

Guidance Materials for Parents of Children with Clefts

HOWARD LEE WYLIE, M.D.
BETTY JANE McWILLIAMS, Ph.D.
Pittsburgh, Pennsylvania

This investigation resulted from an interest at the Cleft Palate Research Center, University of Pittsburgh, in developing an effective method of parent guidance. Initially, questions were raised regarding the advantages of resorting to certain printed materials designed to provide basic information about clefts, resulting handicaps, methods of treatment, prognosis, and psychological implications for parents and children.

As a first step in the process of determining the desirability of using such materials, a segment of the Center's clinical research group (a plastic surgeon, a psychiatrist, a clinical psychologist, and a speech pathologist) entered into preliminary discussions relative to the various implications of preparing and utilizing printed information designed to meet the needs of parents. At the outset, it was obvious to this group that parents and their children differ widely in major life dimensions and that, as the result of this, they have different problems to be met. Secondly, certain difficulties—such as hearing loss—which are likely to occur in many children, do, in reality, arise in a variety of sequences and according to differing time schedules. Added to these already awesome problems, was the recognition that parents were bound to react to printed materials in terms of their own previous experiences, education, knowledge about clefts, and both resolved and unresolved attitudes toward the particular child in question. However, in spite of this prior knowledge, it seemed that materials meant for general use would of necessity have to be geared to the 'average' parent of the 'average' child with cleft palate. This recognition led to still other even more specific questions that the group found almost impossible to deal with. We wondered how a team could prepare a pamphlet which would give just the proper amount of stress to each area of coverage and how we might avoid presenting a biased picture which reflected our own particular interests and competencies. If we could resolve this initial dilemma, we would then be faced with the even greater one of deciding when

Dr. Wylie is Clinical Assistant Professor of Child Psychiatry and Dr. McWilliams is Associate Professor of Speech, University of Pittsburgh. Both authors are associated with the University of Pittsburgh Cleft Palate Research Center.

This paper was supported by National Institutes of Health Research Grant DE-01503.

parents should be given certain information, which bits and pieces of information might lead parents to new insights, and which might lead them to unnecessary worry about matters of no concern to their particular child or, on the other hand, might lull them into a false sense of security. We felt unable to predict how parents might respond to the information provided in a printed pamphlet.

As we discussed these difficulties, three basic questions emerged: a) How can one piece of literature deal effectively with all possible combinations of problems? b) How can a publication be developed to reflect team thinking in a truly unified and well-integrated manner? c) How will the parents for whom the information is meant react to what they read?

It appeared that there were two basic approaches to these problems. First, authors of such material might try to include everything available. Secondly, they might select certain things as being relatively more important than certain other things. This selection might be done on the basis of known statistical frequency of occurrence of certain problems in children and/or in their parents. The selection might also take place on the basis of the professional philosophy and training of the author or authors, or empirical evidence of important areas to be included might be employed. Whichever method might be selected, it was logical to assume that there would be a certain lack of focus in the resulting end product.

The questions and doubts expressed by the discussion group led to the decision that no one was quite ready to commit himself to preparing capsulated counseling materials for parents who, so far as we knew, were similar to each other only to the extent that they had a child with some type of cleft. Therefore, it was decided that two of the discussion group would contact the departments of health in the 50 states and the 78 cleft palate clinics listed in the 1963 *Directory* of the American Cleft Palate Association in an effort to learn what materials they had prepared for use in their particular programs and how they had dealt with the three problems which we faced.

Results

Twenty-five of the 50 states responded, and 23 of the 78 clinics answered the letter of inquiry. The materials received from these 48 facilities are summarized in the annotated bibliography appearing in the Appendix.

Seventeen of the facilities which responded reported that they used no such material at all. This was the most frequent reply received. Most of these offered no explanation for not having adopted or developed such information. A few replied to the effect that they felt some dissatisfaction in this area and were currently attempting to decide what ought to be

done. One reported that they had unpublished material which they were in the process of formalizing.

Ten respondents reported the use of McDonald's *Bright Promise*; more respondents named this publication than any other. Several clinics added the unsolicited comment that they had found this helpful and planned to go on using it. One clinic reported that, while they used it and liked it on the whole, they had learned that it was not equally applicable to all parents and had found that they must exercise judgment in distribution.

The second most frequently reported publication was the Children's Bureau Folder No. 37 entitled *The Child with a Cleft Palate*. This was reported by seven organizations.

Each additional publication named was used by only one or two groups. Twenty-six clinics had materials unique to their particular programs. In all, the 31 groups who replied that they used some form of printed material listed a total of 44 publications, indicating that a few were using more than one.

