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9

Collaboration between parents and professionals

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FOREWORD

> Parents and professionals have a common objective, in the pursuit of which each brings differing skills and activities; their joint aim is to aid the development of the parents' mentally handicapped child, and to enable that child, as he grows, to lead as good a quality of life as possible. The primary task falls to the parent, day in and day out: the job of the professional is to aid the parent in the performance of that basic task. Without genuine collaboration between them, service to the mentally handicapped person will inevitably be diminished.

This was the starting point for the group of people listed on the inside back cover of this report, who came together in an effort to understand more clearly the practical implications of that statement. It was agreed that collaboration is necessary: but what do parents and professionals have to do to achieve it?

The initial residential meeting, instead of answering that deceptively simple question, merely laid bare the emotional depth and complexity of the problem. Another meeting was necessary before parents and professionals even began to understand one another, and several further meetings took place before they finally felt able to commit themselves to this unanimous and deeply-felt statement. As the paper concludes:

> Joint partnership does involve mental effort to shake off old habits and outlooks. It will not be achieved overnight..... Parents and professionals alike have to change their traditional stance. But we unitedly believe that this is the right way forward. And the delightful thing is: it is an improvement which does not cost money.

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COLLABORATION BETWEEN PARENTS AND PROFESSIONALS

A statement by
a group of parents and professionals
meeting under the auspices of

King's Fund Centre, London
and
The Association of Professions for
the Mentally Handicapped

THE TASK

1. Parents and professionals have a common objective, in the pursuit of which each brings differing skills and activities: their joint aim is to aid the development of the parents' mentally handicapped child, and to enable that child, as he grows, to lead as good a quality of life as possible. The primary task falls to the parent, day in and day out: the job of the professional is to aid the parent in the performance of that basic task. Without genuine collaboration between them, service to the mentally handicapped person will inevitably be diminished. We argue this basic need because it is plainly impossible for the professionals to use their skills and knowledge other than through the hands of those who provide for everyday needs, all day and every day. To begin to be effective, the professional needs to understand the unique feelings, attitudes and experiences of each particular family in its daily struggle to cope. The professional has to utilise the hands, heart and brain of the family. What is needed is a continuing inter-action between professional and parent which will enable each to make his contribution more fully.

2. Parents and professionals are often short of resources: together they should form a powerful, unified, co-ordinated lobby for more and better facilities and for the better use of existing resources, for agreed targets. Professionals should not see parent pressure groups as a threat - they should be allies in securing the better services they both desire so much.

3. We are anxious to encourage joint effort between parent and professional, on the basis of equal partnership. But we must not throw the baby out with the bath water: real professional skills are in short supply. True professionalism, based on knowledge, experience, judgement and skills, is essential to real progress: it is when the professional sees himself, or is placed by the parent, on some elitist pedestal, that the hope of collaboration is in real jeopardy.

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THE PARENT

4. The sheer emotional problem of the new parents coming to terms with the fact of having a handicapped child, and of each parent coming to terms with the other, must be recognised. It has been well set out in Right from the Start (1) and we will not elaborate here. But from that point on, one of the greatest sources of stress in parents is not knowing for certain what can be done to cope with the present, or to plan for the future. Many new parents see their greatest problems not as strictly medical or physical, but as centring around such broad issues as: lack of language; behaviour difficulties; home management; and the long and sapping process of coming to a decision for or against residential placement. Sometimes professionals are able to demonstrate to parents what can be done, and teach them how to do it: at other times they are at a loss. If the professional lets himself run out of ideas, the parent is likely to run out of stamina. So the professional must continue the struggle to find something practical which can be done, or at least tried: the discovery of something which will attract the interest of the child and stimulate action - something as simple as newspaper at the foot of a pram or bed, which rustles when the child or adult kicks his feet; or varying, by means of professional skills, the behaviour modification which unknowingly goes on all the time at home; or working together at plans for some alterations to the house.

5. Another great source of stress lies in relationships: amongst the immediate family of the handicapped child, including brothers and sisters; with nonplussed or perhaps even accusing and hostile grandparents; with near neighbours; with workmates. Being asked for a photograph of the new baby can be a torture for some parents in this situation. Professionals with the right combination of skill and concern should be able to offer some counselling or support which might help parents round these difficult corners of life, which occur from birth on through adulthood.

