children — their development can be extremely uneven and they may have a "normal" appearance. For most children in this group, however, the precise cause

is unknown and the family faces uncertainty, wondering why the handicap has occurred.

The children are often floppy with low-muscle tone, and apathetic, showing no signs of visual attention or interest. They do little for themselves and are dependent on others doing everything for them. They usually respond to a consistency of approach in handling and to stimulation of various kinds including excitement.

2. DAMAGED GROUP.

Children in this group would have been normal but have been brain-damaged, either at or after birth. They tend to be more responsive, with higher motivation than the children in Group 1. Their handicap often makes them hyperactive. Usually someone or something can be blamed for the handicap and the family is assailed by episodes of medical intervention.

Children in this group vary greatly but can be roughly classified as follows:

i) those damaged *before* birth due to inadequate blood supply to the brain; perhaps very active, "run around" children

ii) those damaged *at* birth resulting in spasticity or an inability to direct movement; frequently display continuous reflex actions to no purpose; deficiencies of co-ordination or presence of spasticity exaggerated if upset

iii) those damaged when *very young* through the brain being starved of oxygen; can be either ataxic (floppy) or athetoid (wriggling, writhing)

iv) those damaged *later* through illness or accident; may be like the children described in Group 1.

Diagnosis may not be important to the outcome or handling of the child but it is very important to the family and should be provided if at all possible. In planning a treatment programme the child's individuality must be taken into account. It is difficult to provide guidelines on how to encourage the development of fundamental skills in handicapped children, such as learning to stand up or to speak, as so little is known about the way normal children acquire such skills. Training or fashioning the child's behaviour — either by stimulation or restraint — needs to be started as early as possible. Problems of management are likely to be exacerbated in adolescence."

4. Outcome of discussion on each of the four issues

1. *Which children?*

1. There is a need for wide dissemination of information, not only to workers in the field but also to parents and prospective substitute parents, about the availability of professional skills and resources to meet the needs of the mentally handicapped.
2. There is a need to enable parents of handicapped children to "wait and see" by providing adequate support services to help them keep the child at home and to discover what the child can do, rather than what he cannot.
3. In principle, every child is a suitable candidate for substitute family care. In practice, it is difficult to see the rewards for substitute parents in caring for children with severe behaviour problems, or for the profoundly multiply handicapped who show little apparent response. "Shared care" is a possible solution, either shared care between two families or, as in the Leeds scheme, part-time residential and part-time family care.
4. Mentally handicapped people need to learn to tolerate the human emotions of pain and grief.
5. Every handicapped child has a right to a "home", if not with his own family then with a substitute family or small group. Hospitals should be used only for specialised services, if needed, which cannot be provided elsewhere, or for short periods of admission for the purposes of assessment of the handicap and development of appropriate programmes of training, or to give the family respite from continuous care.

2. *Finding families*:

1. Recruitment campaigns should be carried out consistently. This is hard work calling for a high degree of energy, enthusiasm and commitment on the part of social workers.
2. Sporadic advertising is a waste of money. Every medium of communication — press, radio and television, as well as posters and photographs — should be employed. Some local newspapers will carry weekly features on children which has proved to be an effective method. Local radio is a powerful ally in many parts of the country.
3. Using the media calls for a high degree of skill. Help should be sought from a journalist and/or public relations officer.

4. Descriptions of children must be honest but it is important to draw attention to their good points as well as describing their handicaps. The reality of caring for a handicapped child must be conveyed but it is also important to bring out the challenge of the task and to show that the child can contribute much to the family.

3. *The support network*:

1. Natural parents adapt to their handicapped child's needs as they go along. Substitute parents and their handicapped child must also learn to adapt to meet each other's needs. Substitute parents should be provided with the same kind of training and advice by workers in the field of mental handicap as natural parents receive to help them make the necessary changes in themselves and their handicapped children.
2. Short-term relief schemes, similar to the Bridgwater scheme portrayed in the video tape "A chance to breathe" and the Leeds scheme (see Appendix 2) are needed throughout the country. Short-term relief is needed by foster- and adoptive-parents as much as by natural parents and should be readily available to them.
3. Adequate community nursing services are needed, the community nurse acting as "friend of the family", giving practical advice in the home setting and arranging for the handicapped person to receive necessary services — such as occupational-, speech- and physio-therapy, other out-patient facilities, dental care and hairdressing; short-term care and emergency beds; playgroups during school holidays.
4. An adequate and named support network, and general information about all aspects of it, should be available to all parents of handicapped children, whether natural, foster or adoptive.
5. Provision of support services varies greatly from one part of the country to another. Services in some areas are still inadequate. Lack of facilities for handicapped school-leavers gives rise to particular anxiety. Where other facilities are lacking participants considered that special schools which are well-equipped and exist in every area, should be viewed as possible resource centres as it seems logical that the facilities they possess should be utilised outside of the school day and during school holiday periods.

4. *Family relationships*:

1. The impact of a handicapped member on a natural family results in changes in the parents and other relatives, especially any other

children. Substitute families experience most of the same pressures to which natural families are subject, the significant difference being that they make a positive choice. As well as being provided with the same support services that are available to natural families, prospective substitute families should receive specific and adequate preparation for the task ahead of them.

2. Substitute parents bring no feelings of loss or guilt to the parenting task.

3. The natural children of the family are involved in the decision to offer a home to the handicapped person. Nevertheless, many are affected by the presence in the family of a handicapped member and this is evident at various ages — for example, some are embarrassed about bringing their friends home; others experience taunts and cruelty from schoolfellows. It is important to try to balance the needs of handicapped children with those of their normal brothers and sisters.

4. Agency workers involved in finding families for handicapped children have a responsibility to warn potential recruits of the possible damage to relationships within their families. Parent support groups can help considerably to get the message across, sharing their experience with prospective substitute parents and balancing the risks with the satisfactions.

5. More evaluation and research is needed into the effectiveness of publicity campaigns and the kind of parents who respond to them as well as the best ways of preparing substitute parents for their new role and of giving them the information and support they will find most useful. It was hoped that the study being carried out by the National Children's Bureau into the work of "Parents for Children" would yield valuable information.

5. Topics for group discussion

Each participant was assigned to one of four groups, each group being given a specific task to carry out. The tasks set, and the summarised reports of each group, are as follows.

GROUP ONE

Task:

On behalf of a social services department, devise a programme aimed at increasing the number of family placements of mentally *handicapped children. Include the work of voluntary agencies.*

Report:

Members of Group One reported that they would work to the following plan:

1. Set up a multi-disciplinary steering committee comprising: staff of the local social services, education and health authorities, at senior practitioner and senior management level; representatives of voluntary agencies; foster parent group; elected member(s).
2. Survey what already is being done and identify unmet needs.
3. Draw up terms of reference and mount a pilot scheme.
4. Seek committee approval for pilot scheme. Case for additional finance — for the appointment of a project worker and other staff, and for mounting a publicity campaign — could be argued on the grounds that the project would represent good standards of practice and that it would be cost effective.
5. Project worker's task would include: establishing administrative procedures; trying to break down barriers with the help of committee members; contacting existing foster parents; identifying the training needs of staff and foster parents and measuring them against existing resources.
6. On the grounds that the pilot scheme would need to demonstrate its effectiveness, children most likely to be placed successfully would be the first priority. It would be important, however, to balance the need to succeed against the requirements of severely handicapped children who would be less likely to be placed successfully so that this group would not be overlooked and, in addition, more realistic evidence of the possibilities would be obtained.

GROUP TWO

Task:

How does Dr. Ricks' presentation affect your views on family placement?

Report:

Group Two members were pleased that Dr. Ricks had emphasised the need to focus on the individuality of the child, irrespective of his handicap. Members spent considerable time discussing whether "professionals" who work in adoption agencies, or with the mentally handicapped, have the right to expect families to expose themselves to hurt and stress. They went on to consider whether, if families *have* offered, such professionals had the right to deny them the experience? They believed that handicapped children can, and do, give something positive to families.

The courage needed by social workers when taking the risk of placing a severely handicapped child in a family setting should not be under-estimated.

Some members expressed doubt about the wisdom of attempting to place very severely handicapped children with families and took the view that a small residential unit might be a more appropriate setting. After much thought, however, it was concluded that *home is best if home can cope.*

GROUP THREE

Task:

Comment on the network of support services listed in paragraphs 1-21 (under 16s) of the Stamina Paper No. 3 (see Appendix 2) published by the National Society for Mentally Handicapped Children.

Report:

Group Three considered that, if all the support services listed in the Stamina Paper were available, there would be few problems facing families. However, members suggested some additional points, as follows:

1) the need for early assessment of the child. Families should be given resultant information through "a key person" who is a member of the assessment team, possibly the consultant

2) the need for all reports concerning the child to be available to both natural and substitute parents.

3) the importance of telephones and transport amongst the support services.

The group regarded its greatest priorities in terms of support services as follows:

1st priority — paragraphs 1-4 of the Stamina paper

2nd priority — paragraph 12 of the Stamina paper (short-term relief).

The group recommended that responsibility for agreeing to medical treatment should be delegated to foster parents. Liability insurance cover for foster parents should be provided. The specialist social worker should be named and known.

GROUP FOUR

Task:

What kind of information or knowledge do we need to plan an improvement in the number and quality of family placements of mentally handicapped children?

Report:

Group Four recommended that research along the lines set out below should be undertaken now into (1) substitute families of mentally handicapped children (2) children needing family placements (3) facilitating agencies.

(1) *Families.* A small study of successful placements using standardised interviews could reveal: age, type and experience of family; motivation or trigger; type and history of child; support services received.

(2) *Children.* A study should be planned on a broader base, looking at groups of children at the time of their placement and a year later to assess the degree of change (if any).

(3) *Agencies.* Methods of recruiting substitute families should be studied and data gathered for future use.

5. To sum up

1. Family life is the first choice for any mentally handicapped child, if the family can cope.
2. Every handicapped child has a right to a "home", be this with his own family, substitute family or within a small group. Admission to hospital should be for specific purposes only, such as for comprehensive assessment, medical care or other specialised services, or for periods of planned short-term care to provide relief to the family if alternative short-term accommodation is not available eslewhere.
3. Families with a mentally handicapped child are much more likely to be able to cope if they can rely on:
   - adequate relief services
   - financial support
   - a tolerant and caring attitude on the part of society

— a named network of readily accessible professional support services to give early and continuing advice and guidance on effective training and management.

4. Foster and adoptive families have the same need for support (as outlined in 3) as "natural" families and in addition require specific and adequate preparation for the task of caring for a mentally handicapped person.

5. It is clear that foster and adoptive families can be recruited for handicapped children, but only if a vigorous family-finding campaign is carried out by a highly committed and well motivated staff backed by skilful and honest publicity.

6. Relief schemes (see Appendix 3) can be started with very modest outlay and have been shown to be cost effective.

7. Experimentation, evaluation and research is needed now. Information should be shared so that examples of good practice can be repeated in other parts of the country.

8. A service to increase the number of family placements for mentally handicapped children can be achieved by the redeployment of existing staff.

PART II. APPENDICES

Appendix 1. Scene-setting papers circulated before the workshop
Appendix 2. Other resource material used at the workshop
Appendix 3. Examples of existing low-cost relief care schemes
Appendix 4. Useful addresses
Appendix 5. List of workshop participants

Appendix 1.
Scene-setting papers circulated before the workshop

1. BRINGING UP DISABLED CHILDREN

D. M. RICKS, Consultant Psychiatrist, Harperbury Hospital, Shenley, Herts.

A major interest, for any professional involved with families of handicapped children, is the interaction between the affected child and other family members. Clearly, this interaction directly affects the families efforts to care for and cope with their handicapped children and, in particular, their success at improving their performance. This is the case with all children who grow up in their families but the distinctive feelings generated by a handicapped child, and the extreme dependence of that child on other family members, makes this interaction crucial to the success or failure of any help professionals offer.

The more I observed and involved myself in this interaction, the more concerned I became about the effect of "natural" responses on a handicapped child's progress. A great deal of work has to be directed towards helping normal parents to come to terms with what they know to be effective, but feel to be un-natural, child rearing. I think this conflict occurs in many families, often without recognition and support from professionals, yet it causes much distress.

