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#### **ABSTRACT**

The study surveyed the informational needs of parents (N=367) of children, ages birth to 8 years, with disabilities and developmental delay. The questionnaire used, revised for this study, attempted to determine information needs by asking about interests and problems in child rearing through the use of "titles" of articles. It also surveyed attitudes and demographic information. Results are summarized for interests, problems, and preferred sources of information by the following categories: fathers and mothers combined; mothers versus fathers; mothers' level of education; mothers' race; mothers' marital status; age of child; gender of child: number of children; child rearing attitudes. Over half the parents expressed a strong concern over whether they could help their children reach their full potential. High readership ratings were given to titles about helping their special needs child adjust, building their child's self-confidence, enhancing learning and academic skills, developing imagination, and discipline. Strong irterest was expressed in learning how to deal with the emotional highs and lows of parenting a child with special needs. Mothers with less than a high school education differed from other groups in preferring to get child rearing information from family and friends. In general, parents preferred different sources for information on different parenting topics. The questionnaire is appended. (Includes 33 references.) (DB)

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# Informational Needs of Parents of Young Children with Special

Needs: Technical Report

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Running Head: Informational Needs

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Informational Needs of Parents of Young Children with Special Needs

### Introduction

All parents need and want information regarding various aspects of parenting. This need is especially significant for parents of children who have disabilities or are experiencing developmental delays. Parents of normally developing children have a variety of resources for information to guide their childrearing efforts. Numerous books on child development and parenting can be found at bookstores and newsstands. They can draw upon their previous experiences with, and observations of, other children for information about developmental milestones and typical child behavior. Friends and families can be turned to for advice on parenting.

Although these resources can provide much information that is of value to parents of children with special needs as well, they are not sufficient and sometimes are not appropriate. For instance, children with disabilities often follow the same sequences of development as do normally developing children (Wachs & Sheehan, 1988). But since they usually follow these sequences at a slower rate, books which tie developmental milestones to particular ages are not satisfactory. Normal parenting techniques, such as the use of reinforcement to manage behavior, are appropriate for all children, but most children with disabilities require special parenting techniques as well. To meet their children's needs, parents of children with disabilities and developmental delays also require information about special resources such as community programs, financial assistance, and the legal rights of their children.

Recent federal legislation also highlights the informational needs of parents of children with special needs. Public Law 99-457, the 1986 amendments to the Education of all Handicapped Children Act of 1985 (P.L. 94-142), recognized the rightful role of parents as the primary decision-makers regarding the care and education of their young children. This legislation is in step with the growing trend toward enabling and empowering parents to seek and select services and to advocate for their own children (e.g., Dunst, Trivette, & Deal, 1988). Parents are no longer viewed as passive recipients of parent training and services, but as active decision-makers. In order to make informed decisions, parents need information about child development, parenting, and resources for them and their children.

The purpose of this study was to survey the informational needs of fathers and mothers of children, ages birth to eight years, who have disabilities and developmental delays. The intent was to yield results which can guide the development and mobilization of parenting information by professionals so that the desired information is readily available to parents. The study employed an expanded and slightly revised version of the questionnaire used in a survey of the informational needs of mothers from the



general population who had children ages birth through three years (Sparling, Lowman, Lewis, & Bartel, 1979; Sparling & Lowman, 1983).

The study also assessed parents' preferences regarding sources for different types of information. It is not enough to simply amass information on topics of interest to parents of children with special needs. This information needs to be available through the channels which parents find most helpful and desirable. In an earlier study (Sparling, 1976), parents reported that they frequently obtained information about children from their friends and family, books, doctors, and television. In the present study, parents were asked which sources they would prefer to use to obtain information about a variety of topics related to childrearing.

In their survey of parents from the general population, Sparling et al. (1979) found that parents' informational needs and preferred sources for information differed as a function of certain family characteristics. For instance, parents with lower levels of education and income expressed more interest than did middle-class parents in topics related to promoting health. Therefore, in this study interest in gaining information regarding various topics and through various channels was examined for different subgroups of parents (e.g., mothers versus fathers, single mothers versus mothers with partners).

### Method

### Subjects

The subjects for this study were 367 parents of children with special needs ages birth to eight years. The parents were recruited through the network of Handicapped Children's Early Education Program's (HCEEP) demonstracion projects. The HCEEP program was established 17 years ago with a mandate to develop model demonstration programs for the delivery of special education and related services to young children with disabilities from birth through the third grade. The projects provide services for all of the major handicapping conditions including at risk, other health impaired, orthopedically impaired, trainable and educable mentally retarded, visually impaired, deaf/hearing impaired, deaf-blind, emotional/behaviorally disturbed, speech/language impaired, specific learning disabilities, and multiply handicapped. Projects are located in rural areas, inner cities, small towns, and suburban communities throughout the United States. The children and families served have diverse social, ethnic, and economic backgrounds. It was because of the diversity of parents and children served, as well as the broad geographic coverage of the projects, that the HCEEP network was selected as the recruiting focus.

Of the 83 HCEEP projects contacted, 23 were deleted for the following reasons: 7 would not be serving parents until after data collection was completed, 1 project was bankrupt, and 15 because the program or the population served were felt by the directors to be inappropriate for inclusion in this study. For example, two programs were television projects with no direct contact with parents and three programs served substance abusing



mothers with low reading levels.