6. The parents' role is not fixed: it may change from time to time, varying from dependence to co-partnership, and on to leadership at times. A parent may move from one kind of relationship to another, depending upon the need at the time. But it is our strong view that if a basis of co-partnership has been

developed early in the life of the handicapped person, it is likely to persist, even though occasionally interspersed by periods of much greater dependence. Sometimes technical help, or information, may be all that is needed: at other times, anger, hostility, resentment and criticism may call for support of a psycho-therapeutic nature. This is where the presence in the team described in paragraph 11, of a professional trained in these skills, is so badly needed: too often, parents have to break down before help is organised. A steady collaborative relationship, in the course of which each can refer to the other's ideas and, more important, feelings, will minimise the otherwise ever-present risk of parent and professional developing different, perhaps conflicting, objectives. And if the relationship is based on sharing occasional failures, or producing only tiny changes, or understanding that there is no wonder cure, or weighing assets rather than deficits, or on showing respect for the child or adult as an individual, no matter how severely he is handicapped, then realistic developmental objectives are much more likely to be formulated.

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Reference

1. SPAIN, B and WIGLEY, G. Right from the start: a service for families with a young handicapped child. London, National Society for Mentally Handicapped Children, 1975. pp.95.

THE PROFESSIONAL

7. What seems to distinguish the good professional, over and above questions of training or skill, is an almost indefinable attitude which directly affects the essential quality of the relationship between parent and professional, and which seems to intensify the effectiveness and depth of any technical service which is given.

8. Although we say that this professional attitude is almost indefinable, it is not quite so. In this paper we use the term 'professional' broadly - extending to all, whether qualified or not, who work with or for mentally handicapped people, and we would hope that they would develop qualities of a certain kind: words like empathy, respect, dignity, and recognition, spring to mind. We would look for willingness to provide time and privacy for parents to talk with the professional about their thoughts, feelings and ideas. And we would expect imagination, flexibility of thought, and an attitude of curiosity, willingness to cross demarcation lines, and a sincere respect for the skills and knowledge of others - including parents. Among technical skills which we would hope for, according to degree of experience or qualification, would be the ability to work to realistic developmental goals; to accept the mentally handicapped person for what he is, whilst always being aware of the possibilities of growth and change; the ability to communicate clearly; awareness of the significance of daily events in the life of the mentally handicapped individual. And over and above all this, we would hope for the man or woman who has stayed in this work for the right reason - because he has become committed to the well-being and growth of mentally handicapped people, seeing them as people first and as handicapped second.

9. For the professional the work can be painful - particularly the frustration of impotence: direct contact with apparently insoluble situations can be distressing, and the temptation to refer problems to some other agency is ever-present. It is work which demands emotional resources without which even the best of professional training is simply not enough. To help him, the professional needs to work from within a team setting, in which he can recognise and declare his own

weaknesses, and be strengthened by the knowledge, attitudes, sympathy and support of his colleagues.

10. A fruitful relationship between parent and professional is more likely to develop if the professional says in effect - "we have tried a number of approaches together: what next can we do?" It is difficult for collaboration to spring up unless at the outset the professional shows by his demeanour and action an openness and readiness to respond. He needs to show compassion for the needs of the family, be prepared to give time, be aware of his own limitations, to know where and when to enlist other sources of help. Even so, attitude is not enough: his skills and knowledge need to be of the order which will generate trust and esteem on the part of the parent. Not only is the parent consulting the professional: the professional is consulting the parent for clues which will enable him to do his job better.

11. For the parents to have confidence in the professionals, the group working in the health, education and social services, need to work together regularly with the parents, and to let it be seen that they are a co-operative team, working to agreed goals and standards; a general pool of information and help, rather than a collection of disparate and independent contributors, providing conflicting advice. We see this group approach as likely to be more supportive than the selection of one particular speciality to provide the point of contact with the parent: parents will relate to the team member with whom they feel most easy or confident - it might be quite a junior person.