Below I have set out the context of a paper on this topic which I presented to the Royal Society of Medicine in June, 1976. Since some of the parent interactions described relate to the child's handicap *whoever* cares for him, while some relate to his being *their* child, I feel the paper is a useful foundation for discussion. Hopefully it will highlight the contrasting problems faced by natural parents and the problems which they share with others.

The following paper was published in the Proceedings of the Royal Society of Medicine, Vol. 70, January 1977 and thanks are expressed to the Society by BIMH for permission to reprint it in this report.

"The realisation in a family that they have a handicapped child is a profoundly tragic event, often combining unhappiness with self-recrimination. As he grows the child is pitiable but frequently exasperating, so the unremitting burden of his care wears down patience, and strains all relationships. The initial reaction of parents is to ask why it has happened to them; doctors are usually equipped to deal with this area of enquiry or have access to colleagues who are. Parents then begin to enquire about the likely consequences of this handicap for their child or for themselves, asking questions which are of understandable emotional significance to them but are often either unanswerable or simply invite conjecture, e.g. will he walk, will he talk, will he earn his own living?

Such questions reveal how the parents project their anxieties far into a bleak future, at the same time suffering a sense of helplessness about what to do in the present. At this stage a constructive step is to lead them into considering more immediate problems, taking care always to concentrate on certain practical issues. These are to guide the parents how best to improve the functioning of their child as well as care for his health and disabilities, to try and set a sequence of targets in a time span which is realistic and, above all, to involve the parents themselves both in discussions and in the implementation of any programme agreed upon. One of the most disabling features of parent anxiety at this stage is their vulnerability to suggestions good and bad about how to help their child, and this makes them prey to advice and suggestions, whether from kindly neighbours or from commercially motivated organisations.

Efforts to help the progress of the severely handicapped child in these early years obviously depend partly on the extent of the child's handicap but also on the way he is managed by, and interacts with, those most involved with him — his parents. Their success will depend on the extent of his pathology and on its effective unravelling and treatment; it will depend also and less obviously on the child's individuality. Some handicapped children seem to be more highly motivated than others to work hard, together with their parents, in whatever programme is set up. The child himself and his disability form one variable affecting the success of any programme; another variable is the way he is handled.

It must be admitted that very little is known of how normal children acquire those skills that parents strive to elicit in their severely handicapped child. Although information abounds about attainment of particular capabilities at particular stages there is very little insight how a child passes from one stage to the next; and so parents, teachers or therapists faced with helping a child along this sequence have little to guide them. Indeed there is a growing body of interesting evidence suggesting that some fundamental early skills, like reaching (Bruner & Koslowski 1972), vocal communication (Ricks 1975), or judging perspective (Gibson 1965) are not taught and do not even seem to require preliminary experience before they appear. But, however they are learned, the handicapped child has to acquire these skills within the context of the family, and it is at this crucial point that the distinctive interaction between parents and their handicapped child becomes significant.

Those who deal with severely handicapped children appreciate a very striking fact: the initial reactions of parents, quite appropriate to normal children, often aggravate the disability of their handicapped child.

In the case of a spastic child, for instance, it is a common experience to discover the child in his home sitting in his particular chair or corner of the settee with little incentive to move because other members of the family do things for him. It is well known, however, that experience of movement is particularly valuable for the spastic child who develops spasm and reflex postures when he initiates movement. Mothers with young spastic children find that picking up their child results not in snuggling and enjoyment (which is an important component of the normal child's motor learning) but in spasm, discomfort and alarm. This makes his mother more anxious; handling the child becomes not a pleasurable experience but a rather frightening one, so she tends to handle the child less. The less experience of movement he gets the more readily he develops spasm when moved and thereby the more he frightens his mother into not picking him up. This anxiety spreads to all members of the family, for the mother's concern makes her more protective, preventing other members of the family handling the child.

The problems of the ataxic child (*a child with the inability to co-ordinate voluntary movement) are similar. It is the child who is prepared to 'have a go' who at any given level of ataxia improves his

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* The descriptions given in brackets have been inserted into the original article for the benefit of readers of this Report who may not be familiar with the original medical terminology.

mobility. This readiness to have a go depends on the child's apprehension, which in its turn depends on how much anxiety is conveyed to him by the understandable misgiving of his parents as he stumbles about in his efforts. The anxious parent, by inhibiting the confidence of the ataxic child, makes him more anxious and less able to overcome his ataxia.

Another large group of motor-handicapped children where the family response is similarly disruptive are athetoid children (children with uncontrolled, continuous movement). With his poorly aimed, inco-ordinated movement the athetoid child is at his most jerking and wriggling when his attention is focused on his own efforts to direct and control his activity.

Consider the athetoid child sitting with his family at breakfast, with father late for work and mother anxious to get the children off to school; as the athetoid child reaches for the milk to pour on his cornflakes it is surely inevitable that other family members will be alert to the possibility of its being spilled in their laps as he struggles to carry it across the table. If he does so successfully there may well be a sigh of relief which would direct his attention to his efforts no less than the exasperation which will result from his spilling it.

Such reactions are often even more spectacular in the ambulant mentally handicapped child. For example, it is well known that the needs of the hyperactive distractible child are consistent management in a regular routine. His basic handicap, often associated with diffuse hypoxic cortical damage (brain damage as a result of lack of oxygen), is a short attention span and consequent inability to focus attention and link cause and effect unless they are presented repeatedly in a similar fashion which eventually becomes predictable.

Consider such a child playing in the kitchen while his mother washes up. He is quite likely to be knocking objects over so that his mother, like any other, becomes exasperated when he does so, but with such a child tends not to correct him, at least not initially. This again is a very normal response since she may well feel that he cannot help it because he is retarded, or brain damaged, and by this term she is not infrequently frightened into a belief that her child is in some way fragile, so that she cannot risk the vigorous reprimand she would give her normal child. He then in his hyperactive way does the same thing repeatedly until his mother's patience snaps and she may reprimand him suddenly and severely. She is then overcome with guilt and may become even more permissive. Such inconsistency would cause a normal child great difficulty in appreciating what was required of him; how much more so does this apply to a child with the learning defects associated with hyperactivity.

An even more striking example is to be seen in parents with non-communicating children. In discussing management of such children with their parents, one becomes aware of how essentially verbal we are in our control of children's behaviour. However much parents understand the difficulties in comprehension of, for example, an autistic child, and however sensibly they appreciate that they need to say the same thing in the same way in the same situation, to enable their child to comprehend or indeed even to listen to language, they are nevertheless in times of stress at the mercy of quite normal responses which are just the opposite.

Watching and listening to any mother with an active exploratory 3-year-old in a supermarket is very revealing in this context. If the toddler in his efforts to 'help' takes down a variety of tins she will initially tell him 'No', but if he persists she will quite rapidly embroider her statement, changing her tone, adding his name, explanations or perhaps a few oaths, so that the verbal content of what he hears suddenly becomes much more complicated. This is usually effective in the case of the normal child, or at least has a reasonable chance of being so, whereas it is quite often disastrous with the autistic child. Instead of helping him to understand, it inevitably bewilders him and confronts him with his own disability, which is his limited understanding of language.

The conclusion to be drawn from these observations would seem to be that parents are the least suitable people to help their handicapped child. This is clearly not the case. Not only does the handicapped child enjoy the security and love inherent in growing up within his own family, but what emerges from discussion with parents and clinical involvement with them and their children is how expert as therapists parents do eventually become. Most workers in the field discover with growing respect how effectively parents do come to learn to control difficult behaviour, to anticipate crises and to encourage the child in his efforts to overcome his disability. The severe emotional strain imposed on them in achieving this expertise is due, in large measure, to their need to suppress initial natural responses."

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2. THE HANDICAPPED CHILD IN THE FAMILY

MARY McCORMACK, Parent and Journalist, 35 Larchmere Drive, Hall Green, Birmingham.

I did not choose to have a mentally handicapped child. Nor did I find out he was handicapped until he was almost a year old. I knew absolutely nothing about mental handicap — and not much about babies come to that, being a first-time mother. So I had to start from scratch — finding out, adjusting my ideas about the future — while struggling with the emotional shock.

All this must give me a different attitude from that of people who *decide* to foster or adopt a handicapped child. I find it difficult, really, to put myself in their position. They *must* be more confident, capable and informed than the majority of natural parents, like me, who have no option but to take on the task. What was a great problem to me, might be a minor irritation to them.

Of course the problems depend on the age of the child and the degree of handicap — and I do tend to talk with a bias, as the mother of a multiply handicapped 13-year-old. I am aware that a two-year-old Down's syndrome child would fit far more easily into a family than my child. The following ideas, therefore, are culled not only from personal experience but from interviews with 50 families as research for my book *A Mentally Handicapped Child in the Family*. Very few of the parents experienced all the difficulties mentioned — a few had not encountered any.

Fitting in

It demands the skill of a tightrope walker to balance the needs of your handicapped child with those of the rest of the family. Having a handicapped child *does* change your life. It would be naïve to think otherwise. You do not have to stop doing the things you enjoyed previously, but you do have to adapt, to fit them around the child's routine.

Always, with a severely handicapped child, you have to consider him or her — and a hundred related practical problems — before doing anything whether it be moving house or going out for the evening. I think it is important to "do your own thing," retain your own interests so that the child, though an important part of your life, never becomes your whole life. You are far more likely to simply go under from the strain if that happens — and then you will be of little use to anyone in the family.

Mothers undoubtedly take the brunt of the strain and there are ample statistics to show that marriages are ten times more likely to break up when there is a handicapped child in the family. There can be very strong differences of opinion between husband and wife about how the child should be treated — and there is no Spock to get down from the book shelves for checking on the right way.

Mothers often resent the fact that fathers take much less responsibility, emotionally and practically, for the child but then this frequently happens with normal children. It can be much harder to get to know a mentally handicapped child, especially when you see him for only an hour or so each day after work. Often fathers simply do not have time to get close to the child. One mother insisted that her husband never understood, or genuinely cared about, their brain-damaged child.

Then there is the other side of the coin. Some couples claimed that having a handicapped child had given them a common interest, a joint battle to fight, that had brought them closer together.

Other children

"For the sake of the other children" is an over-used excuse to justify something you are not quite sure is right for your mentally handicapped child. There are exceptions, of course, but the majority of brothers and sisters benefit, if anything, in the long run. It is true the benefits may not always be apparent, particularly in cases such as mine when there is only one other child who is younger and, therefore, expects a big share of whatever attention and time you have to offer.

"Why", my daughter demanded crossly when she was five, "is your face all smiley when you look at Patrick and it's not when you look at me?" It was not easy to explain that smiles are one of the few methods of communication I can be sure her brother understands, even when I do not feel deliriously happy, whilst she can cope with words. Until she mentioned it, I had not even thought about it myself.

You automatically tend to give more of your time to the child who needs you most — the handicapped one. One mother I talked to said she had "lived a double life" for 15 years, being one kind of person for her handicapped daughter and another for the normal one.

It is hard for a younger child not to feel a little resentful seeing how much fun and freedom her friends enjoy — and the grass always looks greener on the other side of the fence. You cannot wake up one sunny morning, pack a picnic basket and take off to the country; those kind of school holiday outings are not on. Taking a severely handicapped child along, or leaving him behind in safe keeping, involves a major planning operation. Spontaneity is definitely out.

I have tried to compromise with Clare — who is nearly six years younger than her handicapped brother, Patrick — by getting him into a play group or a shortstay hospital unit for occasional day care during the school holidays (and not every family has even these limited provisions to hand). It means we can go somewhere, though we are tied strictly to time. It is not *quite* enough. Clare cannot go skating on a Saturday morning or to the park on a Sunday. We tried swimming lessons one day a week after school, but people who were coming in to sit frequently had their own crises and, at the last minute could not make it. That was bad for Clare's nerves and mine — and she missed more lessons than she attended.