These deletions left 60 available, appropriate demonstration projects of which 37 projects (62%) participated and 23 (38%) declined because the project's staff or the parents were overcommitted. In addition to the 37 participating demonstration projects, four similar projects related to participating projects volunteered for the study bringing the final total to 41 projects.

Of the 567 parents who consented to be in the study, 374 (66%) returned completed questionnaires. Five of the responding parents were later deleted because their children were too old, and two were deleted because their questionnaires were not fully completed. The final sample of 367 parents included 267 mothers and 100 fathers. The response rates by project ranged from a high of 100% to a low of 25% with a mean of 74%.

Demographic characteristics of the sample. Data on demographic characteristics of the fathers and mothers in the study are reported in Table 1. The majority of the respondents had more than one child and were between ages 20 and 39 years, Caucasian, married, and of middle socioeconomic status. As might be expected, the family income of single mothers was substantially below that of married mothers. Approximately 65% of the single mothers had incomes of less than \$10,999, while only 10% of the married mothers fell in this category. Slightly more than one half of the mothers reported that they were not employed outside of the home. The children with special needs ranged in age from birth to eight years; there were somewhat more males than females.

#### Procedure

A letter requesting project participation, an abstract describing the study, and a consent form were sent to the directors of each of the HCEEP demonstration projects. Follow-up phone calls were made to each of the project directors to ensure receipt of the materials and to answer any questions that they might have had regarding the study. Follow-up calls to encourage participation, as well as duplicate materials, were sent to the projects as needed.

Once the project consent forms were received, materials were sent to the parents involved with each of the consenting projects. Parent recruitment materials included a letter describing the study and requesting participation, and a consent form. Once parental consent was obtained, the projects either provided us with a listing of the parents' addresses so that correspondence could be sent directly, or they distributed the questionnaires to the parents.

If the questionnaire was not received back from the parent within a reasonable time, a second questionnaire and a follow-up letter were sent. Several weeks after the first follow-up, a second follow-up letter encouraging the return of the questionnaire, completed or not, was sent to all of the parents who had not yet retuned their questionnaire.



Demographic Characteristics of Parents and Children

Table 1.

			hers - 267)		Fathers $(n = 100)$	
			Percent	N	Percent	
Race:	White	229	88	90	92	
	Nonwhite	31	12	8	8	
Marital Status:	Married	212	80	100	100	
	Single	52	20	0	0	
Age Group:	< 20 years	3	1	0	0	
	20-39 years	227	87	79	81	
	> 39 years	31	12	18	19	
Living Situation:	Alone	34	13	0	0	
	With Other	18	7	0	0	
	With Spouse	212	80	100	100	
Education Level:	< High School	20	8	4	4	
	High School Diploma	63	24	10	10	
	Post High School	102	38	44	44	
	College Degree	80	30	42	42	
Employment Status:	Unemployed	149	57	6	6	
	Part-time	64	25	2	2	
	Full-time	46	18	90	92	
Family Income:	< \$11,000	55	21	4	4	
	\$11,000 - 29,000	100	39	46	48	
	\$29,000 - 47,000	73	28	36	37	
	> \$47,000	30	12	11	11	
Special Needs Child		212	86	94	97	
of Present Marriage	? No	35	14	3	3	
Child's Age:	G-35 mos	99	37	43	43	
	36-59	103	39	28	28	
	60-96	64	24	29	29	
Child's Sex:	F	104	39	45	45	
•	M	161	61	55	55	
Race of Child:	White	225	87	92	94	
	Nonwhite	34	13	6	6	
No. of Other Childr	en 0	67	25	25	25	
in Family:	> 0	196	75	74	75	

Note: There are missing data for some items.



### Instrument

The instrument which was used was a revised version of the one used by Sparling and his associates in their national survey of parents from the general population (Sparling et al., 1979). Information needs are difficult to determine directly by questionnaire. The necessity of collecting data rapidly (and typically without personal contact) led in the present study, and its precursor, to the strategy of avoiding the direct use of the "needs" concept. Instead, two other related concepts from which needs might be inferred were employed. The related concepts used in developing the instrument were interests (information topics) and problems (in child rearing). While an adequate theory or knowledge base is not available regarding the relationship of these concepts, it seems likely that needs incorporate all problems and some interests.

Fc some needs (as problems), individuals have a negative awareness. For some (as interests), they have a positive awareness. And for some needs, they may have no direct awareness. An example of this last group is illustrated by parents' need for information about the effects of sorbitch on toddlers whether or not they have ever heard of the substance. These parents, however, may have an expressed need for information regarding their children's health needs. These various types of needs, and there may be others, make it difficult for the respondent to answer the straightforward question, "What are your information needs?," without an interviewer who can help them explore the issue.

By measuring interests and problems, the present instrument taps the two major aspects of informational needs to which the parent can readily respond. The instrument is flawed by its inability to assess parents' informational needs which are not covered by the finite set of items included in the questionnaire. However, this flaw is accepted since a much more expensive and complex approach involving personal interviews would have been required to remedy it.

In addition to the two aspects of need (i.e., interests and problems), the questionnaire assessed parents' attitudes about childrearing and preferences for informational sources as well as collecting demographic information about the parents and their special needs child. Preferences for sources of information can determine which information channels will be "open" and how much information may be received in response to need. Attitudes about childrearing and certain demographic variables were assessed because they may serve as mediators of parents' informational needs. The five sections of the questionnaire (interests, problems, attitudes, informational sources, and demographic information) will be described in more detail below.