12. Parents cannot be prepared in advance, for rarely is there warning of the coming of a handicapped child. But all professionals could and should be prepared in advance for the collaborative relationship which this paper has tried to describe, and which we consider of central importance, under-pinning all efforts, however diverse, towards better services. If professionals do not perceive for themselves the need for a truly collaborative relationship, then pressure from parents will hardly bring it about: and the parents and the handicapped child will be the real losers. Not everything can be included in the syllabus of basic staff

training, but we believe it to be essential that this philosophy of equality and collaboration between parent and professional be firmly implanted at the outset, even though training in some skills and techniques may have to await later stages of the educational programme. Textbooks need constant surveillance to ensure that the attitudes they propound are acceptable: existing staff need to be encouraged in their efforts to move over to a more egalitarian stance.

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ACTION TOGETHER

13. Absolute honesty by the professional is essential. This particularly applies to honesty about the practical problems which may be expected in looking after a handicapped person at home. But admitting that the situation is difficult or the outlook gloomy, is a far cry from saying flatly, or even implying, that there is nothing more to be done. For who knows if this is so, in a field of work so full of surprises? Certainly it is wrong to give false hope, but it is equally wrong to destroy hope. Parents must have hope, not for a wonder cure, but for the chance that something more - however modest - may be done to alleviate the situation or prevent deterioration. Even if together, parents and professionals seem to have tried everything, there is still the hope that by remaining open to new thought, and recognising that there must be no full-stop, something may emerge which may help in the human dilemma. There is always a need for parent and professional to do something together, to interact all the time, for by such interaction the unforeseen solution to a problem is sometimes made clear. The inclusion of the handicapped person in that interaction, if he has reached that stage, then becomes a natural step: his own wishes and ideas can then receive consideration.

14. The continuous process of joint activity between parent and professional and the handicapped person, is mutually educative and demanding: all stand to benefit. No longer is there a one-way traffic of ideas: this is a situation in which all parties are learning. As parental strength and confidence grows, professionals are encouraged to cast around for newer approaches, or to support the parents in maintaining old but necessary routines. This new relationship requires professionals to be able to admit that they do not always have ready answers: sometimes all they can offer is to try and find out: not always an easy position for the professional to adopt. Yet the need of parents is not always for answers. Sometimes just an awareness of the shared concern and understanding of the professional will of itself make more possible the effort required to bear the stress which only comes to parents. There is always a need for drawing up a positive programme of activity, some sort of plan for a living-pattern, be it only what is to happen next year or in the event of some family contingency: even a knowledge of the next stage of resources often helps people to cope with the present.

15. We urge the widespread use of the practice which already exists in some enlightened quarters, of parents being present and actively involved as equal partners in the case conference and assessment process; of parents being instructed in, and contributing to, an ongoing programme of training and treatment; of parents being given written assessments and programmes in clear plain English; and of progress being reviewed from time to time, between professional and parent, against these written documents.

16. In a collaborative atmosphere such as we have been attempting to describe, the sharing of information between professional and parent is likely to evolve as the ordinary pattern of life, rather than presenting itself confrontationally as a rights issue. We are quite certain that parents have the right to the passage of information and reports described in the preceding paragraph: they have the right to know what is being said about their own child and about themselves, and the right to question it. They ought to know that they have this right. Although some of us have misgivings about the degree to which the working notes of professionals should be laid bare to parents, we are united in our belief that clear written reports based on these notes should be given to parents, and should be explained. However, we must emphasise our deep conviction that any professional programme, however expertly drawn up, is greatly weakened by the absence of parental involvement: yet parental involvement is impossible to visualise without sharing of information. So whilst, as a last resort, this is an issue of civic right, we prefer to see it as an issue of trust and goodwill.

17. It may be argued that some parents appear to have switched off - that they do not want information: we would say that it is the duty of the professional to try to discover why this has happened, and to persist in his efforts to interest parents in this vital topic: to sit down with the parent and to take him through the report, explaining as they go along.

18. There must surely be some very special circumstances indeed before information about his own offspring is positively withheld from a parent, or revealed only in part. Examples might be where a parent is already under great psychiatric stress, or is acutely ill, or where there are personal or legal problems associated with divorce or separation.

19. Are all parents and professionals ready for this collaborative relationship? Inevitably the answer must be 'no'. Some professionals already work in this way; some would like to but are prevented by the nature of the organisation within which they work; others again genuinely feel that they must keep a distance between themselves and the parent. Some parents may be unable to grasp the meaning of situations adequately enough to be able to participate in such a relationship; others may have sunk into apathy after years of effort; others again may have rejected their offspring years ago, or they just do not actively seek or accept this co-operative relationship. Whatever may be the reason for the parents' hostility or apathy, it is important that the handicapped person should not suffer from the backlash of his parents' problems. Surely it can be said that it is the duty of professionals to encourage parents to try to work towards a collaborative relationship as a basic necessity.