This is the sort of situation that a council-run "sitting service", providing someone to pop in regularly for a few hours a week, could solve, or a flexible local day-care unit. Parents do not want their children to grow up feeling bitter about a handicapped brother or sister. Whilst not lumbering them, parents want them to retain links with, and continue to visit and care for, the handicapped member of the family when they are no longer able to do so.

I cannot agree with the parents who do not want their normal children to have any responsibility for their handicapped brother or sister on the grounds that "they have their own lives to lead". We all have limitations and responsibilities and I do not think it will do much for the children's characters if they grow up encouraged to be that irresponsible. On the other hand, one very intelligent 18-year-old boy I met insisted that he would only marry a girl who would have his multiply handicapped brother live with them. I should imagine he will remain a bachelor.

Having friends in (the children's that is) is another potentially sensitive area. We had a six-year-old once who took one look at Patrick, shrieked: "I want to go home", and would not be comforted till she did, despite her mother having forewarned her what to expect. Most of my daughter's friends accept Patrick as part of the furniture and, unless it crops up, I do not automatically launch into explanations about damaged brains — but then, I do not feel particularly confident about communicating with children. I know several mothers of handicapped children who always explain to visiting children and it is probably a good idea. So, if you feel up to it, is giving a light-weight talk at the school the handicapped child's brothers and sisters attend — it might nip any nastiness in the bud.

Many brothers and sisters in their early teens are sensitive about having a handicapped person in the family, even if they do not show it. One 13-year-old, with a handicapped brother a year older, told me how friends had teased him after seeing nappies hanging up to dry when they had come to visit and how classmates, passing the house and seeing his brother looking out of the window, used to "say things". In the end it stopped bothering him, he said — he got used to it.

Another couple, proud of taking their spastic daughter everywhere, had no idea how embarrassed her sister was, till she pleaded with them not to take her to socials at her school — her friends had made jokes about the faces her sister pulled. I would like to think such incidents are rare — and many children said friends of both sexes were always kind and understanding or they would not have had them as friends — but I am not certain.

I talked to several teenagers and adults who had grown up with a handicapped brother or sister. None seemed to have been damaged by the experience. Several claimed that it had made them more observant and considerate of other people — and grateful for their own normality and good lives. Two very balanced women in their early twenties, with an 18-year-old brain-damaged sister, explained it like this: "It was never Mum and Dad helping Mandy and us standing on the sidelines watching. We all joined in as a family — encouraging her to feed herself, getting her toilet trained. We had responsibilities too. It was all of us helping Mandy — she belonged to us all."

Problems

It is hard to talk about physical handicaps, or general things like feeding and toileting, because they vary so much from child to child. Certainly, the parent workshops and psychological services which exist now are a great help and a tremendous improvement on the void that existed in the self-help area when my son was very young. It is essential for parents to be taught to help their children at home. As a parent, you feel so helpless and depressed watching a child fail at things and not knowing how to help. Going to a workshop where you can meet other parents and talk about the children is a help. They can be more helpful than the experts.

The single problem that makes many parents most desperate is sleeplessness — the child's — and theirs as a result. Some children treat the strongest tranquilliser like a drink of water and wake up every night in the early hours demanding attention. It puts families under terrible stress, a fact GP's often do not seem to appreciate.

Illness is another worry. Few GP's know much about the mentally handicapped and they can look completely bewildered when called out. Is the pain in the child's head, tummy or big toe? It is hard to know with a child who does not communicate. Eventually, I think most mothers develop a sixth sense (born of desperation) about the seriousness of any ailment.

I do not feel bad any more about calling out the doctor, however minor Patrick's ailment, rather than wrestling with a hysterical child in a crowded waiting room. It's less harrowing for half the neighbourhood. On the same basis, I prefer to attend dental, orthopaedic and other specialist clinics at a local mental handicap hospital. This evolved after several miserable visits to a general hospital, where we waited for hours, to see staff who seemed to have little appreciation of the stress such visits invoke.

"Behaviour problems" — nice term that — are the worst of all drawbacks to a relatively normal family life. The term can encompass anything from the child who shrieks hysterically if you take him out in a wheelchair and stop for a minute at the curb (one of Patrick's favourite tricks) to the hyperactive tornado who sweeps everything off the supermarket shelves and much more besides — but public manifestations of this kind are enough to cause embarrassment to anyone without the hide of an elephant. Which brings me to another topic:

Other people

As a parent of a handicapped child you still have to live with other people and their reactions to your child are important. How they react depends largely on how you act. People who know nothing about the mentally handicapped have no established attitude and tend to reflect yours. If you are awash with sentimentality and old wives tales, neighbours can be ruined for life! If you treat your child sensibly and matter-of-factly, so will they.

It sounds dreadfully pompous but we, as parents, have a duty to educate the public. If we, and our children, do not, who else will? If members of the public do not talk to parents and get to know the handicapped children, how can we expect them to accept them into their hearts and neighbourhoods in this heralded move to community care?

Foster and adoptive parents tend to do better at this. People approach them more easily, probably because they assume they will not be the bundles of neuroses they imagine natural parents are. Actually, few parents have the predicted hangups — such as the myth of the guilty parent — but it is said so often it becomes accepted. The public at large has some funny ideas about parents of mentally handicapped children, seeing them as martyrs, masochists, or "a bit peculiar" to have produced such a child in the first place. I expect they have even stranger ideas about foster and adoptive parents!

I have known parents of normal children who have stopped their offspring from playing with handicapped children. One mother explained that her daughter was copying the handicapped child and "beginning to sound mental". I have known other mothers who would not let their children *see* a severely handicapped child "because it might upset them". In fact the squeamishness is their own, the parents. There are many people who have a good attitude towards mentally handicapped children and adults and who want to help, though they do not always know how and have to be asked. It is hard, if you are independent, to ask for help but, with a handicapped child, you need it. I have found church groups, of many denominations, invaluable over the years though I am not a practising member of any of them. You have to accept that some people stare, some people look the other way and some rush to help. It is lovely if you have a handicapped child whom you can take everywhere but some of them react so badly off "home ground" that it becomes merely an act of bravado — and an unkind one — to put them through it in the name of normality.

Getting a break

Allowing that you cannot take the child everywhere the family might want to go, you still need a break. You cannot be on duty 365 days a year and still be efficient. There are several ways of getting a break but not all of them are as readily available as they should be. They include:

1) *for a few hours a day, while the child is at school.* Why do special schools not offer a special service, however they juggle staff, and stay open 50 weeks a year? The long school holidays must be the single biggest cause of exhausted families, with bored, fractious mentally handicapped children, asking for full-time residential care.

2) *for an evening out or a couple of hours during the day.* It is difficult to find baby-sitters whom you can trust and who would want to take on a handicapped child. (My best bet is a local Young Wives group whose members do it on a voluntary basis — not all groups are so thoughful but you could give yours a push in the right direction by suggesting such a scheme). There is a desperate need for a flexible sitting service and for those "friendly neighbourhood units" we hear so much about where, by picking up a 'phone, you can leave your child for a few hours or overnight.

3) *for holidays.* Either you take the child, leave him in care, take separate holidays or stay home. Most people with a difficult child opt for sending him on a special holiday provided by one of the voluntary societies, or to a short-term bed in a home or hospital.

This last aspect is a wrench, however sensibly you talk about the needs of the rest of the family taking priority for a week or two. You can end up worrying so much that you come home a nervous wreck, needing the rest of the year to recuperate. Again, it is a case of a big gap in the services and the obvious ideal holiday being missed out. It would be so nice to be able to take the handicapped child along on an organised holiday with day and night sitting services available as a matter of course for when the family wanted to go out without him.

Taking a choice from what does exist, it is important to match the child to the holiday. We sent Patrick on a "handicapped" holiday with a well-meaning but inexperienced (with severely handicapped children) group of volunteers. It seemed better in theory than the alternative, hospital. He came back painfully thin, dehydrated and covered in sores around his nappy region — but still managing a feeble smile at the teenage helpers who played with him. They simply did not know how to care for him. Now he goes to an acceptable hospital unit where he is fed ('though be objects) and watered — but is still not very happy — and I have never been able to bring myself to take any holiday longer than a week.

The ideal, I suppose, would be that friendly neighbourhood unit. He could go in regularly during the year for pre-planned weekends, holidays and day-care, and hopefully it would be almost a second home. It would have to be staffed by friendly and familiar faces for the benefit of parents and child. One of the saddest things about parent/professional relationships is how icy they can be because they neither know nor understand each other. Frequently there is no relationship at all and parents have no contact with any professional. They would not know who to call in an emergency. Every family should have *someone* — and not just a 'phone number in a social services office, but a name and a face — to whom they can turn for help.

Parents

Having issued all these dire warnings, I feel I should add that I am not permanently depressed or a nervous wreck. Nor were the other parents I interviewed. On the contrary, most had well-developed senses of humour and would tell you affectionately funny stories at the drop of a hat about the dreadful things their children had done, usually in public and causing great embarrassment!

For many parents, once the early emotional problems had eased, tackling the practical ones was a challenge. And a tiny bit of success was a heady experience. As one woman said, "When my handicapped son wrote his name for the first time, it was just as exciting as my daughter going to University".

A few people simply had not experienced any difficulties. One mother of a three-year-old Down's syndrome boy said that she had been waiting for terrible problems to descend but that they had not so far and she was actually thoroughly enjoying looking after her son. Where, she wondered, had she gone wrong?

A surprising number of people insisted that, even if there were a magic cure, they would not want their children any other way. And even those of us who would not go that far put up a fair fight to keep our children at home and out of residential care, which must prove something.

At home, as part of the family, my son is an individual — and a pretty obstreperous one at times! Despite severe handicaps, he has a personality all his own, with likes and dislikes, good points and bad ones. The fact that he would lose that in a busy residential unit because nobody would have the time to notice, is the best reason for keeping him at home and for keeping — or placing — all mentally handicapped children in families.

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3. SERVICE NEEDS AND AVAILABILITY

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> "A handicap is a disability which, for a substantial period or permanently, distorts or otherwise adversely affects normal growth, development or adjustment to life".
>
> *Fit for the Future* (Court Report), 1976.

This description covers a wide range of handicapping conditions. Estimates of the incidence of handicap in childhood vary according to the severity of the handicap so diagnosed. But the Isle of Wight Survey (Rutter, M. *et al.*, 1970), perhaps the most detailed study, suggests that, even in a prosperous corner of the United Kingdom, one child in seven will meet the terms of the definition at some point in his/her childhood years.

Handicap will always be distressing and disturbing, whatever the degree of disability. Indeed, handicap is often totally disruptive of family life. Not for nothing did a mother write to the Dame Eileen Younghusband Working Party in 1970, (Younghusband, E. *et al.*) declaring that "truly a handicapped child is a handicapped family". A family with a handicapped child (whether a natural of a foster child) will have to revise its relationship with the wider family and community. Sometimes, real barriers pose fewer problems than the emotional barriers which may be erected because of fear, protective instincts or sheer lack of knowledge of the real potential of the child. As the Carnegie Trust stated in its report *Handicapped Children and their Families* (1964), "there is a different kind of balance in the family containing a handicapped child, a restructuring of attitudes which has implications for all members of the family".

The parent's perception of handicap

The pronouncement that a much-desired baby is handicapped will sound like a death knoll to his parents. Handicap may be a natural disaster — it is usually totally unexpected. Additionally, the birth of even a normal, healthy baby is a stressful as well as an exciting occasion. All births change family life but the birth of a handicapped child may seem positively to distort it. Parents often feel guilty because their first feelings are for themselves. They feel that their own life-style, their hopes and expectations, will be challenged and damaged. The birth of a handicapped child has, indeed, been compared to a death or stillbirth in the family. Until what Freud described as the "work of mourning" has been gone through, the child will not be accepted and the parents will manifest the varied and distressing behaviour patterns which are appropriate to people facing death in the family.

Handicap will also make both husband and wife place heavy demands upon each other. If there is a serious breakdown in mutual support, the marriage may be in danger. Unfortunately, handicap also has repercussions on the traditional support system within the extended family. Grandparents and other relatives also grieve; they may feel guilt, inadequacy and fear — often expressed in terms of criticism and blame for the other partner. In this sense, counselling and support must accept the wider implications of handicap in the family and *accurate, sensible and sensitive information must be readily available.* This is particularly important with regard to the conflicts of meeting special needs within everyday family life. The obsessive mother is more common than the rejecting one.