### Design of the Original Questionnaire

The questionnaire used in the present study is a slightly modified version of an instrument used with a large national sample of parents of



children without disabilities (Sparling et al., 1979). It includes five parts made up of closed-ended questions. The first part assesses parents' information-seeking interests. The second part is an assessment of parents' problems. The third focuses on parent attitudes. The fourth part identifies the sources of information which parents prefer. And the fifth part gathers demographic information on the parents, child, and family. The design of the original questionnaire is described below. Revisions which were made for the present study are described in the next section.

Interests. Title rating, a technique used by the U.S. Information Agency, among others, was the model for the part of the questionnaire measuring parent interests. In title rating, a story or topic--real or hypothetical--is given a descriptive title. A respondent is asked to rate the title according to his or her interest in reading it. A typical instruction is:

If you are completely sure you would want to read the article, score it 100. If you are completely sure you would not want to read it, score it 0. If you are not completely sure, use any number between 0 and 100 that best expresses your interest in reading the article. You may use any number as often as you like (Stevenson, 1977, p.17).

A series of studies has shown that any message that can be expressed as a verbal concept can be accurately pretested for audience interest and give substantially the same results as testing the whole message (Haskins, 1975). Title rating in the present study, for example, meant that parents were asked how much they would like to read an article entitled "Build Your Child's Self-Confidence" rather than being asked if more information on self-confidence were needed.

When a 100-point interest scale is used, as in this survey, the estimated readership of an article is the proportion of respondents who score it 90 or higher. Validation studies of the scale have shown that the mean error of prediction is about 6-7% (Haskins, 1975; McLaughlin, Haskins & Feinberg, 1970; Stevenson, 1973) which is only slightly higher than the sampling variation from one through-the-book survey to another. In through-the-book surveys, recipients of an actual publication are interviewed in person several days after receiving the publication. With the interviewer, they go through the publication (or book) page by page, indicating which specific articles they have read (Stevenson, 1977, p. 1). These timeconsuming surveys are considered to give very accurate readership estimates.

<u>Problems</u>. The second part of the questionnaire explored information needs that are not based on interests--but on worries, concerns or problems. Part II was designed to cover content similar to the interests section but from a problem perspective. It was hoped that by offering these two perspectives, a fuller range of parents' informational needs would be detected.

Warner, Murray, & Palmour (1973) in a survey of the informational needs of Baltimore residents found that less than ten percent of those surveyed



indicated a need for more information about education or child care. Yet Dervin (1976) found that problems about child care, family, and "personal" ranked high among those cited by a cross section of Seattle residents. One explanation for these differences, anticipated by Warner et al., (1973) is that many people (particularly the urban poor) may not relate information to the solution of their problems; they express their problems as complaints, rather than as a need for help or information. Therefore, survey respondents may answer questions about the kinds of information they want quite differently from the way they will answer questions about what kinds of needs or problems they have. This distinction was interpreted by the present investigators as having implications for the way in which survey questions are worded and resulted in a dual approach (using both interests and problems) to attempt to elicit the maximum response from both middle- and lower-class respondents. The topics included in the problems section of the questionnaire were derived from a study of concerns expressed by mothers of newborns (Granoff, 1977) and a report that categorized the problems parents "called-in" to a large pediatric practice (Mesibov, Schroeder, & Wesson, 1977). Additional problems specific to rearing children with disabilities were selected, using the process described below.

Attitudes. A pilot test regarding parent attitudes grew out of an investigation of home-school interaction (Schaefer & Edgerton, 1979) through which approximately 400 parents had been previously interviewed over a three-year period. In the Schaefer study, parental attitudes were correlated with children's school achievement and classroom behaviors as rated by the teacher. Three areas were covered in these interviews--early educational experiences, the importance of family privacy, and traditional educational philosophy.

A factor analysis of all of the parental attitudes scales and items yielded a large, general factor, traditionalism. Lower scores on this factor (replicated over the three years with increasingly heterogeneous populations) were seen to predict higher school achievement scores. The traditionalism scores represented the sum of the following seven scales, each composed of at least three items: parent authority is absolute, aim of education is to instill information, children learn passively, all children should be treated the same, teachers' authority is absolute, children misbehave if allowed to, and children are born bad. Respondents with scores higher than one standard deviation above the mean were designated "high-traditional"; those with scores lower than one standard deviation below the mean, "low-traditional." Another factor, conformity, which correlated .55 and .58 with traditionalism, was used in the substudy to expand the subject pool.

Sparling and his associates (e.g., Sparling et al., 1979) felt that a traditionalism scale would be a useful addition to their national survey to reveal what relationship there might be between traditionalism scores and interest in informational topics. They conducted telephone interviews with twelve of Schaefer's subjects who scored low on traditionalism and an equal number who scored high on traditionalism or related factors such as conformity. Each subject was asked to indicate the preferred member of ten pairs of information topics. One topic in each pair represented an



information interest which Sparling and his associates thought might be related to traditional education attitudes, while the other topic was thought to be related to progressive attitudes. No respondent during the 5-minute interview had difficulty understanding the procedure, though occasionally an item had to be repeated.

One item was omitted from the analysis because all respondents chose the same alternative in answering it. The group identified by their high-traditional attitudes chose an average of 4.75 of the information topics assumed to be traditional and 4.25 of the information topics assumed to be progressive. The low-traditional parents chose an average of 3.25 traditional information topics and 5.75 progressive topics. These "traditional information scores" correlated .31 with the traditional attitude scores obtained more than a year earlier through the Schaefer and Edgerton (1979) study.