Reference to the Appendix will reveal that informative materials for parents have been developed with at least three different goals in mind. Some are meant to provide a brief, concise overview of the problem. Others are written about the scope of activities of a specific clinic and are designed to orient the parent to a set of experiences which he has had in the past or soon will have. Still others are designed to deal with isolated problems such as feeding or speech or dental care.

It is important to note that the two most frequently named publications are general in nature and are sufficiently broad in concept so as not to come into conflict with existing policies in particular clinics. *Bright Promise*, written by a speech pathologist, discusses possible causes of cleft palate, what a cleft is, what it means, repair, speech, intelligence, hearing, dental problems, and personality development. This is accomplished in an easy, relaxed manner. It is not a 'do-it-yourself' manual and so does not attempt to tell parents *how* to prepare a child for hospitalization, *how* to feed him, or *what*, specifically, to do for his speech. The pamphlet was written to help with the emotional reactions to having a child with a cleft. The author's thesis is that parents are fearful and worried because they are uninformed and that many of the fears and worries can be dispelled by giving them appropriate information. Most of the examples in the book are drawn from individual or group meetings with psychologists. The implication is that the author sees the need for personal involvement in counseling and that the booklet is an effort to extend this kind of program to a wider group of parents.

The Child with a Cleft Palate, published by the Children's Bureau in 1953, was the second most frequently selected publication. This is a relatively brief pamphlet incorporating fifteen sub-headings. Because

of the brevity of the booklet, various topics are discussed in a general manner. It is possible that this may provide something for the parent to grasp, provided that it is combined with personal counseling and conversation about specific problems where the need arises. Like most of the materials reviewed, it attempts to offer such a quantity of information for the uninformed parent that there is the real possibility that it may raise more questions than it answers.

An outstanding example of materials designed to serve the needs of a particular clinic is the series of six letters written by a speech pathologist and designed for use by a state crippled children's agency. These letters prepare parents for what is to come and review with them what has previously occurred. The material suggests activities designed to help the child with speech development but never do the instructions become overwhelming or confusing.

Discussion

After spending many hours reading, abstracting, and discussing information covered in the printed materials submitted for review, we must conclude that our original three basic questions have not been satisfactorily answered.

Originally, we wondered how a single piece of literature could deal effectively with all possible combinations of problems. No single publication succeeded in offering information that a particular parent could apply without alteration to his own child. For many parents, it was apparent that too much material was provided too early, perhaps at a time when the parent was not even sufficiently knowledgeable to ask appropriate questions even if he were in a position to discuss his problems with the proper professional people. Since, in the general literature, many areas were developed in a minimal way, some parents were almost bound to be attracted by aspects of the problem with which there would be no real need for them to become involved. On the other hand, the more restricted materials—such as those related to feeding—might prove helpful at a given time in a child's life but could hardly be construed as adequate to take care of other aspects of the cleft condition. None of the materials dealt in depth with the subject matter under consideration. It appears then, at best, that they could be helpful only until the parents' needs became more complex. This may be the reason for one surgeon's comment to the effect that he found such publications of value in the very beginning but rarely used them later on or in the absence of qualified people with whom the parents might talk from time to time.

Our second question had to do with the development of a publication which would adequately reflect team thinking. Reference to the Appendix shows that many of the materials do not list an author or authors. Where the authors are included, the names of people from speech

pathology appear frequently in connection with materials which are not primarily concerned with speech. Although much attention is given to the 'feelings' of parents and to the goal of modifying certain mal-attitudes, there is no evidence that psychiatrists have cooperated in the writing and clinical psychologists appear as authors only rarely. While it would be unwise to draw conclusions from a survey of this kind, the inference can be made that the speech pathologist often speaks for the cleft palate team and that, as a result of this, speech *per se* may be given relatively greater weight in literature for parents than are some other phases of management.

This leads quite naturally to the conclusion that materials are usually included on the basis of author bias. In addition, since the most recent of the publications is now five years old, and one was written twenty-one years ago, it seems likely that there will be conflicts among the various publications and with more recently emerging philosophies and plans of treatment.

Our third question dealt with the manner in which parents were likely to respond to what they read. We found no evidence to suggest that these materials had been 'consumer tested' on parents from various educational, socio-economic, cultural, and personality groups. Some parents, it would seem, might be unable to read even the simplest of the materials and would be overwhelmed by the more complicated things, particularly those designed to instruct them in certain aspects of rehabilitation. Other mothers and fathers, particularly if they were exposed to several different publications, might well wonder about the wisdom of subjecting children to treatment in the hands of people who seem unable to agree among themselves about how often clefts occur; at what age they ought to be repaired; *if* they ought to be repaired; whether there will or will not be resulting speech problems; whether there are or are not concomitant problems such as hearing loss, mental retardation, and other physical anomalies; and by what mechanism emotional deficits enter the picture. In short, there is such a diversity of opinion expressed in these publications that it requires a somewhat sophisticated reader—and perhaps one not involved emotionally—to understand that this body of literature reflects the diversity of opinion prevalent in the field of cleft palate rehabilitation. Parents, often even those with professional training themselves, are seldom able to bring sufficient objectivity to their children's problems to make this kind of evaluation possible.