This initial crisis period cannot be ignored in the subsequent care of the handicapped child. There is considerable evidence that parents who are told "badly" are more aggressive and difficult to help later (Cunningham and Sloper, 1977). They fail to make use of available facilities and have a persistently dissatisfied and aggressive perception of the caring services. Unfortunately, most families have two quite separate needs. On the one hand they need immediate help with the machinery of day-to-day living — advice on aids and appliances, help with feeding, advice on sleeping or mobility difficulties — and they may need much practical demonstration of how to handle a child. On the other hand they also need counselling, and sympathetic and uncritical support. The latter is time-consuming and may take many professional man-hours.

Parents can get things badly out of perspective. They can be the victims of family folk lore as well as of the general feelings of incompetence which afflict all new parents. Therefore, they need sympathy and support of a positive kind over a period of time. Sadly, the statement made nearly a decade ago that "a continuing and comprehensive casework service for families of handicapped children does not exist at present" is still true (Younghusband, E., *op. cit.*). Most professionals are aware of parents' needs but the exigencies of crisis intervention, rather than preventive work, make it difficult to offer a more comprehensive service. However, where regular support is available, such as in the Parent Involvement Project at the Hester Adrian Research Centre, University of Manchester (Pugh and Russell, 1977), it has been well demonstrated that parents have a much more positive attitude to professionals and a more optimistic attitude to their child's developments.

This need for constant support, with compensation for the loss of the expected "normal child" combined with positive action to help the handicapped child, is of equal importance when a child is in substitute home care. Foster parents will have the advantage of an absence of personal guilt for the birth of a handicapped child but they may have the "secondary handicap" of difficulty in getting access to realistic assessment and accurate information on the child's condition. If the foster parents not only cope willingly with the problems of handicap in the family but can also help the natural parents, they will be performing a unique task. Unfortunately, being *in loco parentis* can also mean that they are literally isolated like natural parents and unable to perform the parenting role effectively. In this situation, the substitute parents have even more acute needs because in all probability they have not lived with handicap throughout the child's life and have no idea of local resources or help.

Practical help

The research of the Family Fund and Research Unit, (Bradshaw, 1975) and the Disability Alliance (Baldwin, 1977) clearly illustrates the practical problems of living with handicap. Many parents do not know of the availability of *ex gratia* payments through the Family Fund and are unaware of the possibility of assistance with holidays, washing machines, special play equipment and clothing.

The *Court Report* (1976) has emphasised the wide divergence in the take-up of services between classes and regions. Unfortunately, the law of inverse care also applies to the DHSS allowances and the Family Fund. Many natural (and foster) parents are not aware of eligibility for the Attendance and Mobility Allowances. Many handicapped children spend long periods in hospital, often in specialist units many miles from their homes, whose families are unaware of possible financial assistance with hospital visiting and the special needs of these "long-stay" children. As Lord Plowden noted in his introduction to the Economist Intelligence Unit's report *Whose Benefit*? (1978), there is a Kafka-like world in which the disabled and handicapped have to exist". All families with a handicapped child need concise written information on all potential sources of help, well in advance of a crisis situation being precipitated. Information should also be available on local authority provision under the terms of the *Chronically Sick and Disabled Persons Act* with regard to the installation of telephones, assistance with aids, adaptations and holidays. A study carried out in Avon in 1977 (Butler, N. *et al.*, 1978) found that even in a relatively "well-provided-for" area, 56 per cent of parents of severely handicapped children had no idea of where to go for assistance with housing applications and special equipment and, of the 44 per cent of families with severe problems in using the existing bathroom and lavatory, only 12 per cent had received practical help.

Clearly, lack of communication can produce a situation in which the mother — in the words of a parent — finds her day-to-day life preoccupied with the "monotony of coping". A satisfactory physical environment is essential if the family, natural or substitute, is to help the child. Equally, where a child is placed on a short-term- or respite-care foster scheme, it is essential that there should be a "pool" of special equipment for loan or, alternatively, resources to provide adequate transport from one home to another.

Respite-care and parent relief

There is considerable evidence that many parents reach breaking point precisely because they have never been given a break in caring for a handicapped child. The family is a remarkably cheap and continuous treatment resource, provided that it is not sacrificed to a concept of community care which is child — but not family —centred. The development of the Somerset, Leeds and Northumberland short-term fostering schemes (Cooper, J., 1978) has clearly demonstrated that the tremendous practical and emotional support which can be given by substitute families should not be overlooked, since they also have existing family structures to maintain.

Foster parents can provide a valuable role in helping the natural parents to care for their handicapped child. It has been said that a good professional can create a web of personal confidence within which work with a handicapped child can take place. The foster parent can also provide this support and offer a strategy for coping. But it is both tough and sensitive work to enable a parent to revalue him/herself as "a competent person capable of improving her or his own situation" (Bronfenbrenner, 1974).

Foster parents need to be taught to care for *parents.* If they can be frank and admit that they also find certain communication or behavioural problems hard to handle, they and the natural parents may share a common dilemma in a constructive way. It is worth remembering that parents (natural or substitute) share the same day-to-day problems of living with handicap. Many children are handicapped in the family less by their developmental or physical problems than by the *overt manifestations of their handicap* (that is, behaviour probems such as self-mutilation, poor sleep, unsociable behaviour). Equally, any treatment programme has to recognise the *chronological handicaps* of coping with a difficult child in a family situation. If a mother has other children and a timetable dictated by school 'buses, family meals and other constraints, teaching programmes and intervention devices must recognise the importance of daily routines and work within them. Helping the handicapped child in the family means realistic appraisal of the parent's time and sensitive use of skills and concern. Precisely because many natural parents lack a sympathetic family member or friend who really shares their knowledge of the child, the foster parent may perform an invaluable role. Providing counselling and support can be difficult and not every foster parent will wish to sustain such a role. But the establishment of a caring "domestic" relationship on an ongoing basis may be a crucial factor in helping the family to cope. In this context, the increasing sense of professionalism felt by many foster parents (and hopefully nurtured by the local authority) will ensure that foster parents can accept natural parents as an integral part of special foster placement. This pastoral role will in turn reduce the threat which foster parents traditionally present to natural parents.

The dual role of the foster parent should not be minimised in terms of investment of time and energy. Foster parents, as well as natural parents, need breaks. Equally, the handicapped child needs a chance to extend his horizons and experience other patterns of care. Respite provision should be available as of right and information on local services through voluntary and statutory sources should be provided routinely, well in advance of need. Families should not feel the need to justify their demand for such support. Where foster parents may be working in some isolation from other families with handicapped children, it is helpful if they are invited to become "honorary" members of any local groups for the handicapped. A second safety net will then be established for the dissemination of information on local services and (hopefully) the family will be encouraged to express its own needs. Frequently the availability of special services (such as provision of home-helps and a baby-sitting service) are determined less by actual resources than by *demand*. Foster parents may be more inhibited in admitting their own weariness or stress. If these needs are not recognised, there will be a real risk of breakdown of a placement.

Parents as partners

Increasingly, parents are being regarded not only as the providers of family care but also as co-therapists in the development of their handicapped child. The diagnosis of a handicap is so often presented in terms of negative disability, so it is particularly important that all professionals should encourage the family to also perceive the child's *functional ability*. Although a few parents will have illusions of "miracle cures", particularly in the early days, most are at risk of under-expectation. Handicapped children are naturally deprived of normally-experienced stimuli in their home environment. Because of mental, sensory or physical handicap they may experience great difficulty in picking up "cues" from normal childhood activities. Parents have a unique knowledge of their child but they may need confidence in utilising this ability and in accepting that *they* can help their child to develop. In the words of the *Court Report* (para. 14.50), "they (the parents) frequently feel excluded from the treatment regime, caretakers of the child rather than partakers in his treatment . . . successful care within the family would be much easier if the potential contribution of parents to assessment and therapy were more widely recognised and welcomed".

The notion that parents can work as co-therapists with professionals can be a disturbing one. Yet parents have continuous contact with their child, and the motivation to help him improve. One development in services for parents of handicapped children has been the parent workshop. A number of initiatives has been taken in this area, including those run through the Hester Adrian Research Centre, the British Institute of Mental Handicap and the Birmingham Psychological Services. Workshops can take a number of forms but are, basically, ways of helping parents to help their children by teaching and demonstrating certain principles and techniques which can be tried out and adapted at home. The critical provision is a training programme which will enable *parents* to observe and assess their child, to use developmental charts or other relevant material, and to select and achieve goals. The use of parents as co-therapists places heavy demands on professionals. Verbal communication is unlikely to be sufficient but demonstration, backed by group support from other parents, can be an economical usage of professional time. Home-teaching programmes like the Portage Project also offer parents the chance to participate in helping their child and "do something". But, again, utilising the parent's skills will in turn demand emotional support and counselling when the child goes through "plateaux of no-growth" and when progress seems impossible or unduly retarded. The successes which can be gained by early involvement of parents as educators have been demonstrated by the Hester Adrian researchers' estimation that, by two years of age, the median IQ of the "education" group was 69.9, whilst that of the control group was 54.5. Whilst such dramatic improvements in IQ quotients may not always be attainable, the same research found that involved parents had a more positive attitude towards other professionals and — perhaps most significantly — were much more relaxed and optimistic in their attitude to the child.

Planning joint services

The involvement of parents in programmes for handicapped children presupposes the existence of a multidisciplinary approach to handicap. Handicap is increasingly treated less as a purely medical model of care, than as a problem requiring educational, social or paramedical solutions. The development of the concept of the family support centre — epitomised in Honeylands (see *Shared Care, op. cit.*) — means that an increasing number of parents can find a concentration of relevant services in one place. The idea of the district handicap team, and the increasing use of multi professional assessment procedures with in-built mechanisms for ensuring regular review and on-going treatment, means that services for handicapped children and their families are changing. Multidisciplinary services will never be simple. They require not only a blurring of professional identities in order to provide a flexible service but also a sharing of information with parents. At the Child Development Centre, Charing Cross Hospital, staff themselves receive counselling on working together. Direct access by parents and fellow-professionals may seem a frightening concept, but it is the corner stone of a total service for young handicapped children.

The building which houses a family support unit is not important.

Balidon House in Somerset developed from an opportunity group in a church hall. Honeylands is a former sanatorium. The Parents' Advisory Centre in Coventry is housed in prefabricated huts. Family support units are also intrinsically flexible. The Special Families Centre in Tower Hamlets works specially with Asian families of mentally handicapped children. Their lack of English, combined with cultural taboos on mental handicap and appalling housing conditions require particular support and counselling in the early periods.

Honeylands, situated in a stable and semi-rural health district in Devon, has a well-developed home therapist service for families of very young handicapped children. "Developmental therapists" visit weekly wherever there is a young child under 18 months referred with a major developmental problem, such as cerebral palsy or Down's syndrome. The goal is to bring a positive service into the home as soon as diagnosis has been given. Four to six weeks after referral — and thereafter at six-monthly intervals — the family and therapist spend a whole morning at Honeylands for a team assessment, with the therapist remaining as key figure and co-ordinator. Honeylands has worked with foster parents and has been successful in facilitating the placement of a number of severely and multiply handicapped children.

A multiply handicapped child will place heavy demands upon any family. But the availability of a service (which offers professional help combined with respite-care) is uniquely equipped to help families cope with a handicapped child—whether natural or fostered. Foster parents, like natural parents, have clear-cut needs if they are to offer more than custodial care. Too often negative or commiserative advice encourages a family to perceive the problem but not the potential. A domiciliary service will be necessary at times, utilising peripatetic physiotherapists, speech therapists, home teachers and specialist health visitors. The home is a major learning environment and, if professionals have never been there, they may well have difficulty in assessing realistic goals and training programmes for the child within the family. Equally, families should not be made to feel excluded from mainstream services for "normal" children. The Warnock concept of the "named person" is a valid one but must depend for efficacy upon the motivation of local services to permit the "named person" to act as advocate and advisor and to alert services to need.