The telephone survey results indicated that general values and beliefs such as traditionalism are somewhat stable over time and have some relationship to information interests in that the obtained correlations were in the appropriate direction. Based on these results, two brief attitude scales were adapted from Schaefer's items and were added to the original national survey instrument. One of these was retained in the revised instrument used in the present study. (A copy of the revised instrument is presented in Appendix A.)

Sources of information. The Sparling et al. (1979) survey included a section on the parents' preferences regarding sources or channels of information in order to guide the users of the survey results in designing appropriate information dissemination strategies. An earlier study (Sparling, 1976) revealed that a broad spectrum of information sources including both interpersonal sources and media sources were used by parents. This same study showed that various channels were content-specific. That is, they tended to carry only one or two types of information.

As a result, the original questionnaire, as well as the revised questionnaires used in the present study, asked parents to fill in a simple matrix which paired information sources with information topics. Parents were asked to say where they would like to get various types of information, even if information was not currently available from that source. This "ideal" response was used in order to give users of the survey results a goal to strive for rather than a report of current information limits.

<u>Demographic information</u>. Sparling et al. (1979) reported that previous studies (e.g., Walters, 1977) had found that the demographic characteristics of parents were associated with differences in information interests, therefore, they included in their questionnaire several questions to gather descriptive information on the parents, child, and family. Similar information was gathered in the present study.



## Revisions Needed for the Present Study

Revisions in the original questionnaire were guided by a literature review, critique from parents and professionals, and pilot testing. Research focusing on children with disabilities and their families indicates that, in addition to the normal stages and tasks of development, these families face additional challenges which create special informational and service needs (Battle, 1974; Travis, 1976; McKeith, 1973). The review of literature confirmed the need for research on information needs for parents of special children and suggested that these parents have particular and specialized needs in the broad areas of understanding their child's condition and physical health, community resources, child adjustment, and parental emotional adjustment (Moroney, 1981; Peterson, 1987).

Advisory groups. To translate these broad topics into survey items and to provide ongoing guidance for the instrument development process, an Advisory Committee was convened consisting of four parents of special children, a developmental day care director, and three university professionals who specialized in developmental disabilities. These experienced individuals made recommendations regarding the desirable features of a survey instrument for parents of children with disabilities, the process of making contacts and securing permissions, and the content of the questionnaire.

Seven professionals from the OSEP/HCEEP network also provided comment and critique on the same general survey considerations. Contacts were made and feedback received by mail and telephone. In the process it became clear that certain additions would have to be made to the original questionnaire if the informational needs of parents of children w'th disabilities were to be adequately assessed.

From the suggestions of the Advisory Committee and the network of professionals, a list of 28 additional items were created. It was decided to reduce this list by identifying those items most likely to differentiate among various groups of parents. Therefore, a panel of ten researchers and graduate assistants from the Frank Porter Graham Child Development Center were asked to rate each of the titles. The items judged most likely to reveal differences based on gender of parent, age of child, and severity of child's handicap were selected for use in the revised questionnaire.

<u>Pilot test</u>. The draft revision of the questionnaire was pilot tested with parents of children attending four centers serving children with disabilities. This pilot test revealed that titles including a more personal, active role for parents (e.g. "Parents discuss discipline and the special child") were preferred over more generic titles (e.g. "Discipline and the special child"). Thus, the more personal forms of nine titles were selected for the final instrument.

Summary. The final version of the revised questionnaire contained the original 50 titles in the "interests" section and the original 25 childrearing



problems and added 10 titles and 10 problems specific to rearing children with special needs. Since it would have been difficult to do, no attempt was made to assess parents' interest in information specific to their children's disabilities. It is simply assumed that most parents would want this type of information. The childrearing attitudes section of the final questionnaire retained the six items which assessed parent's attitudes about desirable child qualities. Parents were asked to rank order six child qualities (e.g., to obey parents, to think for themselves).

The section assessing parents' preferences for sources of information was considerably revised resulting in a seven sources by seven topics matrix rather than the nine by five matrix which was in the original questionnaire. The revised instrument takes about 15 minutes to complete. A copy is included in Appendix A of this report.

#### Results

Results from the parents' rating of titles, childrearing problems, and sources of information on childrearing are reported in this section.

### <u>Titles</u>

Based on fictitious article titles, parents rated their interest in reading 60 articles on a variety of child rearing and child development subjects. Ratings were made from 0 to 100, with 0 indicating that the parent had no interest in reading the article and a rating of 100 indicating that they would definitely read the article.

Reported below are results of the responses of all parents, as well as the comparisons of the responses of subgroups of parents on the title section of the questionnaire. The rank order for each item is presented and is followed by the percentage of respondents who rated that item between 90 and 100. Each of these scores presents different information. The rank order score provides information regarding the informational priorities of the group, and the percentage score indicates the extent of this interest for the group. The rank order of a given item may differ among groups while the percentage scores may be quite similar or vice versa. For this reason, both scores will be presented throughout the report.

Fathers and mothers combined. Responses of parents to the 60 titles indicating their interest in reading articles on these topics are reported in Table 2. The titles are grouped into five levels in accordance with the percentage of parents who rated the item between 90 and 100. Eleven titles were judged as receiving high readership scores, that is, 50% or more of the parents rated them between 90-100. Nine of these titles dealt directly with childrearing. A strong interest in promoting socioemotional development was reflected in the two top-ranking titles, and interest in facilitating cognitive development was indicated by four citles on this topic rated highly by more than half of the parents. Parents also indicated strong interest in discipline, toys and games, and in understanding the developmental cues of



Table 2.

