

SYMPOSIUM ON PROFESSIONAL RELATIONSHIPS IN THE FIELD OF MENTAL HANDICAP

I—IMPROVING COMMUNICATIONS BETWEEN HEALTH SERVICE PROFESSIONALS AND PARENTS OF HANDICAPPED CHILDREN; A CASE STUDY

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Introduction

A small working group of which I was chairman carried out an extensive survey into services for severely handicapped children and their families in the Brighton Health District on behalf of the Brighton Community Health Council throughout 1975/76. The survey took two forms: (a) meetings with parents of handicapped children and with representatives of the health, social and educational services, and (b) a postal questionnaire to all parents at three special schools in the District, plus as many other pre-school-age children as we could find. E.S.N. children were not included, only severely physically handicapped and S.S.N. children. The results of the survey are written up fully as a report and this paper focuses on one aspect of it, namely the findings in relation to the issue of the quality of the information given to parents.

The information which parents need comes in two categories, information about their child's condition and prognosis, and information about services and benefits available to them. During our meetings with parents before we undertook the questionnaire survey we were very much struck by the strength of feeling with which they made it clear to us that information of either kind was very hard to come by. We met with three different groups of parents numbering about forty in all, and remarks that doctors seldom gave full information or allowed adequate time for questions were commonplace, as were comments that they had had to find out for themselves, often from other parents, about any services available to them. Against this background we decided to see how widespread these views were by devising a questionnaire to test parents' views about the quality of the information they had received, or, where possible, to test how much information they actually had.

The questionnaire had four parts: (a) asking about the degree of contact with appropriate organisations, (b) testing their awareness of selected services available to them, (c) asking where their information came from, and (d) asking them to assess the quality of the information they had been given about their child's condition. The questionnaire was sent out through the special school to about 250 parents, of whom 120 replied. Although the replies were anonymous, it was the considered opinion of all three Heads that it was generally the more articulate and resourceful parents who had responded, indicating that the following results probably err on the side of over-optimism. Of the parents who replied, 65 had severely mentally handicapped children, 36 had severely physically handicapped, and 11 had doubly handicapped, the remaining 8 being unclassifiable through lack of information. The ages of the children ranged from 2 to 17, of whom 9 were aged 3 or less.

The Findings

(a) Contact with Statutory and Voluntary Organisations

We listed ten agencies and asked parents to indicate which they had been in contact with. Only 50% reported contact with the Social Services, and only 57% reported contact with Health Visitors. This last figure is surprisingly low, and since this may well have been due to the ages of the children, we checked the responses of parents with children aged 6 or less. Even here we found that of the 37 families concerned, 9 parents, 24%, reported no contact. Again, this seems a surprisingly high figure, and if it in fact means that the families have really had no contact it indicates a major breakdown in the routine surveillance services. We asked the District Management Team to verify the information from their records; they had to collect the data de novo for themselves, and unfortunately the information was stolen before it was published, so we have received neither confirmation nor refutation of our findings on this point.

In respect of mentally and doubly handicapped children, only 54% had been in contact with the local Society for Mentally Handicapped Children.

We asked parents to indicate whether they had received any help, however they conceived of it, from the organisations they had been in touch with. Taking just the three main ones, 93% of those in touch with Social Services, 70% of those in touch with Health Visitors and 51% of those in touch with the S.M.H.C. had found them helpful. 14% of parents reported contact with none of the ten organisations listed, and 21% reported having received no help from any of them.

(b) Parents' Information of Services Available

One of the main aims of the survey was to discover the extent of parents' awareness of services available to them. We did this by listing seven of the major services and asked them to indicate which they had heard of. Not all services were potentially equally available to all parents, i.e., some were for the physically handicapped only, and this has been taken into account in presenting the findings, given in Table 1.