Conclusion

Special fostering places heavy demands upon professional staff — as, indeed, does the presence of any handicapped child in a family. It also offers a unique opportunity to offer a sensitive, flexible and *local* service for short-term or longer-term placement of handicapped children in substitute families in the community. Recent developments in support services for families with handicapped children have highlighted the need for longer-term and respite- care to be provided in the community rather than in institutions. With the improvements in personal social services, the greater involvement of parents in therapeutic and treatment programmes, community care has become a realistic goal. Yet numerous studies of families with handicapped children reveal the very real difficulties in identification of services, lack of practical information and the need to involve the child's day-to-day caretakers (whether substitute or natural) in the setting of goals and the implementation of programmes to achieve those goals.

Precisely because special foster placements will make heavy demands on social services and other community facilities, it is vital that the foster parents are seen as part of a team service. Indeed, in articulating their special needs, foster parents may actually improve services for all parents of handicapped children. Natural parents are likely to experience handicap without prior anticipation; they have personal and emotional barriers to contend with. This "grief work" is not needed by the foster parent, who comes to the new task with anticipation, perhaps with training, and certainly with some sense of professionalism. This professionalism is an important facet of the "new" foster service, since many parents could feel their inadequacies compounded by a competent foster parent. Their depression could be very real if an apparent stranger can succeed in coping with difficulties which they have found almost insuperable. But natural and foster parents have much to offer and share. And it is to be hoped that substitute family care will develop as a viable alternative to some of the current patterns of institutional care. Perhaps in developing channels of communication with foster parents, we may in turn develop lines of communication with their natural counterparts.

In the often quoted words of the *Court Report,* "we know of no better way to help the child than to help his parents, whether natural or substitute, to do so".

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4. BEHAVIOURAL ASPECTS AND BEHAVIOUR PROBLEMS

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Anyone who has worked with mentally handicapped children and those who care for them will understand that such children regularly produce behavioural problems. These problems can be seen as arising under two broad headings.

Firstly, there are the problems which arise because a handicapped individual is usually a person who learns slowly or with special difficulty. This means that the individual often has a large variety of deficits and requires special care in teaching and training.

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Secondly, problems arise from the fact that many handicapped people develop behavioural excesses—behaviour that makes the individual stand out as unusual or unacceptable. Attempts are usually made to decrease or eliminate such behaviour.

In the past, professionals who, like me, have taken a behavioural approach to managing the handicapped have either been labelled as "behaviour modifiers" and caricatured as dispensers of smiles and Smarties, or they have been seen as rather unpleasant, naïve people who advise that difficult behaviour should be ignored or punished. I would like to move away completely from such views and discuss some of the important underlying principles on which our interactions with handicapped people and their families are based.

1. Define the client

In many professional situations, the client is defined for us. In the case of a handicapped person it seems obvious that he or she is the client. But a behavioural approach, without denying complex genetic and physiological causes of behaviour, focuses attention on the individual's environment as a crucial determinant of behaviour. A first step in bringing about change in the behaviour of a handicapped child is to produce some change in the environment which determines that behaviour. This invariably defines our second client, the family.

In the case of children living with their natural parents, we are often in the position of having to educate the parents to accept that *they* must change; that *they* are, in practice, our primary clients. With sufficient understanding and preparation it may be possible to avoid some of this difficulty with parents who foster or adopt a handicapped child.

2. Be constructional

In recent psychological literature the term "constructional" has been used to describe an approach to changing problem behaviour. This approach focuses on the importance of constructing new repertoires of behaviour or transferring them to new situations, rather than trying to eliminate them (Schwartz & Goldiamond, 1975). There is much good evidence which demonstrates that explicit attempts to remove problem behaviour meet with limited success. In the mentally handicapped, a move away from such eliminative procedures to an approach which is constructional, and builds upon the assets and strengths of the individual, is crucial.

Where the possibility of an alternative family placement exists, then the early introduction of a constructional approach could do much to foster the child's progress. It is worth noting that it is easy to place impossible demands on a family unless considerable care is taken in the choice of realistic goals for such teaching.

3. Beware the myth of "behaviour modification"

The term "behaviour modification" seems to imply that, if we can specify an objective target behaviour and gain control of a reinforcer which will increase that behaviour, we have all that is necessary for successful teaching. Or perhaps alternatively, if we can specify a problem behaviour and the consequences which reinforce it and we can remove those consequences, we are in turn likely to be successful in removing the behaviour. The focus has been on the changing of *behaviour* through the manipulation of its *consequences.* This is an important area in the understanding of teaching and it is essential to see that very often the behaviour itself is *not* the focus of change. Rather, it is the *relationship* between a particular piece of established behaviour and the environment in which it occurs which is the focus for change. Frequently we do little to change a particular behaviour demonstrated by a child. Instead, our efforts are concentrated, for example, on changing the conditions under which the behaviour occurs —the antecedents. This process may sometimes equate with bringing a behaviour under social control.

Perhaps two simple examples will clarify. Firstly, in toilet training children, the behaviour of urinating is invariably at strength. We do not change that behaviour appreciably in our training but we bring it under the control of fairly complex environmental stimuli so that gradually the same behaviour, urinating, occurs only in the presence of things such as the toilet bowl. Later on, we teach a whole series of complex social behaviours which must occur before the behaviour of urinating takes place. The basic behaviour is not modified, but its relation to its antecedents is changed. Secondly, we may all be familiar with the child who is described as "unable to undress" but who is labelled also as a child who "strips off his clothes in public". Again, it is not the child's behaviour of removing clothes that has to be modified, but the controlling relationships between that behaviour, the antecedent conditions and the consequences.

4. Observe contingency relationships

As noted above it is the relationships between a particular behaviour and its environment which are the basis to understanding and changing behaviour. The relationships have been studied extensively by psychologists but it is possible to draw out some fundamental principles which are particularly important.

A. CONSEQUENCE RELATIONSHIPS

We are all aware of the effect that the consequences of behaviour can have. Some consequences when contingent (dependent) on behaviour can lead to an increase or a strengthening of that behaviour. These we call *reinforcers*. Other consequences may lead to a decrease in behaviour and these we call *punishers*. This is fairly standard information.

A further important distinction is between *arbitrary* and *natural* consequences. A simple example is the child who is taught to put on his coat for the natural consequence (reinforcer) of going out to play. Eventually, it should be possible to maintain this behaviour under the normal circumstances in which a child is expected to put on a coat and to ensure that the behaviour generalises to the various settings and conditions in which he needs a coat on. If, however, we choose an arbitrary reinforcer such as food, instead of a natural reinforcer such as going out, we could find, in a rather extreme case, that the child only puts on his coat when he is hungry.

A similar distinction is important for the family of the handicapped child and may lead to a deliberate choice of arbitrary consequences. Handicapped children often provide very little natural reinforcement for a parent. They often have difficulty relating to people and their slow progress may be unrewarding. Without expressing the facts in behavioural terms Edna Stead, in a recent article on substitute family care, described a system in which foster parents were rewarded financially and with the status of a colleague to the social worker, both of which are arbitrary reinforcers. She did note, however, that although such rewards were effective initially, "rewards in terms of response and developmental progress are essential in the long term". The arbitrary rewards available for any individual can often provide a useful way of establishing a behaviour repertoire, provided this arbitrary relationship is understood and later changed to some natural contingency.

B. ANTECEDENT RELATIONSHIPS

The importance of antecedent behaviour relationships in teaching has already been touched upon. Once again, the arbitrary-natural distinction can prove valuable.

In teaching the handicapped we regularly set up arbitrary relationships without realising it. In teaching a complex skill, we often advise that the help provided should start off as a physical prompt, to ensure that the behaviour actually occurs; should then gradually be changed to a gestural prompt, to make the person less dependent on us; and should finally be left as only a verbal prompt, so that the person no longer depends on being pushed or pointed at. We then wonder why the individual never becomes independent and may literally remain still until we tell him to move.

The relationship established between the prompts and the behaviour is an arbitrary one, designed to ensure success during teaching so that the reinforcer can be effectively programmed. The natural antecedents (behaviour relationships) we require are more often between one piece of behaviour of the individual and another. For example, the behaviour of washing one's hands is usually the antecedent for picking up a towel and drying them. By involving a verbal prompt as the antecedent which determines the behaviour of drying one's hands we make it very difficult to establish the natural relationships between washing and drying which are necessary for independence. The verbal prompt is extremely difficult to "fade out".

5. Observe the principle of gradual change

The principles of gradual change and small steps for teaching have been recognised for a considerable time. Many of the more valuable teaching principles deriving from a behavioural approach, such as shaping, prompting and errorless learning (Cullen, 1976), are based upon them. For a mentally handicapped person, gradual change is a must. It is easy, however, to run into problems with such a principle.

Many people are encouraged to decide on a teaching target and to analyse the behaviour required breaking down this large skill into small steps working back from the final target. The process can produce a long list of apparently logical steps which an individual would need to learn in sequence to reach the final goal. Such a list may, in practice, turn out to be totally unrelated to the actual behaviour of any specified individual. In teaching a handicapped child and, more importantly, in teaching a parent to teach a handicapped child, any "programme" of teaching must be based upon the assets of the particular child and parent. Any steps chosen for teaching towards the eventual target must depend on the actual response observed in the child and the parent. Each behavioural analysis must focus on the individual and his needs and not be based upon preconcieved programmes of training.

6. Be experimental

An experimental approach implies some simple steps. Firstly, it requires a good observation and assessment of the present position and a statement of what is to be changed. Secondly, it requires a reasoned statement of possible manipulable events which might be used to bring about change. Thirdly, it requires that some event is manipulated in an effort to bring about the desired change. And finally, it requires that observation and assessment is continued in order that any change can be detected.

In a behavioural approach, whether it is the behaviour of the handicapped child or of the parent that is the target for change, this experimental method offers several advantages. For example, it ensures that any change in the child is detected. This assists in the making of future informed decisions about targets and teaching methods and also makes it clear to parents that their efforts are worthwhile so that their behaviour is reinforced by natural consequences which may otherwise have passed undetected. It also ensures that specific procedures which prove to be effective for the child can be described clearly and used again, not only for the same child but perhaps for others. Finally, it can prevent parents from continuing to use an unsuccesful teaching method by giving them clear evidence of their lack of effect.

In conclusion

This paper has attempted to describe a number of principles of a behavioural approach which can be used to help handicapped people and their families. These principles are not exhaustive and are intended to be applied both to the handicapped child and to the behaviour of the parents. They can be used as a guide in dealing with problem behaviour and the teaching of new behaviour.

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5. SPECIAL NEEDS OF THE MULTIPLY-HANDICAPPED CHILD

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The special needs of the multiply handicapped child are very complex and depend on the type and severity of his handicaps. The needs of the family as a whole must also be considered. Parents' reactions to the facts of their children's handicaps vary a great deal and it is no use having a stereotyped approach to a certain handicap. Two children with apparently similar problems may have to be treated quite differently because of such factors as the child's place in the family, parental attitudes, social circumstances, the location of the child's home and whether transport is readily available.

A child has to fit in to the life of his family and therapy programmes should be apropriate to this. If, in the early months and years, we meet the parents' needs by supporting them through the initial shock, explaining the problems and demonstrating practical ways of helping the child to make progress, we shall lay the basis for a constructive partnership from which the child can only benefit.

In many instances parents instinctively do all the right things, stimulating the child in just the right way, and one's role as a professional is simply to reinforce, and perhaps to direct an emphasis, in what the parents are already doing.

In this paper the term "multiply-handicapped" implies a mentally handicapped child with an additional complication of physical handicap (for example, cerebral palsy), visual defect or hearing loss—one child may have several specific handicaps. The needs of a multiply-handicapped child can only be met if all the experts work together as a team, together with the parents. These may include the doctors, health visitor, physiotherapist, social worker, speech therapist, teachers in the special schools and specialist teachers for certain handicaps, psychologists and so on.