<u>Estimated Readership on Sixty Informational Articles</u>

Item	Article Title	Rank	Percent of Rating 90 -	Item
High	Readership			<u></u>
1.	Being different is OK: Parents help youngsters with special needs adjust.	1	62.1	
2.	Build your child's self-confidence.	2	60.0	
}.	Parents of special children discuss the emotional highs and lows of parenting.	3	58.0	
٠	How mental abilities develop in children.	4	57.8	
•	Developmental cues and signals: Your special child.	5	57.2	
•	Toys and games for special children.	6	55.6	
	Knowing your community's special resources.	7	52.6	
•	Active learning: Games to enhance academic skills.	8	52.3	
•	Parents discuss discipline and the special child.	9	51.8	
0.	Parent-infant games that can help a baby learn.	10.5	50.4	
1.	A child's imagination: Activities for growth.	10.5	50.4	
<u>lode</u>	rately High Readership			
2.	Prepare your child for learning.	12	49.6	
3.	Identify mental handicaps in preschoolers.	13	47.1	
4.	How to respond to stuttering and other speech problems in children.	14	46.6	
5.	Help brothers and sisters get along with each other.	15	46.3	
6.		16	45.C	
7.	Fathers of special needs children describe their role in parenting.	17	44.4	
	Baby exercises to develop motor skills.	18.5	44.1	
9.				
	with a special needs child.	18.5	44.1	
0.	The sick child: What to do.	20	43.0	
1.		21	42.0	
2.	How well does your child see?	22	41.4	
3.	Using community resources for your baby: Do you know how?	23	41.3	<b></b>
24.	Prevent common childhood illnesses.	24.5	41.1	
25.	Protect your child's teeth.	24.5	41.1	



Item	Article Title	Rank	Percent of Rating 90 -	Item	
Mode	rate Readership				
26	Establish a partnership with your child's preschool.	26	39.2		
27.		27	39.0		
28.		28	37.6		
20. 19	Learning in the first year of life: How can parents raise smarter kids?	29.5	37.3		
30.		29.5	37.3		
31.	Impact of TV on today's children.	31	35.4		
	How your child's diet changes as s/he grows.	32	35.2		
32. 33.	For kids' sake, think toy safety.	33	34.9		
34.	A guide to birth defects.	34	33.8		
	The difference between loving and spoiling.	35	32.4		
	Independence: How much, how soon?	36	32.2		
	What infant movements meanarm waving has a purpose.	37	31.1		
	A reading list for story time.	38	30.8		
39.		39	30.5		
<u>Mode</u>	rately Low Readership				
40.	How do babies learn trust?	40.5	28.9		
41.	Immunize your child.	40.5	28.9		
42.	What to do with angry feelings toward your baby.	42	25.9		
43.	Family changes that come with adding children.	43	25.3		+
44.	Getting your church or synagogue to include your special needs child.	44	25.1		-
45.		45	23.7		÷ : : : : : : : : : : : : : : : : : : :
45. 46.	Pregnancy disorders: 8 symptoms to report to your doctor.	46	23.4	•	Ì
47.	When does punishment become child abuse?	47	21.8	<b></b>	
48.	How can I tell what my baby wants when s/he's crying.	48	21.5		
40. 49.	What does it cost to raise a child these days?	49	20.7		
<del>∀</del> 2.	milac does to oos, oo xaabo a ciilla ciiba aaya.				



Table 2 (continued)

Item Article Title	Rank	Percent of Parents Rating Item 90 - 100
Low Readership		
50. Choose a balanced diet from the grocer's baby shalves.	50	18.5
51. Raising a family as a single parent.	51	16.4
52. Boy or girl: How different are theyhow alike?	52	16.1
53. Caring for the premature baby.	53	13.1
54. When is your infant ready for a baby sitter?	54	12.5
55. Explaining divorce to children.	55	12.3
56. When it comes to your baby, does your mother really know best?	56	9.8
57. The challenge of being a teen parent.	57	8.7
58. What do other parents do about naps?	58	8.5
59. Be a successful stepparent.	59	7.4
60. Techniques for baby's bath.	60	3.8

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their special needs children.

In addition to the items related to child issues, 58% of the parents indicated a high interest in the third-ranked title, "Parents of special children discuss the emotional highs and lows of parenting". Parents also indicated a strong interest in learning about their community's resources. These results suggest that parents of children with special needs may themselves have special needs as they attempt to deal with the demands of parenting.

The parents in this study also indicated a strong interest in gaining information specific to rearing a child with special needs. Ten titles were added to the questionnaires that contained the term <u>special children</u> or <u>special needs child</u>. The survey results show 8 of these 10 titles in either the high or moderately high readership categories.

Mothers versus fathers. Mothers indicated more interest in reading about childrearing than did fathers. Of the 60 titles, 15 were scored between 90 and 100 by 50% or more of the mothers whereas only one title ("Build your child's self-confidence") was given a score of 90 - 100 by 50% or more of the fathers. The percentage of respondents who scored individual titles 90 100 ranged across titles from 5% to 67% for mothers and from 2% to 51% for fathers.

