

Personal practice

Putting it in writing

Written assessment reports for parents

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SUMMARY Parents of children attending for comprehensive assessment at a multidisciplinary child development centre were given written reports summarising the results of the assessment and their reactions to the reports were noted. Ninety eight of 115 parents were satisfied, 7 needed further explanation, 11 had some moderate difficulty, 9 parents found the written reports upsetting, and 8 found them very useful, on 133 occasions when reports were used.

The assessment report prepared for the parents was compared with that provided for the family doctor. Parents' reports were shorter, less technical, often had fewer results expressed numerically, and were sometimes modified so that the information was less distressing. This modification of information raises ethical questions and is not always effective.

The assessment team had some reservations about providing written reports but now feel that although judgement is needed in preparing these, reports are a useful addition to the assessment process. Written reports cannot, however, replace face to face consultation and counselling.

Parents and patients often do not remember accurately what doctors have told them;¹ putting this information in writing improves recall.² A previous survey of parents whose children attended Warwick Child Development Centre showed that parents' and doctors' views of the children's handicaps differed, often quite widely. Some parents wanted written reports, which have been shown to improve recall at Greenwood Children's Centre, Nottingham (unpublished data), and since 1980 we have been using this technique at Warwick. Recently I reviewed the processes involved, studying a sample of written reports.

Preschool assessment

Warwick Child Development Centre assesses preschool children with actual or suspected handicaps which are serious enough to affect schooling. The Table outlines the Centre's assessment and treatment programme. After the first case discussion and parental counselling the paediatrician prepares a report for the general practitioner using extracts and summaries from the Warwick team's reports. This

Table *Warwick Child Development Centre assessment and treatment programme for preschool children*

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| Detection. (Neonatal and preschool surveillance.) |
| Referral. (General practitioner→paediatrician→child development centre.) |
| First assessment. (Eight visits in two weeks.) |
| Case discussion. (Professionals' summaries presented and key worker selected.) |
| Counselling. (Parents told results by paediatrician and key worker.) |
| General practitioners' summary prepared. (Circulated to other agencies with permission from parents.) |
| Parents' summary prepared. (Modified from general practitioners' version.) |
| Summary delivered by key worker at home. (Comments noted.) |
| Follow up, treatment, and review assessment. (0 to 4 years) |
| School age. (Final report and discharge.) |

general practitioner's report (approximately 3000 to 4000 words long) is divided into: (1) diagnostic formulation, (2) associated problems, (3) skills and progress, (4) recommendations, (5) reassessment date, (6) counselling notes from parents' interview, (7) circulation list, (8) medical summary, (9) health visitor's report, and (10) individual child development centre team members' reports. It is repetitive, technical, contains numerical data, and gives subjective impressions of the family. Shorter, review assessment may be needed at 6 month or annual

intervals (with further reports) and a final report is prepared when school placement is being considered.

The paediatrician also compiles a written report for the parents from extracts which the Warwick team provide. Some team members reword their findings extensively for the purposes of the parents' report, some do not wish to contribute, and others provide their original report unaltered. The assessment team member most involved in follow up (key worker) may also edit this parents' version before giving it to them. The key worker then comments on the parents' reactions.

Parents' reactions

From 1980 to 1982, 133 parents' reports were prepared on 115 children (115 first and 18 review assessments). Most parents (98) were said to be satisfied with the report, 8 exceptionally so, but 7 needed considerable time to discuss technicalities and 11 had to have isolated difficulties and disagreements explained. Only on 9 occasions were parents seriously upset by results in writing. Their reactions included dissent ('Don't agree with a word of it'), sorrow ('Very depressing—I can't show my husband this'), agitation ('Questioned every word of the report') and hostility ('It's offensive—criticising us as parents'). Five of these 9 parents had already shown disquiet at counselling but in four this reaction was not anticipated.

Child development centre team reactions

At first the team had misgivings about providing written reports. Some professionals did not want numerical scores and quotients included, fearing misinterpretation—they used more general terms ('a little below average'), or age equivalent terms ('at a 3 year old level'). Other team members preferred quotients—maybe because these were less immediately obvious.

There was fear of betraying confidentiality—or rather, the reverse—that parents would become aware that private information was already being disseminated. Therapists also had reservations about including subjective impressions from general practitioners' reports in parents' reports ('she has always been extremely spoilt', 'a bizarre home situation'). Finally, therapists did not want a colleague to alter or summarise their reports, or were hurt if their findings, duplicated elsewhere, were not included.

These early uncertainties are being reconciled: team members participate in preparing reports and indicate what they do want included for parents,

though some prefer to omit their contribution. These issues recur in team discussions.

How information is altered

General practitioners' and parents' reports—two versions of a child's assessment—provide one instance of how medical information is conveyed. I recently compared a random sample of 32 of each. On one occasion only were the versions identical: the other 31 pairs of reports differed in length, technicality, amount of numerical results, content of potentially distressing information, and the extent of rewording or omission of team members' comments. There were also differences in these variables among parents' reports.

The differences between doctor and parent versions and between parents' versions were sometimes related to the child's handicap, the parents' social class, their acceptance of assessment, and whether they reacted painfully to seeing the results in writing.

Report length. The 32 parents' reports were often shorter than those for general practitioners as follows: same length (15), three quarters of length (12), two thirds of length (4), half of length (1)—none was longer. The higher social class families (I to III non-manual, inclusive) received longer reports, otherwise the length of the report was not related to other variables.