Obviously, not all these individuals will be attacking the same child at the same time! At different stages in the child's life different needs are the most pressing. The person in the team with the most relevant knowledge at any one stage will be giving the child the most attention at that time advised by colleagues at intervals. The child and his parents should not be confused by introducing too many people into direct work with the child.

The role of the physiotherapist

I will now discuss the child's needs in terms of motor development since this is the aspect of development in which the physiotherapist is most interested. Mainly, I shall describe how the physiotherapist can help the very young child, since this is the age group with which I myself am most involved.

Motor development is in many ways the basis for development in other spheres. A normal baby learns by being constantly on the go—watching everything with great interest, grabbing everything within reach, crawling around and bumping into things—his admiring parents and friends always encouraging him to do more. If a mentally handicapped baby of 9-12 months is unable to hold up his head, manipulate and play with toys and move around on the floor, he is going to be held back in social development and in learning about the world.

Since early motor development is so important, the physiotherapist is usually closely involved with the very young handicapped child and it is at this stage that her contribution is most effective.

Cheltenham has a comprehensive community physiotherapy service and I am able to see all young babies at home. There are many advantages in being able to do this. Mother and child are relaxed in their own surroundings and I can adapt my approach according to the home situation. I can see the difficulties at first hand—what the baby *really* does when he sees that spoonful of mashed dinner approaching (which he has made up his mind to reject!) while at the same time a toddler is making a din in the corner because we are giving our attention to his brother and not to him! At home, grannies and aunties may be enlisted as helpers. Over cups of tea, queries and worries can be discussed and solutions to problems often come to mind while looking at the ordinary household equipment and furniture.

The children

The babies I see fall into two main categories: those whose motor development is following the normal pattern but is delayed; and those whose motor development is not only delayed but abnormal due to cerebral palsy.

CATEGORY ONE: DELAYED MOTOR DEVELOPMENT

The first category includes children with Down's syndrome and the majority of other mentally handicapped children. Mentally handicapped children vary and some progress within the range of normal motor development, but usually slowness in achieving head control, hand function, crawling and walking, is part of the overall picture of retardation. The baby may be very hypotonic (floppy) and inactive, sleeping a lot. Lack of response on the baby's part affects the way the mother handles him, so one may find a six-month-old baby behaving like a six-week-old, and his mother treating him like one. There is thus little stimulation for the baby to progress.

The aim of the physiotherapist is to take this baby through the stages of normal development, showing his mother how to encourage him to achieve the next stage. He can be helped to come on to the 2-3-month level in many ways. These include talking and playing with him on one's lap, and getting him to smile and pay attention. He may be able to balance his head if he is held up—if so, he should be moved around to the limit of where he can do so, so that he has to make an effort to hold it up until, eventually he can lift his head himself when he is lifted up. He should be shown where his hands and feet are and helped to get his hands into the midline and handle rattles. Sensory stimulation (such as cuddling, tickling) is also important (especially if a visual defect is there as well) so that the baby becomes aware of his body and limbs.

Future problems can be avoided if simple advice is given early. The baby may dislike lying on his tummy unless he gets used to it at an early age. Being a conservative fellow, he does not experiment and begin to roll, so he lies stranded on his back or propped up in some way. He will learn to sit, but the prone sequence of development (on his tummy, looking up, pushing upon his arms, pivoting round after toys, creeping and crawling) does not take place. He may learn to shuffle around on his bottom and become so adept at this that he firmly objects to getting on his feet! This may lead to a child, aged four or more, who is still shuffling around and not walking because he has never developed good muscle tone in his back and legs and the ground feels strange under his feet.

A mentally handicapped baby should be placed in, and played with in, different situations during the day—in the baby chair in different parts of the room, with different toys or a mobile to look at; in different positions, sometimes on his back, sometimes on his side (encouraging him to reach forward for a toy and roll over), sometimes on his tummy (looking up to see where the interesting sounds are coming from). Older children in the family provide invaluable stimulation and should be encouraged to play with the handicapped baby. The baby is not as fragile as we may think—he is not going to drop to pieces if he is bounced around by his father or given a bearhug by his loving sister. Rough-and-tumble play, accompanied by shouts and laughs, gives the baby experience of fun which he will not get if he is too cosseted and protected.

Few of the babies in this category need special aids and appliances although the physiotherapist may sometimes arrange for a special chair to be loaned. She will advise the parents on suitable commercially-made baby-chairs, push-chairs and baby-walkers and, if the child has outgrown ordinary walkers and is still not on his feet, may advise that the DHSS "Cell-Barnes" walker be supplied. She will also advise on what *not* to use, for example "baby-bouncers" do not encourage a good weight-bearing pattern and I would not recommend them.

Each developmental stage may be very prolonged. Sometimes, a child may reach the point of almost walking alone but may stay there for months and months. He may walk round the furniture, energetically push a pushcart about and stand alone, yet lack the confidence to take a step unaided. His mother needs to be reassured that he will walk eventually although it is impossible to predict when and that the main thing is that he is enjoying being on his feet and is getting around exploring his environment.

When a child starts to walk he may have very flat feet which may worry his parents. This is due to his hypotonia and the fact that, as a late walker, he is heavier than a normal child at the same stage. The child's muscle tone will improve as he becomes more active and a pair of well-fitting leather shoes is all that is usually required.

In Cheltenham, we have a therapeutic playgroup for handicapped children between the ages of one and three years. This is held at the Children's Hospital and is run by a speech therapist, a play leader and me. Our facilities are very cramped but the team spirit is excellent! We work primarily through the mothers, most of whom accompany their children and enjoy meeting each other. The senior medical officer for child health visits regularly and also sees the children at home. We have regular meetings to discuss each child's progress and future placement.

Once the child is walking, the physiotherapist usually fades out of the picture, except in an advisory capacity. Normal activities, such as going for family walks, P.E. lessons and swimming—and not too much television—will help the child to become as physically active as possible. Activities with a purpose are usually more beneficial than focussing attention on a child's poor posture or co-ordination. Sometimes poor performance in this sphere is associated with perceptual problems which may need to be analysed (one of the reasons why early sensory experiences are so important). However, the child's needs are now primarily educational and other colleagues take over.

CATEGORY TWO: ABNORMAL MOTOR DEVELOPMENT

I will now look at the needs of the mentally handicapped cerebral palsied child, in whom motor development is not only delayed but abnormal. Brain damage has caused spasticity (muscle tone is too high causing the child to feel "stiff" and to resist movement when handled and to have fixed abnormal patterns of movement) or athetosis (muscle tone varies between too high and too low causing sudden, uncontrollable reflex movements). In the child with a spastic hemiplegia (only one side of the body affected) for instance, the arm and leg are held in postures which are never seen in normal development.

In the early months, the picture may not be altogether clear since the baby is usually floppy at first. Spasticity appears later and becomes more severe as the child gets older. Contractures of joints may occur, necessitating orthopaedic operations later on.

It is essential that the baby with cerebral palsy is referred for physiotherapy as early as possible. It is a mistake to "wait and see", since by then the spastic patterns are so fixed that potential function is lost and the mentally handicapped child is at even more of a disadvantage in life.

Consider a child of six months with a right-sided spastic hemiplegia. He is now at the stage when he should be making a two-handed approach to toys, passing them from hand to hand and putting them in his mouth; pushing up on both arms when he is on his tummy. Instead, he is showing a marked preference for the left hand and is ignoring the right. At this stage the physiotherapist can influence the course of his development by simple measures. She can advise his mother on ways of playing with and handling her baby, which will inhibit spasticity and facilitate normal movement on the spastic side. If she sits on his right side when she feeds and plays with him, and arranges his baby-chair so that he sits symetrically and looks to the right to see her moving around the room, he will gradually become more aware of his right side and begin to use his right arm. He can be encouraged to take his weight through his hemiplegic arm and leg, by pushing him onto that side to stimulate the balance reactions and by dangling him upside down to get the parachute reaction.

If a hemiplegic baby is left untreated until nine or twelve months of age it is much more difficult to get any function out of the hemiplegic arm. He is now firmly orientated towards his unaffected side and resists any attempts to get him to use the hemiplegic arm by swivelling away. He is probably bottom-shuffling, not having been able to crawl, and all the time the spasticity is increasing as he over-compensates with the unaffected side. He will have a very unsightly posture and gait as he gets up onto his feet. In my experience, if a child has not obtained some useful function in his hemiplegic arm by the age of eighteen months he is unlikely ever to obtain it. He may co-operate by doing exercises but he will not spontaneously use the arm in play.

This illustrates the importance of early treatment for all children with cerebral palsy, many types of which are much more disabling than hemiplegia, for example, spastic quadriplegia (paralysis of both arms and both legs). Of course, children with cerebral palsy are not necessarily mentally handicapped but other difficulties are often present, especially perceptual problems.

The mentally handicapped child with cerebral palsy will need prolonged physiotherapy, extending into his school life. As with all mentally handicapped children we have to ask ourselves: what are our aims? And, are we achieving them? In the early years the physiotherapist's aim is often that the child should walk. This is certainly the parents' aim and most parents want to know if this will be possible. The physiotherapist should try to reassure them but she must keep her predictions within the bounds of probability. There are some children who will never walk. Some of them will cope well with life in all other respects, but some are so profoundly handicapped that, despite years of therapy and devoted effort by their parents, they will remain totally dependent on others for every need.

Sooner or later, the children reach a plateau of achievement in the motor sphere, and the physiotherapist should assess when this point has been reached. A person with a physical handicap does not necessarily require physiotherapy. He only requires physiotherapy if it can achieve some results! This applies to children as well as adults.

The physiotherapist's aims must be realistic. In some cases an enormous amount of time and effort may produce a small clinical improvement but it may not be resulting in improved function in normal life. Her time, and the child's, would be better spent in another way. In such a situation, it is better to accept the physical handicap as it is and to concentrate on helping the child to develop in other ways, for example in social skills or in speech and language development.

Family placement

This workshop is considering placement of mentally handicapped children within the family. I hope that the thoughts I have outlined above do not sound too daunting a programme for prospective adoptive and foster parents!

There is no doubt that the needs of the mentally handicapped child impose great demands upon any parents. Those of us who have chosen to work in this field must work together with those who may choose to foster or adopt.

A secure family life is the best possible basis for good progress by any mentally handicapped (or normal) child. It is well-known that few will do well if placed in institutions. People who are prepared to foster or adopt a mentally handicapped child are meeting his most basic need, and are making it possible for him to attain his own potential for an independent and happy life.

6. FINDING PARENTS FOR SEVERELY HANDICAPPED CHILDREN

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Finding substitute parents

Can a child be too severely handicapped to be placed for adoption? At Parents for Children we are still looking for the answer. When we began to place handicapped children, in October 1976, we hoped we were right to think that we would find parents for young Down's syndrome children. Two years later eight of these children have been adopted and we have not yet found a child too handicapped to be wanted by a family. We thought a 15-year-old severely retarded girl might have remained unplaced but she did not; and we are now working with a family which has become interested in an even more severely brain-damaged girl of 14. A 13-year-old ESN boy with cystic fibrosis has found a mother who is an energetic widow with grown-up children. An 8-year-old boy with a fatal degenerative disease and multiple physical and mental handicaps is being adopted by a single parent. We feel justified, therefore, when we say that every child is placeable until proved otherwise.

Even if we believe that there is a family somewhere for each child who needs one, can we really be sure that severely and multiply handicapped children will benefit from family life? Again, we can only say that we have not yet found a child who did not react positively when placed with a family, very often with spectacular results. However, social workers, who also work with grieved natural parents who cannot accept a handicapped child, may find it very hard to accept the idea of people becoming substitute parents to just such handicapped children.

At Parents for Children our sole work is finding substitute parents for children who are in the care of a local authority or are in long-term hospital beds. We make full use of every possible publicity method — radio, television, articles in the national and local press and women's journals. Responses are followed up without delay and enquirers invited to attend an information-giving open meeting.

As the children we are being asked to place seem to be increasingly handicapped, so we have found it more difficult to give prospective parents a true picture of the child. Our work with parents always centres around the needs of one particular child but, we have found that with multiply handicapped children, even talking to their teachers, nurses, and residential workers, seeing the available photographs and reading the file does not adequately prepare families for the experience of meeting that child. Several introductions broke down after periods of apparently thorough preparation of both parents and child. One multiply handicapped teenager was introduced twice and each time a different aspect of the child's disabilities made it impossible for the families to carry on.