In much of the information provided for parents (particularly that dealing with speech) the implication in one paragraph is that the parent is totally uninformed about clefts; but in the next paragraph he is told that he must take over and manage the child's therapy program even to diagnosing such nebulous conditions as 'nasality' and articulation disorders. The procedures which he is supposed to follow are not always clearly spelled out, sometimes have a poor theoretical foundation, and

might well render the experienced clinician confused and uncertain as to what is expected. Unfortunately, the same criticism applies to much that is written about 'handling' feelings. Most intelligent people know that there is no logical reason in the world for the panic that accompanies claustrophobia; but many intelligent people suffer from claustrophobia, and telling them not to does not make them less afraid the next time they are faced with entering a crowded elevator. Yet it is exactly this kind of help that is usually given to parents. They are told that they will feel guilty but that they must not if they are to avoid doing permanent damage to the cleft-palate child's personality. This would seem to add up to double guilt for the parent who is unable to quiet his initial guilt. He must now, if the books are right, worry about the way in which he is destroying his child already into trouble enough because of his cleft.

These criticisms of the materials available for the parents of children with clefts should not be interpreted to mean that we dispute the basic truth of much that has been written in order to help parents come to terms with a difficult problem. However, after careful consideration, we must conclude that no one has yet succeeded in preparing materials which adequately meet the counseling needs of the vast majority of parents. There seems to be no substitute for the personal involvement of qualified clinicians and, further, the most successful printed materials appear to be those which are used as adjuncts rather than as primary sources of aid. While the work to date on materials for parents reflects much thought and concern for the problems encountered, it is our opinion that further attention should be given to publications which are tailor-made to a particular clinic and its philosophy, to appropriately timed and somewhat specific information as opposed to broad general coverage, and to printed literature in combination with ongoing personal contacts with parents and children.

*Cleft Palate Research Center
Salk Hall, University of Pittsburgh
Pittsburgh, Pennsylvania*

APPENDIX: Parent guidance materials used by 48 state and local cleft palate clinics. All materials were submitted by users to authors for review.

| <i>Title</i> | <i>Author(s) and Degree</i> | <i>Publisher</i> | <i>Publication Date</i> | <i>No. of Pages</i> | <i>Emphasis</i> | <i>Number Reporting</i> |
|------------------------------------------------------------------------|-------------------------------------------|--------------------------------------------------------------------------------------------------------------------|-------------------------|---------------------|-----------------|-------------------------|
| Bright Promise | Eugene McDonald, DEd | The National Society for Crippled Children and Adults, Inc., Chicago, Ill. | 1959 | 21 | general | 10 |
| The Child with a Cleft Palate (Children's Bureau Folder No. 37) | not given | U.S. Dept. of Health, Education, and Welfare, Social Security Administration, Children's Bureau, Washington, D. C. | 1953 | 13 | general | 7 |
| About Children with Cleft Lips and Cleft Palates (A Guide for Parents) | Eugene McDonald, DEd | Pennsylvania Society for Crippled Children and Adults, Inc., Harrisburg, Pa. | 1956 | 15 | general | 2 |
| Helpful Hints for the Child Who Does Not Chew or Swallow Easily | not given | New Mexico Dept. of Public Health, Santa Fe, N. Mex. | not given | 8 | feeding | 2 |
| Speech Training for Cleft Palate Children | T. G. Blocker, MD Virginia Blocker, MD | University of Texas, School of Medicine, Galveston, Tex. | 1948 | 43 | speech | 2 |
| The Child with a Cleft Palate | Ollie Backus, PhD and others | University of Michigan, Ann Arbor, Mich. | 1943 | 33 | general, speech | 2 |
| We Learn About Our Speech | June Smith, EdD and others | Lancaster Cleft Palate Clinic, Inc., Lancaster, Pa. | 1952 | 40 | speech | 2 |
| Advice to Parents of Cleft Lip and Cleft Palate Children | not given | Hospital for Sick Children, Toronto, Ontario | not given | 6 | general | 1 |
| Aids in Speech for the Cleft Palate Child (Age up to two years) | not given | Hospital for Sick Children, Toronto, Ontario | not given | 6 | speech | 1 |

APPENDIX: Continued.