Numerical results. All numerical results were omitted in 8 parents' reports, some were missing in 17, but all were retained in 7. First assessment reports were less likely to contain numerical results than review reports: by then parents would be aware of the assessment process, and probably would share a common viewpoint of their child's handicap with the team. When the child's development quotient was less than 50, numerical results were less often given.

Technicalities. Technical terms such as 'anterior fontanelle', 'expressive language delay', or 'the SSD have overall management of the situation' were less common in the parents' version but were not always reworded and needed explanation when the key worker delivered the report. The reports for 9 parents were effectively 'jargon free', 9 had been altered but still contained technical terms, and 14 remained full of technicalities. There were more technical terms in the reports to which parents reacted unhappily.

Distressing information. Unexpectedly severe handicap or value judgements on family dynamics were

usually modified. Four general practitioners' reports did not contain any such information. Nine of the remaining 28 sets of reports had distressing information removed in the parents' version, in 8 this was retained, and in 11 this was reworded. Reports varied considerably in the amount of distressing information they contained; parents unsure of the need for assessment and those whose child had a development quotient of less than 50 were more likely to get reports with distressing information removed. Unexpectedly, reports for higher social class parents were more likely to have distressing information omitted. The parents who reacted unfavourably to reports did not receive an excess of unmodified, distressing information.

Team variation. The 32 reports for general practitioners contained 279 summaries provided by the assessment team—about 9 professional contributions for each child—and 57% remained unchanged in the parents' version. Nine parents' reports lacked the social worker's summary and 13 the health visitor's. Some team members almost always modified their comments extensively (speech therapists, health visitors), some never (audiologists), and the remainder varied between these extremes. Upper social class parents and those parents who accepted assessment need were more likely to get a social worker summary. There had been less rewording in the reports of parents who reacted unfavourably.

Discussion

Doctors and assessment centres vary considerably in the extent to which they use the written word to convey information. The new education act requires authorities to provide parents with the data on which remedial education decisions are made. We have found that our misgivings about written reports for parents have not been confirmed; they have proved useful and popular among parents. We include numerical results increasingly as parents do not misinterpret or find these alarming when they are suitably presented.

It is probably inevitable that some parents should react unfavourably to results in writing but part of this distress is preventable. Parents reacted unfavourably in 9 instances and this could have been anticipated in five. These 9 reports tended to be less modified, to contain more jargon and numerical results than the others, and their recipients were often of lower social class. The length of report, content of distressing information, a development quotient of less than 50, and the inclusion of the social worker's and health visitor's comments were

not associated with distress. The single factor that might have predicted distress most reliably was the readiness with which the parents had accepted the need for their child to be assessed. Reluctant parents were highly likely to react with distress to written reports. Unfortunately we did not, in this sample, modify the reports of such parents as perhaps we should have done.

Telling parents what we think is wrong with their child is associated with various dilemmas. We do not want to cause unnecessary pain when we share our suspicions with them. The import of our findings may be doubtful and though parents may be reluctant, we may need to assess the child again. Sometimes we suspect that the parents' inadequacies are related to their children's problems.

These difficulties explain partly why the parents' reports differ from those intended for general practitioners. The way we modify our findings can sometimes be highly effective; those which are technical or potentially hurtful may be explained without causing unnecessary distress or muddle. It is debatable whether value judgements should be included in the general practitioners' reports. One early tendency in preparing parents' reports was to omit altogether, or modify excessively, potentially distressing information. If the written report is prepared after the parents have been seen face to face in the counselling session, it is easier to decide to what extent painful data should be omitted or included in the report. Several interviews may be necessary and parents may need time to confirm for themselves the extent of their child's handicap. The balance between telling too much, too soon, and not telling enough is difficult, but it is, I think, necessary to convey concern.

Unless we *do* convince parents that there is a need for concern, they will not see the need for intervention or change, they may be uncooperative, and not keep appointments. This is more likely to happen if we carry to excess our tendency in communications with parents to be brief, to simplify, and to omit embarrassing data and numerical results, and if we cannot find ways of letting them know our thoughts about their skills and problems and how they affect their children's development. Sometimes we resist putting things in writing, not because we are afraid of being misunderstood but because we are afraid that we *may* be understood—it is not so easy to be vague and evasive in writing. I think that it is possible to express doubts openly—to admit that we cannot be sure what is wrong and how serious it may be—and we can also put these in writing. Written reports cannot replace the consultation and the skills of counselling but they can be a valuable asset.

References

- ¹ Ley P. Towards better doctor—patient communications. In: Bennett AE, ed. *Communications between doctor and patient*. Oxford: Nuffield Provincial Hospitals Trust, 1972:75–96.
- ² Gauld VA. Written advice: compliance and recall. *J R Coll Gen Pract* 1981;**31**:553–6.

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The problems associated with parents having the right to see medical reports about their children are discussed by H Jolly on pages 601–602.

Twenty five years ago

Nephrocalcinosis infantum

R A SHANKS AND A M MACDONALD (*Glasgow*)

‘Summary

Eight-four cases of nephrocalcinosis infantum have been encountered during the thirty-year period 1928–57 and of these 60 occurred in the last decade. It is thought that this indicates a true increase in the incidence. Most cases (70%) were found in the first year of life.

An early lesion in which calcium has not yet been deposited can be recognised.

Nephrocalcinosis infantum appears to be a benign lesion and unrelated to the cause of death. It is concluded that the lesion resolves spontaneously during the second year of life and is probably related to symptomless hypercalcaemia however caused.’

(But it is not always so benign. RONALD ILLINGWORTH)

Archives of Disease in Children 1959;**34**:115.