The "Activity Day" experiment

When dealing with such complex mental, physical and emotional patterns there seemed to be no knowing exactly what would get under a family's skin — very often it was the most unexpected factor. So we decided to experiment, with children and parents meeting at the earliest possible moment of the family-finding process and it seemed that the meeting should be both informal but also fairly demanding. We called it an "Activity Day", chose a Saturday and hired three rooms in the National Children's Bureau in London. We sent out a newsletter featuring the seven handicapped children we were wanting to place and invited anyone who was interested in the Activity Day to contact us. As the newsletter was sent out in reply to initial enquiries as well as to those families on our mailing list who may already have attended a series of adoption classes, we asked newcomers either to meet us before the Activity Day or to come half-an-hour early for the equivalent of an information-giving open meeting. In the event, although several new families wanted more details, only one family not previously known to us came to the Activity Day.

We asked families to bring play material to keep one of the children amused in the afternoon and we offered to look after their own children. We also provided large soft toys, a toy farm, a tape recorder, a record-player, a dolls' house and plenty of paper, crayons and balloons.

The local authorities in whose care the handicapped children were, had of course, given permission for the children to participate and we invited their social workers and residential workers or hospital staff to bring them to the Children's Bureau. Six children came. The seventh was withdrawn because, unfortunately, his authority felt that the exposure might do him harm — this little boy was already sad because introductions to a family had broken down but three more families wanted to meet him at the Activity Day and we felt that more failed introductions might have been prevented in this way.

It just happened that on the day six families turned up to be introduced to six children. Four had come to meet one particular child and the remaining two were tentatively matched with the other two children for the occasion. The parents arrived at 10.00 a.m. and, while the new family was introduced to the work of the agency, the others met and mingled over coffee.

The first session was a discussion with the prospective parents led by a residential social worker (who has three handicapped children in her group), a mother of an adopted Down's syndrome child, the single adoptive parent of a severely and multiply handicapped boy, Mark (who was in the room with us) and Two Parents for Children workers. The speakers emphasised the effect of institutionalisation, the normality of living with a handicapped child and the need for acceptance. We asked them to tell us what was nicest and what was hardest about living with their children, what parents needed to know, what kind of support they should have and how they should deal with public opinion.

The last part of the morning was taken up by talking about the children they were going to meet, what the children's expectations might be, and the exact shape the afternoon would take.

During the morning two Parents for Children workers had been preparing lunch in another room, helped by some of the visitors' younger children — the older children had all elected to join the discussion. The tables were arranged to seat one or two families, together with the children they had come to meet. Lunch was cold and set out ready on the tables. When the children arrived with their workers they were welcomed by the families and taken off for lunch. All the visiting social workers and Parents for Children workers ate together in one of the other rooms, while the parents and children began to get to know each other through sharing a meal.

Some of the introductions were rather abrupt. Ralph, who is a $5\frac{1}{2}$-year-old blind, mentally retarded and physically handicapped boy was pushed in by his nurse in a small wheelchair and left with Joan, a single parent who had not felt particularly attracted to any one of the children but had come to gain some first-hand experience of disablement. Ralph came with a bag containing a change of clothes but otherwise Joan was on her own. With encouragement from Ann — Mark's adoptive mother who had led the discussion in the morning — Joan tackled getting to know Ralph by handling him and finding a way of communicating with him. Ralph, who had been described as unlikely to relate, clung to Joan for the rest of the day and delighted her by enabling her to understand his wishes. Her main fear had been that she would not know what any of the children would want and here was Ralph, the most handicapped of them all, making her feel capable and confident.

Jane also immediately clung to Rosemary who had especially come to meet her. Rosemary and David had already adopted a Down's syndrome boy and wanted to add a daughter to their family. Jane, who lived in an institution, had probably never experienced so much individual attention before and her response left Rosemary and David in no doubt about wanting to become her parents.

After lunch the parents and children moved into another large room where play things, including table tennis, were laid out. Each family produced the toys and games they had brought themselves and the real "activity" part of the day began. Mary and Tony and their four children, two of whom are also handicapped, had prepared a scrap book full of pop stars for Martha. They already knew about 14-year-old Martha's preoccupation with the pop scene, had been well prepared for Martha's multiple handicaps, and knew about her two two failed introductions. Sarah and James and their two young children, who had been introduced to Martha previously, had also come to join us for the day and were able to share their experiences with this new family. It was James and Sarah who helped us to understand the need for prospective parents to meet children like Martha first and to prepare for adoption later. This time Sarah and James had come to meet Peter, a 14-year-old Down's syndrome boy who somewhat disconcertingly called them "Mummy" and "Daddy" from the moment he set eyes on them and exhausted them by a non-stop game of table tennis from which he would not be diverted.

While families and children played, the social workers and other care-taking staff who had brought the children discussed the aims and implications of the day. The fact that one local authority had opposed the plan gave ample opportunity for those who came to voice their doubts and to relate the comments of others in their agencies. To some colleagues who were not involved with actually placing the children, and who had no experience of using any form of publicity, it had seemed like a cattle market. Worries were expressed that a child might feel left out of the activities, or that his hopes might be raised by a family's interest which was then not followed up. It was felt by some workers that a multiply-handicapped child might seem deceptively appealing on first sight and others felt anxious about an element of competition between parents if more than one family became interested in one child.

On the other hand, everyone agreed that the children had looked forward to coming and were having an enjoyable day. Some of them connected Parents for Children with finding families but they did not expect to be introduced to new parents this way and Peter, we were told, calls everyone he meets "Mummy" and "Daddy" in any case. Some of the children consider any outing is a party; others accept but do not understand whatever is happening. Martha's social worker remarked that even two failed introductions had had a positive, stimulating effect on her and that a day like this could not harm her.

In order to learn from the children's reactions we asked the social workers to let us know if the children seemed to be affected by the experience. Ralph's worker wrote to say that the silent, apathetic little boy she had brought in the car babbled and giggled and jumped about all the way back and that his nurse had been so impressed by the way Ann listens to her son Mark, who does not speak, is almost blind and is severely retarded, that when she got back to the ward she asked everyone to gather round and announced, "Listen, Ralph wants to tell you something". Some of the children told their social workers what they had done and those children who have met the families again remembered them.

By tea-time, parents and children had been together for 3¼ hours. It was later suggested that it might have been helpful if the Parents for Children workers had joined them for the last part of the afternoon, so that they would have been better able to discuss what had happened with the parents. After tea together the social workers took the children home but the going was not easy for all of them. Alice, aged

14, and severely mentally handicapped had sat by Ann's side all the afternoon but had not wanted to do anything that was suggested to her; now she did not want to go, or to take with her the present that Ann had brought for her. She had shown very clearly how hard it would be to get through to her. John, the most obviously disturbed and demanding of all the children, had worn out his family and it was sad for them to see him go because they knew they would not be seeing him again. It was hard for Ralph and Jane to be prised away and to leave their families empty handed.

The outcome

After the children had gone the parents and the Parents for Children workers shared their feelings about the day. "Shattering", "unbelievably tiring" and "painful" were the immediate comments. Some parents felt that they learnt more with the children in three hours than they could have learnt from days and weeks and months of preparation. Others felt that it had been a singular opportunity not only to get to know the children but to get to know themselves. One father was relieved to know that he could accept the children as individuals rather than as handicapped but, at the same time, he now felt that his family would not be able to cope with a handicapped member. Everyone agreed how hard it had been to keep the children amused for such a long time but inevitably the situation had been artificial and one parent compared it to visiting a child in hospital.

The greatest concern was the same as that of the children's social workers: the effect on the children. Was the exposure worthwhile? We realised that it was our own exposure to the children's constant and overwhelming need for a family which we were finding hard to bear. Finally, as in all our work with parents, it was left to the families to contact Parents for Children if they wanted to learn more about any of the children they had met. Four of the families continued to work with us towards adopting one of the handicapped children; the two remaining families decided that they were better able to consider an older child who might be emotionally, rather than physically or mentally, handicapped.

At the end of the day many questions remained unanswered. Would it make the work with prospective parents easier or harder if they were getting to know the child at the same time? Would the parents who wanted to proceed have been the ones to go on to adoption in any case? Would more parents have been able to share the emotional strain of the afternoon, or would loss of intensity make for loss of commitment?

All in all we felt that our first Activity Day had left us with much to think about and considerable enthusiasm for the next one.

7. RECRUITMENT METHODS — MAKING THE NEED KNOWN

CHRISTINE HAMMOND, Social Work Co-ordinator, Adoption Resource Exchange, 11 Southwark Street, London.

When a large proportion of your working week is concerned with the needs of handicapped children who are unable to live with their natural families, it is easy, but depressing, to make two basic assumptions:

1) that everyone else is equally aware of these children's needs and
2) that, despite their knowledge, none of them cares enough to offer help.

Fortunately, there is good evidence to suggest that both assumptions are false and that successfully dealing with the first, the need for knowledge, quickly disproves the second.

Creating public awareness

The need is *not* widely known. At the Adoption Resource Exchange we have several thousand enquiries about adoption from the general public every year; a sizeable percentage of these are from people who still think of adoption solely in terms of bringing together childless couples and healthy, illegitimate babies. Of those responding to specific publicity, many make comments like, "I have children of my own, so I've always switched off when adoption was mentioned" or, "I did not know there were children like these needing new families". Anxiety about their suitability as substitute parents, such as "We're not regular churchgoers" or "Are we too old, my husband is 36?", also serves to emphasise how little the public is aware of the groups of children needing new families and the qualities and attributes which are sought in prospective new parents.

Wherever possible, we discuss with these enquirers the groups of children currently needing permanent substitute families and the wide variety of people who are coming forward, able and willing to meet these children's need for a caring environment. As a result, many of them go on seriously to consider adopting a child with special needs and this contradicts that second assumption — when they know about the children who are waiting, people *do* care.

Naturally, not everyone can, or will wish to, parent a handicapped child but making the need known as widely as possible has two aims. The first aim is to encourage people to consider taking a handicapped child into their family group. The second aim, which is sometimes overlooked but is of equal importance, is to help create a better climate in the community — more knowledge, more tolerance, more goodwill — which will have positive benefits for both the children and those who take on the role of substitute parent. *Everyone* is potentially a neighbour, relative, or friend of a family with a handicapped child. It is important to do what we can to dispel the profound ignorance which many people have about handicap because where there is ignorance there is often misunderstanding and sometimes fear. Anyone who has tried taking a "normal"-looking but severely handicapped youngster on public transport is likely to have first-hand experience of this lack of understanding.

Making the needs known

Given that we do still need to be making the needs known, what are the most effective methods? There are, of course, many ways of publicising the needs of children who are waiting for substitute family placement. One clear lesson is that people respond to particular children more often, and more realistically, than they respond to publicity about an undifferentiated group of children. People who respond to publicity and express an interest in adopting or fostering a handicapped child are usually responding to that child as a unique individual and accepting that the child's handicap is just one facet of him, the implications of which will be only one of the aspects of learning to live with that child. Generally, prospective parents are not saying "We want to parent a handicapped child" but "We want to parent *this* child who happens to have a handicap along with his other characteristics, positive and negative!"

Individualising the child also helps to dispel the ignorance and fear mentioned earlier. Would-be substitute parents who have been unable to consider taking a handicapped child into their family when discussing such children in the abstract, often take a very different attitude when seeing a "real" child — not surprisingly, since unless they already have some acquaintance with handicap, they will find it very difficult even to begin to imagine "a handicapped child" as part of the family group. A specific child, with a personality to which they can relate and both positive and negative attributes which they can comprehend, is a different matter.

It follows that the most effective methods of making the need known are those which feature individual children with specific needs. It has been our experience that television can be a very productive medium for recruiting substitute families for children with special needs. In the four national series of *Reports Action* programmes for example, 30 children have been featured, representing the whole range of children needing new families including children with severe mental handicaps. Most of these children have now been placed and, in addition, hundreds of people have asked for more information on adopting or fostering "special needs" children. All of these people are, we hope, at least a little better informed about the needs of children unable to live with their birth families and more than 300 of them have now been approved as substitute parents.