Mothers and fathers agreed on six of the ten top-ranked titles (items 1, 2, 4, 5, 7, and 8 in Table 2), indicating that parents share several common interests regarding parenting topics. A comparison of other titles ranked within the top ten by either mothers or fathers reveals some discrepant interests. For example, mothers were much more likely than fathers to express an interest in "Parents of Special Children Discuss the Emotional Highs and Lows of Parenting" (M 2, 64%; F 12, 41%), "Discipline and the Special Child" (M 7, 57%; F 13.5, 39%), "A Child's Imagination: Activities for Growth", (M 8, 56%; F 16.5, 36%), and "Toys and Games for the Special Child" (M 5, 62%; F 13.5, 39%). Fathers expressed a greater interest in physical development as evidenced by their higher interest in "Baby Exercises to Develop Motor Skills" (F 3.5, 48%; M 26, 43%), and "Put Together Your Own Playground" (F 9, 42%; M 18.5, 46%).

There were also some differences between mothers and fathers regarding titles that elicited moderate levels of readership interest. Mothers expressed greater interest than did fathers in a broad range of titles such as "What To Do with Angry Feelings Toward Your Baby" (M 23, 44%; F 39, 22%), "How to Respond to Stuttering and Other Speech Problems" (M 14, 52%; F 22.5, 33%), "Helping Brothers and Sisters Get Along" (M 15, 51%; F 22.5, 33%), and "Birth Defects" (M 32, 39%; F 41, 20%). The titles for which fathers expressed a greater interest than did mothers were mostly health-related topics. Although the percentage of respondents in each group were similar, the fathers ranked higher than did mothers titles such as "How Well Does My Child See?" (F 11.5. 41%; M 28, 42%), "Protecting Your Child's Teeth (F 16.5, 36%; M 24, 43%) and "Immunizing Your Child" (F 31.5, 27%; M



40, 30%). Fathers also expressed a higher priority for learning about "How Trust Develops" (F 30, 28%; M 41.5, 29%).

Mothers and fathers were fairly similar in their responses identifying the areas in which they had little or no interest. They agreed on 9 of the 10 lowest ranked items indicating little interest in the daily care areas such as baths, naps, or sitters, and little interest in areas related to less traditional family styles such as teen parents, single parents, divorce, and stepparents. The latter set of responses was expected since all of the fathers and the majority of the mothers were married, and most of the parents were between the ages of 20 and 39 years.

Mother's level of education. Mothers were split into four groups based on their educational levels: 1) no high school diploma ( $\langle HS, n=20 \rangle$ ; 2) high school diploma or GED ( $\langle HS, n=63 \rangle$ ; 3) some college or specialized training after high school ( $\langle HS, n=102 \rangle$ ; and 4) college degree ( $\langle CD, n=80 \rangle$ ). Results for each group's top ten ranking titles are presented in Table 3. For some groups, this includes more than ten titles due to ties.

Mothers in all four groups agreed on four of the top ten titles selected, expressing a strong mutual interest in items such as "Being Different is O.K.", "Parents of Special Children Discuss the Emotional Highs and Lows of Parenting", "Toys and Games for Special Children", and "Knowing Your Community's Special Resources" (items 1, 3, 6, and 7 in Table 3). The groups also agreed on titles for which they expressed little or no interest. These included titles which dealt with daily care routines (baths, naps, diet, and sitters), and less traditional parenting and family makeup (premature babies, teen parents, step parents, and grandmothers).

Mothers with less than a high school education had responses that were the most different when compared to the other three groups. First of all, 40 of the 60 titles were rated between 90 and 100 by 50% of these mothers. The number of titles rated that highly was greater than the number so rated by any other group, and compares with only 12 titles rated that highly by 50 percent or more of mothers with college degrees. In addition to the number of titles rated highly, the titles selected also varied. Mothers with the least amount of formal education were much more interested in topics related to physical health (items 16, 18, and 19 in Table 3). These mothers also indicated more interest than did mothers with more education in reading about financing (item 17) and about children's anger (item 20) and the impact of TV (item 21).

In comparison to the other three groups, mothers with the least amount of education were less interested in titles related to some aspects of child development. Whereas mothers in all three of the groups with higher education included within their top ten the titles "Build Your Child's Self Confidence", "Developmental Cues and Signals: Your Special Child", and "How Mental Abilities Develop in Children", these items ranked lower for mothers with less than a high school education.

Mothers in the two lower educational groups differed from those in the



Table 3. Percentage of Mothers and Fathers Rating Titles 90-100 for Top Ranking Titles

		Mothers (n=267)		Father (n=100	
		Rank	*	Rank	*
Ite	ms Article Title				
1.	Build your child's self confidence.	3.5	63	1	51
2.	Being different is OK: Parents help youngsters with special needs adjust.	1	67	3.5	48
3.	Developmental cues and signals: Your special child.	6	61	3.5	48
4.	How mental abilities develop in children.	3.5	63	7	45
5.	Parents of special children discuss the emotional highs and lows of parenting.	2	64	(11.5	41)
6.	Knowing your community's special resources.	10.5	54	3.5	48
7.	Active learning: Games to enhance academic skills.	9	55	6	46
8.	Toys and games for special children.	5	62	(13.5	39
9.	Parent-infant games that can help a baby learn.	10.5	54	9	42
10.	Prepare your child for learning.	(12	52)	9	42
11.	Parents discuss discipline and the special child.	7	57	(15	38
12.	A child's imagination: Activities for growth.	8	56	(16.5	36
13.	Put together your own play round.	(18.5	46)	9	42
14	Baby exercises to develop motor skills.	(26	43)	3.5	48



two upper groups in their slightly greater interest in reading about child learning (items 10 and 12) and their lesser interest in "Discipline and the Special Child".