TABLE 1

Percentage of potentially eligible families who reported having heard of the service

Rowntree Family Fund	61%
Disposable Nappies	17.5%
Help with Holidays	45%
Speech Therapy	46%
Physiotherapy	68%
Adaptations to the Home	30%
Aids to Daily Living	55%

Taking all the parents together it was possible to classify them as having a low, medium or high awareness of the services according to how many of them they knew about. For example, parents of mentally handicapped children should have heard of the first four on the list; those who knew about one or none were classified as low, two as medium and three or four as having a high awareness. Table 2 details the findings.

TABLE 2**Percentage of parents with different levels of awareness of available services, by handicap of child**

Child with	Low	Medium	High
Mental Handicap	38	29	32
Physical Handicap	61	19	19
Double Handicap	18	54	27
TOTAL	45	31	24

These depressing figures speak for themselves. Overall only 24% of families had a high awareness against 45% with low awareness, and this despite the fact that nearly all of these children were at school, and all but 17 of them had been in contact with at least one appropriate statutory or voluntary agency.

(c) Parents' Sources of Information

We asked parents to indicate from whom they had heard of particular services, and also more generally to indicate which people had given them the most information both about services and about their child's handicap.

From asking them to indicate who had told them about which services it became clear that, with the exception of school teachers, who tended to act as general referral agents, the professional helpers tended only to tell parents about their own services, i.e., hospital doctors were the source of information about physiotherapy or speech therapy but about almost nothing else, while social service workers were the source of information about social services.

The reply to the more general question about the main source of information re services is given below.

TABLE 3**Number of times parents cited each group as having given the most information about services available**

(N=123)*						
Fam. Dr.	Hosp. Dr.	H.V.	Hosp. S.W.	S.S.D.S.W.	Other Parents	Others
8	8	14	6	20	33	34

Unfortunately school teachers were omitted from the named groups on the questionnaire, which almost certainly led to their being singled out less often than would otherwise have happened. The most striking point about this table, however, is the number of times other parents are mentioned as the biggest single source of information about services, which indicates the importance of parent-to-parent contact as a major link in the information chain.

We also asked parents from whom they learned most about the nature of their child's handicap, with the following results.

TABLE 4**Number of times parents cited each group as having given most information about child's handicap**

(N=142)*						
Fam. Dr.	Hosp. Dr.	H.V.	Hosp. S.W.	S.S.D.S.W.	Other Parents	Others
21	61	9	2	5	10	34

(*Some parents named more than one group)

As we would expect, the medical staff, particularly the hospital doctor, figure much more prominently here. Again, it is likely that school teachers are under-represented, though they appear prominently amongst the "others," as do voluntary organisations and other specialised clinics.

(d) Parents' Views on Information re Child's Handicap

We obviously couldn't assess how much parents did know about their child's handicap, but we could ask them to indicate their degree of satisfaction with the information they had received. We therefore asked them to indicate on a five-point scale in relation to selected medical personnel.

TABLE 5

Numbers of parents reporting different levels of satisfaction with the information given to them about the nature of their child's handicap						
	Very Dissatisfied	Dissatisfied	Neither Sat./Dis.	Satisfied	Very Satisfied	
Hosp. Dr.	22	25	22	34	15	
Fam. Dr.	14	20	35	32	17	
H.Vs.	19	20	27	19	14	

Bearing in mind that hospital doctors were the main source of information for most parents, the findings in relation to them are particularly important, and here it is noteworthy that 47 (40%) parents expressed themselves at least dissatisfied with the information they had received about their child's handicap.

Another disturbing finding was that 45 (37.5%) of the 120 parents reported having received no information from any of the three professional groups which they regarded as satisfactory.