There are two specific advantages of using television to make the need known. Firstly, evidence suggests that it reaches people who do not see (or at least do not absorb) other forms of publicity. Secondly, it enables us to present a three-dimensional picture of the child in a way which is not possible by radio or on the printed page. Nevertheless, other forms of publicity are valuable. Experience in Britain, particularly with the PPIAS (Parent to Parent Information on Adoption Services) newsletter, and in America with various "photolisting" services suggests that a well-written profile combined with a good photograph can also be a very powerful recruiting device. In one State, over a period of nine months, nine Down's syndrome children found new families entirely through the use of this sort of system.

Another effective method is to focus recruitment for a specific group of children in an area where the necessary facilities are available and where an active parent or interest group already exists. Presumably because there is already some familiarity with and understanding of that group of children's needs, people who are already involved, with for example handicapped children, seem more ready to offer to parent them than do members of the general public. At the moment, most people becoming substitute parents for handicapped children are already acquainted with children with handicaps, either through their work or through the extended family. An active local NSMHC group, Down's Babies Association or school group can be a very useful base from which to mount a campaign. As well as using the resource of the parents of handicapped children, with all their accumulated experience, this helps bring the need to the attention of others interested in handicapped children, either directly or by group members "spreading the word" in the community.

Do not underestimate this "ripple" effect — one of the most successful substitute families I ever worked with was a "third-hand" one. They heard of a particular child, whom they subsequently took into their family, through their grown-up daughter who, in turn, heard of him from a friend who was a volunteer in a local hostel for mentally handicapped children.

To conclude

Local recruitment campaigns, television, photolisting and other media usage all have two things in common. They are ways of making the need known and they work! In combination they can be even more powerful. By using the photolisting technique with special interest groups in local campaigns, the Americans have succeeded in placing large numbers of mentally handicapped youngsters and they are now in the position of having a waiting list of people willing and able to act as substitute parents for pre-school children with Down's syndrome. These techniques are not particularly revolutionary and it is clear, from the more limited attempts that have so far been made in Britain, that they can be effective here. In fact, to turn those basic assumptions I started with on their heads, it is not that people do not care about these children with special needs, it is often that they do not know about them and what can be done to help provide them with a caring family environment. Our job is to make the community aware of the handicapped children who are unable to live with their families of birth. As people of all shapes and sizes come forward (and they certainly will!) it is our responsibility to encourage and work with them as they take on the demanding but rewarding task of becoming a substitute parent to a child with special needs.

Appendix 2.

Other resource material used at the workshop

Audio-visual aids

1. "A chance to breathe". Videotape, Somerset County Council.
2. "James is our brother". 16mm film distributed by Concord Films. Council, 201 Felixtowe Road, Ipswich.

Books and pamphlets

1. Conference proceedings "Adoption and Fostering of the mentally handicapped". Published IMS (now BIMH).
2. Adoption in the '70's. Published ABAFA.
3. Fostering in the '70's and beyond. Published ABAFA.
4. Family placement for mentally handicapped children. Published Leeds Social Services Dept.
5. Parents for Children Report. Published PFC.
6. Home from Home. Published Independent Adoption Society/NSMHC/Merton Social Services Dept.
7. Extract from: Stamina paper No. 3. Residential Care of the Mentally Handicapped. Published NSMHC, as follows:

Living At Home

For the mentally handicapped who live at home the following services are essential. Check:

1 That there is regular full support from relevant specialist services, e.g. paediatrician, speech therapist, psychologist, psychiatrist, physiotherapist.

2 That there is regular support from specialist social worker and/or health visitor. This should include visits at home at intervals of not more than two months.

3 That visits are covered by regular reports to the appropriate authority and available to parents.

4 That there is continuing counselling and advice, short-term relief, clinics, opportunity classes, etc.

5 That full information regarding statutory benefits and services of all kinds is readily available and is conveyed to parents by specialist social workers.

6 That priority placement on local authority housing lists is available to families with a severely mentally handicapped child.

7 That parent "workshops", to assist parents with the care of their child, are

organised, and (parents are) **aware that support services for families should be provided by the Local Authority.**

8 That a full laundry service is available.

9 That special equipment, draw sheets, nappies, suitable wheelchairs, washing machines, is available.

10 That adaptations to the home in the form of ramps to doorways, hoists, etc. are available if required.

11 That home help and other kinds of support for families are available.

12 That local short-term care is available regularly, overnight, for weekends, Mondays to Fridays, or in emergencies.

13 That options for short-term care include foster homes and children's homes.

14 That there is a "day care" programme available throughout all school holidays.

15 That any child, irrespective of how difficult, if managed by the parents, has access to short-term facilities.

16 That local authority social and leisure activities are developed or that financial support is given to voluntary agencies.

Foster Homes

All the supporting services listed for the child living at home should also apply to foster homes. Check in addition:

17 That foster parents receive financial remuneration on an agreed scale together with appropriate supplementary finance for clothing, holidays, etc.

18 That the local authority provides regular supervision and support for foster parents.

19 That foster homes are the subject of a regular visit by the specialist social worker.

20 That links between foster parents and natural parents are maintained where possible.

21 That foster parents are encouraged to join, and made welcome in the relevant Local Society for Mentally Handicapped Children.

Appendix 3.

Examples of existing low-cost relief schemes

LEEDS FAMILY PLACEMENT SCHEME for mentally handicapped children

A pilot scheme was begun in 1976 by Leeds Social Services Department in which six families were specially recruited to provide short-term care for mentally handicapped children (up to 16 years of age). The cost of the Scheme — in which each family was to receive three young people (one at a time) for a two-week stay — was to be contained within a budget of £1,500. The cost to the Authority per unit placement per week was £35.06, less than the cost of alternative forms of provision.

During 1979 the Scheme, which is jointly funded by the Area Health and Social Services Departments, operated on a budget of £14,500. 222 placements were arranged with 25 substitute families, involving about 78 different children (up to 19 years of age) with a wide range of handicaps.

Further details of the Scheme are available from the Specialist Social Worker (Mental Handicap), Leeds City Council Social Services Department, Selectapost 9, Merrion House, 110 Merrion Centre, Leeds, LS2 8QA.

PARTNERSHIP WITH PARENTS: short-term care for handicapped children in Somerset

In 1974 a young mother in Bridgwater was admitted to hospital as an emergency. Her mentally handicapped son was received into care and placed in a local foster home but the foster parents were unable to cope and soon asked for him to be removed. He was admitted to Sandhill Park Hospital, about 12 miles away, the only option available.

Following this incident considerable pressure was put on the Social Services Department, by the headmistress of the school which the boy attended and local parents of mentally handicapped children, to make proper provision for such handicapped children, not only in times of emergency but also for holiday and relief care throughout the year. As a result, a pilot Scheme began in 1976. The parents had insisted that it be local, that they should be able to make arrangements themselves direct with "caring couples" rather than through a social worker or other professional, and that their children must be able to continue attendance at their usual school during their placements.

Each caring couple is approved by the Authority. The parents, child and caring couple meet and get to know each other over a period of time. Parents wishing to use the Scheme are issued with a book of tokens. They telephone their caring couple to arrange the child's stay and give to the couple the relevant number of tokens. These are then sent to the local Area Office and form the basis on which payment to the caring couples is calculated.

The initial Scheme was so successful that another five schemes have been started in the County so that now about 200 out of the 300 mentally handicapped children in Somerset have a local scheme available to them.

Further information is obtainable from the Senior Assistant (Health), *Somerset County Council Social Services Department, County Hall, Taunton.*

Note

Alternatively, information about the two schemes described above, and another short-term fostering scheme in Northumberland, can be found in a book by J. Cooper, entitled *Patterns of Family Placement*, which was published by the National Children's Bureau in 1978.

Appendix 4.

Useful addresses

Adoption Resource Exchange, 11 Southwark Street, London SE1 1RQ.
Association of British Adoption & Fostering Agencies, 11 Southwark Street, London SE1 1RQ.
British Institute of Mental Handicap, Wolverhampton Road, Kidderminster, Worcs. DY10 3PP.
National Society for Mentally Handicapped Children, 117 Golden Lane, London EC1Y 0RT.
Parent to Parent Information on Adoption Services, 26 Belsize Grove, London NW3.
Parents for Children, 222 Camden High Street, London NW1 8QR.
Voluntary Council for Handicapped Children, c/o National Children's Bureau, 8 Wakley Street, London EC1V 7QE.

Appendix 5.

List of workshop participants

Ms. H. Argent, Parents for Children, 222 Camden High Street, London.
Ms. J. Bloxam, Church of England Children's Society, "Community House", 133 Loughborough Road, Leicester.
Mr. I. Crosby, Leeds City Council Department of Social Services, Merrion House, 110 Merrion Centre, Leeds.
Ms. J. Dillon, Advisory Team, Cheshire Social Services Department, Commerce House, Hunter Street, Chester.
Mr. K. J. Drinkwater, Church of England Children's Society, 111 Church Hill Road, Handsworth, Birmingham.
Mr. J. Elliott, 42 Charles Way, Malvern.
Mrs. B. Garrett, Somerset Social Services Department, Northgate, Bridgwater.

Mr. A. Hall, Association of British Adoption and Fostering Agencies, 11 Southwark Street, London.
Miss C. Hammond, Adoption Resource Exchange, 11 Southwark Street, London.
Mr. J. D. Hamson, Department of Social Services, County Hall, Exeter.
Mr. J. Hattersley, *formerly* of Lea Hospital, Stourbridge Road, Bromsgrove, *now at* Coldeast Hospital, Sarisbury Green, Southampton.
Ms. K. Hudson, North Regional Children's Resource Centre, Mea House, Ellison Place, Newcastle-upon-Tyne.
Mrs. A. Kerrane, Barnardo's New Families Project, 227 Byres Road, Glasgow.
Miss I. Knight, Barnardo's, Courtney House, Oxford Street, Cardiff.
Mrs. M. McCormack, 35 Larchmere Drive, Hall Green, Birmingham.
Mrs. M. Mawer, Association of British Adoption and Fostering Agencies, 11 Southwark Street, London.
Mrs. P. Mills, 10 Kingsway, Gerrards Cross.
Ms. M. Morrison, South East Scotland Resource Centre, 21 Castle Street, Edinburgh.
Dr. D. Ricks, Harperbury Hospital, Harper Lane, Shenley, Radlett.
Miss J. Roberts, 12 Mornington Grove, Bow, London.
Mr. J. Ross, National Society for Mentally Handicapped Children, 117-123 Golden Lane, London.
Ms. J. Round, Physiotherapy Department, Cheltenham General Hospital, Sandford Road, Cheltenham.
Mrs. J. Rush, King Edward's Hospital Fund for London, 126 Albert Street, London.
Mrs. P. Russell, Voluntary Council for Handicapped Children, National Children's Bureau, 8 Wakley Street, London.
Miss P. Sawbridge, Parents for Children, 222 Camden High Street, London.
Ms. C. L. Smith, Barnardo's New Families Project, Cheshunts Cottage, Church Street, Boxted, Colchester.
Miss S. Smith, Southwark Catholic Children's Society, Russell Hill Road, Purley.
Miss M. Trowell, Adoption and Fostering Section, Department of Social Services, City Hall, Victoria Street, London.
Miss C. Walby, South Glamorgan Social Services, 12/13 Windsor Place, Cardiff.
Mr. R. Waller, Manor House Hospital, Bierton Road, Aylesbury.
Miss A. Whittaker, King Edward's Hospital Fund for London, 126 Albert Street, London.
Ms. J. Woolley, Independent Adoption Society, 160 Peckham Rye, London.
Dr. M. E. York-Moore, British Institute of Mental Handicap, Wolverhampton Road, Kidderminster.

Details of all current BIMH books, periodicals and extracting services are available from: BIMH Publications, British Institute of Mental Handicap, Wolverhampton Road, Kidderminster, Worcs. DY10 3PP

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