* * *

COLLABORATION IN THE RESIDENTIAL SITUATION

20. It will be seen that this statement has centred mainly on the handicapped person who lives at home, and the ways in which the team of professionals can strengthen the efforts of the family.

21. But there are 55,000 mentally handicapped people in NHS hospital care, and about 10,000 in forms of residential care provided by local authorities or voluntary agencies. The nurse or residential care worker seems to occupy a variety of roles, according to need. Where parents or relatives maintain contact and involvement, the staff role can be seen to be a little like that of a house-parent or house-matron in a boarding school. But the less parental involvement there is, the more there develops on the part of the staff a kind of auxiliary parentage, until, with those children or adults who have lost all meaningful parental contact, staff may find themselves occupying a markedly parental role.

22. In the residential setting, the nurse or residential care worker needs to be the channel through which specialised services reach the handicapped person; just as, ideally, the parent of the home-based child should be. We have described how it comes about that parents are sometimes by-passed, and a similar situation can affect the nurse or residential care worker. He needs to be informed of all that is being undertaken or proposed by specialist services, or how can he tell the parents? But sometimes the management system of the hospital, or its organisational pattern, prevents this from happening. We have to ask not only whether professionals are collaborative, but whether the policies of the hospital or residential home are themselves collaborative.

23. We accept that in a few cases it may be the duty of the staff to avoid involving the parent, perhaps already broken down by the stress of the whole situation. But in the majority of cases the duty of the nurse or residential care worker is clear: it is not to shut parents out, but to bring them in. It is to encourage and sustain the involvement of parents in practical decisions and activities concerned with the daily life of the handicapped person. It is to create an

atmosphere in which the parent will begin to feel able to communicate ideas and to share responsibilities.

24. Collaboration of this kind will help to reduce the polarisation between the roles of parent and nurse, and the possibilities of possessiveness or over-protection by staff. We see the fostering of such a collaborative attitude not as a benevolent or liberal notion, but as the fundamental bedrock of an effective service. Without this relationship there can be no good service. It is a duty which falls not only upon the staff who meet with parents, but on the authority responsible for the policies of the hospital or residential home.

* * *

CONCLUSION

25. Twenty-three people at various times contributed to this report. Some were professionals: some were parents of the mentally handicapped. Some might be called co-travellers - parents who are also professionals working in the field of mental handicap.

26. It would have been impossible for this report to have been written at the end of our first two-and-a-half-day workshop. By then we had tried to formulate proposals, construct diagrams, define attitudes, write job descriptions - all to no avail. We had not even begun to penetrate to the heart of the problem. But we had begun to realise how deep the problem is, and how our insights are fogged by our stereotypes of one another. At that stage we were still looking for gates in the fence which divided us. But parents and professionals alike moved their positions considerably over a subsequent series of one-day meetings, until we found ourselves at last dismantling the fence itself, and beginning to understand what are the positive things we must do to achieve true partnership between parent and professional. We had to learn these things for ourselves before we could achieve enough unity to write this modest, but deeply-felt paper.

27. But we have at last achieved consensus and now we would like to share our thoughts with other parents and professionals, and to obtain their reaction. Our statement will go to subscribers to the King's Fund's Mental Handicap Bulletin, and we propose to hold an open conference on the topic at the King's Fund Centre on July 15,1976, at which practical applications will be described and illustrated. This paper will be discussed in open session by APMH at its Annual Congress at Reading University in July 1976. And we hope that all who work with the mentally handicapped, whether in statutory or voluntary settings, whether in health, education or social services, will use this statement as the starting point for discussion with those parents and relations with whom they are involved.

28. Joint partnership does involve mental effort and shaking off old habits and outlooks. It will not be achieved overnight, as we ourselves have discovered.

Parents and professionals alike have to change their traditional stance. But we unitedly believe that this is the right way forward. And the delightful thing is: it is an improvement which does not cost money.

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PARTICIPANTS

These are the people who helped in the discussions, and who contributed to the drafting of this statement. They include parents of mentally handicapped people, therapists, doctors, social workers, psychologists, teachers, administrators, nurses and a health visitor.

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