(e) Parents' General Comments on the Quality of Information Received

The final part of the questionnaire invited parents to make any points they wished about the information they had been given. Of the 120 parents, no less than 84 took advantage of this open-ended invitation, of which 59 (70%) mentioned the inadequacy or lack of information, both about services available to them and about their child's condition. The main themes to emerge were, in relation to services, being left very much to find out for oneself what was available, and in relation to the handicap, being given either no information, inadequate information, being given information in language which they could not understand, or about the lack of interest of the doctors concerned. Typical statements here were: "No one has discussed possible reasons for his condition or his prognosis. No one warned us what to expect," or "I have received very little information about my child's handicap, and most of what has been said has been told using such long medical words that I don't understand, anyway." Another feature of their comments was the oft repeated request to be told the truth, however unpalatable, e.g., "I think we should be told of our child's handicap. The truth, and medical jargon put aside. And told how to cope with it."

There was a depressing regularity about the parents' general comments which contrasted rather sharply with the more hopeful, if still far from satisfactory, picture given in the replies to the other sections of the questionnaire. Taken all in all, the survey indicated that from the parents' point of view there were very serious defects in the process of communication between themselves and the professionals paid to serve them.

The Response of the Authorities

We presented our Report to the Health Authorities, and to the Social Services and Education Departments. We made several recommendations aimed at improving the quality of information reaching parents. In relation to information about services we recommended that a local booklet be published for parents containing the appropriate information, and this was accepted and work has begun on its compilation.

It was not easy to find ways of trying to improve the quality of information from doctors to parents. Here we made a number of recommendations, but all were unacceptable to the Health Authorities. It is worth looking in some detail at the fate of these recommendations since they highlight some of the structural problems needing to be overcome before improvements can occur.

Firstly we suggested that a working party be set up to include Hospital Doctors and parents of handicapped children to examine in detail the problems of giving parents information about their child's condition. We did this because we wanted the doctors to hear for themselves what the parents were saying to us, and because we believed that even if no concrete proposals came from the working party, then at least the process of having taken part in it would be an educational process. The doctors refused to have anything to do with the idea.

They gave four reasons for their refusal: (a) they said that they already did give full and adequate information to parents, (b) that in any case parents often did not want to hear the truth about their child, (c) that parents with a handicapped child often felt angry and resentful and were therefore likely to be dissatisfied with any information they were given, however full, and (d) because certain organisational changes were taking place at the hospital which would improve matters, i.e., a children's assessment centre was being set up.

Certainly there has been a major organisational change at the hospital, and it remains to be seen what effect this will have. What is of particular interest to us here, however, are the other reasons given by the doctors, since they reveal some of the major obstacles in professional attitudes which somehow will have to be overcome before real improvements can occur.

Firstly, what is one to make of their assertion that they already gave parents full information, bearing in mind the massive evidence from the parents that this was not how they saw it? It need hardly be said that we believed that the doctors were speaking in good faith and that it seemed to us that they really did believe that they told parents what they wanted to know. Our explanation of this phenomenon would certainly partly include the fact that no doubt some parents may well have been told things which, in the shock of the moment, they had not retained, which was how the doctors themselves explained the discrepancy. But this explanation merely reminds us that giving emotionally loaded information is a complex process in which the information needs to be repeated over time and checked to see that it has been understood. The knowledge that emotionally upset parents do not always remember what they are told places a clear obligation on the professionals to find ways of ensuring that messages do get through, instead of accepting it as an immutable and unfortunate fact of life, as seems to us to sometimes happen now.

But this explanation of the discrepancy does not go far enough, and for a fuller understanding we must look to the two other reasons given by the doctors, namely that parents did not really want to hear the truth, and would still be dissatisfied even if they did. These two beliefs were held very strongly by practically everybody with whom we spoke in the health service, such that they clearly took

on the status of powerful sustaining myths, the more powerful because of the grain of truth contained within them. Taken together, these two myths effectively served a very useful purpose for the professionals.

Firstly, if you believe that parents do not really wish to hear the truth because of the pain it will cause them it makes it much easier for you as a professional to gloss over the details, especially unpalatable details, since it is by no means easy to face a parent with the pain of the truth. Here it must be remembered that, contrary to the myth, many parents specifically asked to be given the blunt truth about their child.