Mothers who had some post high school education and mothers with college education or beyond were in fair agreement regarding the articles they would most like to read. However, mothers with some post high school education were much more interested than were the college graduates in "The Sick Child: What To Do" and less interested in "Active Learning: Games to Enhance Academic Skills".

Mothers with a college degree or beyond differed from the three lower groups in that they showed a much greater interest in reading about the father's role (item 14) and taking their child out in public (item 15).

Mothers' race. Mothers were split into two groups, white (W, n = 229) and non-white (NW, n = 30). Only 12 titles were rated between 90 and 100 by 50% or more of the white mothers, while 30 titles were rated between 90 and 100 by 50% or more of the non-white mothers.

Five of the titles rated within the top ten for white mothers were rated much lower by non-white mothers. The following titles were ranked more highly by white mothers than by non-white mothers, although the percentage readership scores were similar: "Being Different is O.K." (W 1, 69%; NW, 12.5, 65%), "Building your Child's Self Confidence" (W 3, 64%; NW 15.5, 61%), "Discipline and the Special Child" (W 7, 58%; NW 24, 55%), "A Child's Imagination:
Activities for Growth" (W 8, 58%; NW 34, 48%), and "Knowing Your Community's Special Resources" (W 9, 55%; NW 28.5, 52%). On the other hand, six of the top 14 titles (4 were tied for tenth place) rated by non-white mothers were rated much lower by white mothers. These items were: "Identify Mental Handicaps in Preschoolers" (W 14.5, 49%; NW 2, 74%), "Prepare your Child for Learning" (W 13, 50%; NW 4, 71%), "Parent-Infant Games that can Help a Baby Learn" (W 11.5, 51%; NW 4, 71%), "Learning in the First Year of Life: How Can Parents Raise Smarter Kids" (W 34, 36%; NW 7.5, 68%), "Vacationing and Traveling with a Child with Special Needs" (W 29.5, 38%; NW 12.5, 65%), and "Baby Exercises to Develop Motor Skills" (W 28, 40%; NW 12.5, 65%).

Mother's marital status. Mothers were split into two groups based on their marital status, single (S, n = 52) and married (M, n = 212). Single mothers included those who had never been married as well as those who were divorced or widowed. Approximately the same number of items (18) were rated between 90-100 by 50% or more of mothers in each group.

Married and single mother agreed on six of the top ten ranked items of interest, indicating a fair amount of agreement between the two groups. However, within the top ten interest titles for each group, single mothers expressed a much greater interest than married mothers in titles such as "Raising a Family as a Single Parent" (S 11, 77%; M 55, 8%), "Parent-Infant Games that can Help Baby Learn" (S 5.5, 62%; M 13, 51%), "Prepare Your Child for Learning" (S 7, 59%; M 15, 50%), and "How to Kespond to Stuttering and



Speech Problems" (S 9.5, 58%; M 14, 50%). While the percentages did not differ greatly, the rank order of the items indicated that married mothers expressed a slightly higher interest than single mothers in: "A Child's Imagination: Activities for Growth" (S 13, 54%; M 8, 57%), "Knowing Your Community's Special Resources" (S 13, 54%; M 9, 55%), and "Active Learning: Games to Enhance Academic Skills" (S 13, 54%; M 10, 54%).

Although outside of the top ten for both groups, single mothers expressed a greater interest in "What Does it Cost to Raise a Child These Days?" (\$ 32, 42%; M 50, 17%), and "Explaining Divorce to Children", (\$ 33, 42%; M 55, 9%). Married mothers were more interested in "Fathers of Special Needs Children Discuss Their Role in Parenting" (\$ 44.5, 35%, M 16.5, 50%).

Age of Child. Based on the age of their children with special needs, mothers were split into three groups: mothers of infants and toddlers, birth-35 mos; (I/T, n=99) preschoolers, 36-59 mos (Pre, n=103); and school age, 60-90 mos (Sch, n=64). Thirteen of the 60 items have the word infant or baby in the title and two items have the word preschool in the title, so 15 of the titles are age specific.

Mothers of infants and toddlers were more interested than were parents of older children in "Baby Exercises to Develop Motor Skills" (I/T 10, 55%; Pre 30.5, 34%; Sch 31.5, 39%), and "Parent-Infant Games that Can Help a Baby Learn" (I/T 2, 67%; Pre 13.5, 48%; Sch 26, 44%). Mothers of preschoolers expressed more interested than did mothers in either the older or the younger groups in "How to Respond to Stuttering and Speech Problems" (I/T 23.5, 46%; Pre 4, 59%; Sch 19.5, 48%). Finally, "Prepare your Child for Learning" was of much more interest for mothers of school-age children than it was for either of the two younger groups (I/T 16, 52%; Pre 18.5, 45%; Sch 2.5, 67%).

Gender of child. For the most part, responses of mothers of boys (B, n = 161) were similar to those given by mothers of girls (G, n = 104). The only title which was rated between 90 and 100 by 50 percent or more of the mothers of girls, but not by that great a percentage of mothers of boys, was "Putting Together Your Own Playground" (G 12, 50%; B 23.5, 44%).