| <i>Title</i> | <i>Author(s) and Degree</i> | <i>Publisher</i> | <i>Publication Date</i> | <i>No. of Pages</i> | <i>Emphasis</i> | <i>Number Reporting</i> |
|----------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------|---------------------|--------------------------------------------------------|-------------------------|
| Aids in Speech for the Cleft Palate Child (Ages two to five years) Cleft Lip and Cleft Palate | Margaret Hamlin, LCST not given | Hospital for Sick Children, Toronto, Ontario Pennsylvania Dept. of Health, Div. of Maternal and Child Health, Cleft Palate Division, Harrisburg, Pa. | not given not given | 36 6 | speech general | 1 1 |
| Cleft Lip and Palate Rehabilitation Cleft Lip and Palate in the Total Health Program Cleft Palate Center | Wm. H. Porterfield, MD and others Olga M. Chernek Ermal O'Brian J. A. Salzmann | <i>The Ohio State Medical Journal</i> not given Mt. Sinai Hospital, New York, N. Y. Children's Hospital, Los Angeles, Calif. | 1961 not given not given | 2 3 8 | team approach general clinic orientation | 1 1 1 |
| Cleft Palate Rehabilitation Seminar Feeding Cleft Palate Children | not given not given | Div. of Crippled Children and Nutrition Services, State Board of Health, Dover, Del. Dept. of Health and Welfare, Div. of Maternal and Child Health Nutrition Service, Augusta, Maine | not given not given | 10 | feeding | 1 |
| Feeding the Child with a Cleft Palate | not given | | not given | 5 | feeding | 1 |

| | | | | | | |
|--------------------------------------------------------|--------------------------------------------------|-----------------------------------------------------------------------------|-----------|----|-----------------------------|---|
| Feeding the Child with a Cleft Palate | Mayton Zickefoose | <i>Journal of the American Dietetics Association</i> | 1960 | 6 | feeding | 1 |
| Food for the Child Who Does Not Chew or Swallow Easily | not given | New Mexico Dept. of Public Health | 1958 | 4 | diet, feeding | 1 |
| Happiness is a Boy Named Terrel | not given | The Native Sons of the Golden West, San Francisco, Calif. | not given | 6 | general, fund raising | 1 |
| J. Sutton Regan Cleft Palate Foundation | not given | J. Sutton Regan Cleft Palate Foundation, Buffalo, N. Y. | not given | 3 | clinic orientation | 1 |
| Nassau Cleft Palate Rehabilitation Center | not given | Nassau Cleft Palate Rehabilitation Center, Hempstead, N. Y. | not given | 6 | clinic orientation | 1 |
| Rehabilitation of the Cleft Palate Child | Wm. E. Mosher, MD | <i>Health News</i> , New York | 1956 | 10 | general, clinic orientation | 1 |
| Ronnie Visits the Cleft Palate Clinic | not given | Physical Restoration Division, Dept. of Public Health, Regina, Saskatchewan | not given | 4 | clinic orientation | 1 |
| Series of six letters | Herold Lillywhite, PhD | University of Oregon, Portland, Ore. | not given | 23 | clinic orientation, speech | 1 |
| Services of the Cleft Palate Team | Barton H. Fahlgren, MSW | Public Welfare Board of North Dakota | 1960 | 6 | general | 1 |
| Speech Training for Cleft Palate Children | Charlotte G. Wells, PhD Gretchen M. Phair, MS | Dept. of Public Instruction, Bureau for Handicapped Children, Madison, Wis. | 1957 | 51 | speech | 1 |
| Suggestions for Parents | not given | Montreal Children's Hospital, Montreal, Quebec | not given | 1 | diet, dental care | 1 |

APPENDIX: Continued.

| <i>Title</i> | <i>Author(s) and Degree</i> | <i>Publisher</i> | <i>Publication Date</i> | <i>No. of Pages</i> | <i>Emphasis</i> | <i>Number Reporting</i> |
|-------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------|-------------------------|---------------------|-------------------------------|-------------------------|
| The Care of the Child with the Cleft Lip and Palate This is Laurie | not given (written in French and English) not given | Montreal Children's Hospital, Montreal, Quebec Soroptimist International of Coral Gables, Fla. | not given not given | 8 2 | general general | 1 1 |
| Typical Program of Management for Patients with Cleft Lips and Palates What About the Child with Cleft Palate? | not given not given | University of Iowa, Iowa City, Iowa Dept. of Public Health Division of Maternal & Child Health Services, Mass. | 1962 not given | 3 16 | clinic orientation general | 1 1 |
| What Do You Know About the Problems of the Cleft Palate Child? | not given | University of California School of Dentistry, San Francisco, Calif. | not given | 18 | general | 1 |