Secondly, if you believe that such parents are never satisfied anyway, it absolves you as a professional from examining your behaviour because you can always blame the patient for his lack of satisfaction. It was very much our impression that both these processes were at work, and that they seriously interfered with the giving of full information to parents.

A final part of the explanation for the discrepancy rests in the fact that very often the doctors did not have the information needed by parents, so could not give it, but they were reluctant to admit this to them. The result would be that details would again be blurred and parents would feel fobbed off.

It is clear from this discussion that the passing of information from doctor to patient in this, as in so many other contexts, is very complex. Doctors trained to diagnose and heal do not necessarily have sufficient expertise to communicate effectively with those whom they diagnose, and this by now commonplace observation must be taken more seriously by the medical profession.

The other two recommendations we made to overcome the information barrier were of a different kind. One was that whenever parents were told for the first time that their child might be severely handicapped they should be referred to the hospital social worker, in order that more time could be spent with them than doctors can usually give, and because of the particular skills of the social worker in interpersonal communication. This recommendation was not accepted, partly because of the new arrangements already referred to, but partly also because it was felt improper to interfere with the clinical judgment of the doctor, who alone should decide when such a referral was necessary. This raises two important issues, firstly the relationship between the various professional groups concerned, secondly the doctors' understanding of the role of social workers.

The first of these is again a rather hackneyed theme, but it demonstrates how far we still have to go before the old professional rivalries give way to a concern for the welfare of the patient. The doctors felt it was their prerogative to decide whether or not another professional, with different and in many ways more appropriate skills, should be involved in helping a family come to terms with the shock of being told that their child is handicapped, and the District Management Team saw itself as powerless to affect this decision.

Secondly, the other point which emerged from this discussion was the lack of understanding of some of the doctors about the place of counselling in health care. For instance, one paediatrician told us he did his own counselling, although he admitted that he saw his patients for "as much as" twenty minutes "as often as" every six weeks, with the clear implication that this would represent especially favourable treatment. If he had a really distressed patient he would, he assured us, refer him or her to their G.P., and this despite the presence of a social work department at the hospital!

Our second recommendation was that every family should be visited at home at least once a month during the first year after being given a diagnosis of serious handicap. This was refused on the somewhat discrepant grounds that Health Visitors already visited families as often as they needed it, which might often be more than once a month, and because such a policy would overstretch the manpower resources of the Health Visitors. The clinical judgment of the Health Visitors was given as a crucial deciding factor in rejecting this recommendation, with no awareness on the part of the administrators of the possibility or desirability of underpinning professional judgment with minimal requirement, as in, e.g., the statutory visiting of children boarded out. The main obstacle to accepting this recommendation appeared to be simply poor administration, since, in addition to the professional judgment argument, we were told that the manpower could not take the strain, but were given no figures as to the number of Health Visitors involved and the number of new referrals of seriously handicapped children each year to substantiate this assertion. Our estimate, which we believe is accurate, is that it would involve an average of well under one new case per Health Visitor per year, which is hardly an unmanageable burden.

Thus the suggestions we put forward for improving the quality of information reaching the parents were almost all turned down, though for a variety of reasons: a professional mythology which blamed the patient, inter-professional rivalries, the safeguarding of their position as clinical arbiters by doctors and Health Visitors, and an administration which dragged its feet.

One last point needs to be added to round off the explanation of the lack of progress of the recommendations. The survey from which the recommendations grew was carried out by the Community Health Council, and was presented as a report from the consumers to the providers of the services. It has been our firm impression, throughout all our discussions with the authorities, that this fact in itself was enough to ensure professional closed ranks in the face of the evidence. Certainly the report was critical in tone, which doubtless played a part in provoking a defensive response from the authorities, but it indicates how difficult it will be for those outside the professions to help to effect changes within them, and it is changes in professional attitudes, rather than mechanistic changes in policies, which will really result in the improvements which are so clearly needed.