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EDITORIAL

Among the variety of resources and facilities available to the professional working in mental handicap, the parents have seldom been considered as representing a potentially very powerful force to be incorporated into a team effort. Of course, parents are not necessarily keen and willing to assist, as is witnessed by the numerous half-hearted, sterile and ineffective parent/teacher associations, leagues of friends and parent-staff meetings. Parents of m.h. children are not more forthcoming, more anxious, more self-sacrificing than parents of "normal" children, since they also have their commitments to other members of the family, their business problems, their social obligations, their pressing engagements and so on. These are cogent reasons to hand over the education and development of their handicapped children to the knowledgeable experts, whether they are teachers, nurses, psychologists, doctors or other care staff. Being faced with the strangeness of a m.h. child, who is so different, embarrassing and disappointing, it is a vast relief for them to pass on an obviously intricate problem to those who have specialised knowledge and to trust them to do better than the parents themselves will do. But will they?

The good bedside manners of those experts tend to camouflage the fact that their decisions, or, as they would have it, their advice, as to the best course of action to be taken in a given case, is a matter of informed opinion, of more or less inspired guesswork, of intuition in the best case, of applying a standard procedure in the worst case. There is also a tendency among professionals to accept the belief of other people that they are really experts in dealing with problems. This tends to give them a sort of tunnel-vision and focuses their expertise on the fragment of knowledge they have chosen for their specialty whilst neglecting to take notice of other areas which are the provinces of other disciplines, or of the observations and suggestions by the parents. Being pressed — not unwillingly — into the role of the knowledgeable specialist, who has access to the medicine chest, the expert would disappoint his clients and add to their despair if he were to admit too openly that he can not feel too sure about having advised the best possible course of action even though he is hopeful of some improvement. After all, the specialist's task in this case is not to restore a damaged human being to his former efficiency, nor to strive towards all-round "normal functioning". He has to work towards the undefined goal of a mysterious "full potential" of an unknown nature, and his guidelines and targets are vague and nebulous.

Despite his difficulties in plotting a promising course towards a well defined goal, the m.h. expert fails often to be humble enough regarding the limitations of his particular expertise and he may really believe that a failure of his particular prescription and approach denotes a general impossibility of achieving success and progress by other means, particularly non-scientific ones. Experts of all shades and disciplines are notoriously reluctant to discuss with laymen — the parents — details of treatment, education and training, anticipating the very frequent objections, disagreements, doubts, resistance, fear and opposition of people, too emotionally involved and not conversant with relevant scientific information. They

require cooperation only for bringing the children to the special school, taking them home for a holiday from the institution, adhering to a diet and handing out the medication at the correct times. They prefer to keep away from the "over-anxious, over-protective parent with guilt feelings" and to carry on undisturbed with their particular "management of the case" in the isolation of the classroom, the hospital/institution ward, the day clinic and the developmental centre.

This is, of course, a complete misunderstanding of the necessities of this particular situation, unfortunately supported fallaciously by reference to "normalization". The m.h. has not caught a disease which has to be treated in the special conditions of a hospital ward, nor can he only be developed by professionals in the classroom or workshop, but he is an underfunctioning person, who must be assisted, *all the way round, to grow as a person within the life situation relevant to him.* It is in the nature of his handicap that he is a slow learner, who does not easily generalize and transfer experience from one situation to another. This is a question of "all hands on deck" so as to provide the variety of contexts and people required to give the widest possible experience without sacrificing the consistency of approach.

It is unreasonable and indefensible that willing and keen parents are not roped into the team of expert caretakers where they can make unexpected, but valuable insightful contributions, whilst, at the same time benefitting by the more extensive knowledge of the trained staff. It is again and again the unhappy experience that teachers and carestaff do not know the degree of competence in self-help skills achieved by children at home, and that parents are unaware of the degree of independence their children are permitted to display in the more permissive environs of school and training centre. The assessment of baselines to start work from and to judge the rate of progress, must be a combined operation which, in its turn, must lead to an agreement about the details of assistance to be given, the placing of emphasis in the remedial work and the removal of environmental obstacles.

In the case of the m.h. child we can not afford the "normal" division of labour between parents looking after the emotional and physical well-being, whilst experts take care of academic and occupational aspects. It will require give and take. It may well be that parents will make experts aware of the many additional factors influencing the m.h.'s growth, which are excluded from scientific exploration often merely because no suitable technology has been invented yet to investigate them scientifically. And it may be that parents might gain considerable advantage when they are able to add a disciplined, objective viewpoint to their intuition, optimism and persistence. Perhaps a permanent, established collaboration between those individual parents, keen to participate in furthering their children, and caretakers, desirous to add extra power to their efforts, will succeed in making prescriptive developmental programmes truly effective.