Mothers of boys indicated slightly more interest than did mothers of girls in reading "How to Respond to Stuttering and Speech Problems" (G 17, 45%; B 10, 58%) and "...Get Out in Public with a Special Needs Child" (G 22, 44%; B 16, 51%).

Number of Children. Mothers were split into two groups; those with only one child, the special needs child (One, n = 67), and those with two or more chi' iren (More, n = 196).

Understandably, "Helping Brothers and Sisters to Get Along" was of much greater interest to mothers of more than one child than to those with only one child (More 6, 60%; One 47.5, 28%). Mothers of only one child were slightly more interested than mothers of more than one child in "Prepare Your Child for Learning" (More 9.5, 61%; One 14, 50%), and "Parent-Infant Games That Can Help



a Baby Learn" (More 6, 66%; One 15, 49%).

Childrearing attitudes. Based on their responses to the attitude rection of the survey, 64% of the mothers could be described as having progressive attitudes toward childrearing, while only 5% could be described as having traditional attitudes toward childrearing. The remaining 31% were classified as having mixed attitudes, however, their responses indicated that they were more similar to the progressive than to the traditional parents.

Two titles ranked much higher in readership for the "traditional" mothers (T) than for the "progressive" mothers (P) and "mixed" mothers (M): "For Kids Sake, Think Toy Safety" (T 2, 82%; P 37, 32%; M 26, 39%) and "Financial Management: Dealing with the Cost of Raising a Special Needs Child" (T 6, 64%; P 24, 41%; M 23, 42%). On the other hand, traditional mothers expressed less interest in reading "Parents Discuss Discipline and the Special Child" than did progressive mothers (T 27, 36%; P 7, 57%; M 3, 58%). It must be remembered that these results are tentative given the small number of traditional mothers (n = 11).

## Childrearing Problems

Parents responded to a list of 35 childrearing concerns or problems by rating each one on a three-point scale: often a problem, sometimes a problem, or not at all a problem. They could also indicate that the statement did not apply. For instance, the statement on toilet training might be checked as non-applicable if the child was already trained.

Results are reported for the percentage of parents who rated different statements as being "often a problem". As in the above section on ratings of titles, both the rank order of the problem statement and the percentage of parents giving this rating to the problem are reported. Results for the total sample and for subgroups are presented.

Fathers and mothers combined. The major concern of parents of young children with special needs appear to be how they can help their children reach their fullest potential. This concern was rated "often a problem" by 41% of the parents. Also of high concern were planning for long term needs, understanding the legal rights of their children, their children's acceptance by peers and the community, having sufficient time for themselves, preparing for difficult times, and finding good baby sitters. The problem statements and the percentage of parents who rated each of them as being often a problem are presented in Table 4.

Mothers versus fathers. With few exceptions, mothers and fathers were very similar in the concerns which most of them rated as being often a problem. However, the concern which ranked second for mothers was "I wish I had more time for myself" (2, 34%) was not of great concern for as many fathers, (15, 13%). A greater percentage of mothers than of fathers also indicated that they felt that the drain on their emotional energy of caring for their special needs child was often a problem (M 15, 16%; F 30, 3%).



Table 4.

Percentage of Parents Rating Statements as "Often a Problem"

		*	Rank
1.	I wonder how I can help my child develop his/her full potential.	40.6	${1}$
2.	I wonder how to plan for my child's long term needs.	30.2	2
· •	I wish I knew more about my child's legal rights to services and aid.	29.4	3
	I wonder whether my child will be accepted by his/her peers and the community.	28.8	4
j.	I wish I had more time for myself.	28.0	5
5.	I'd like to be better prepared for the difficult times that face me and my family.	26.0	6
, . ! .	It's hard to find a good babysitter.	24.7	7
3.	It worries me that others can't understand my child's speech.	24.0	8
). 9.	It's hard to get my child to ask for what he/she wants instead of whining.	22.6	9
)	I have trouble getting my child to respond to toilet training.	21.2	10.5
 L.	It is hard for me to find enough time in the day to follow through with all		
	of my child's treatment goals.	21.2	10.5
2.	·	17.2	12
3.	I wonder if my child is eating enough.	16.3	13
4.	My child is impatient and demanding.	15.8	14
÷. 5.	- <del> </del>	14.2	15.
5. 6.		14.2	15.5
0. 7.		13.6	17
7. 8.			
ο.	energy to deal with other areas of my life.	12.8	18
n.	I wonder what my baby wants when she/he is crying.	10.0	19
	I worry that my child will get hurt around the house.	10.6	20
0.	I wish my spouse would take more interest in our children.	10.3	21
1.		9.8	22
2.		9.3	23.
3.		9.3	23.
4.		,,,	
5.	Inere is always so much concern for my child s condition that I worly shows	8.9	25
,	does not have a chance to be "just a kid."	8.7	26
6.	I have trouble getting my baby on a regular sleeping schedule.	8.4	27
7.	The fact that our child has a problem has strained our marriage.	7.9	29
8.	I wonder when I should call the doctor.	7.9	29
9.	Punishing my child seems to make the situation worse.	, . ,	
0.	The other people in my family need some help with adjusting to having a special	7.9	29
	needs child in the family.	4.9	31
1.		4.4	32
2.	My baby's crying makes me nervous.	2.5	33
3.	It bothers me that my child tries to do things alone before she/he is really able.	2.2	34
34.	My baby is hungry at times when I can't stop to feed him/her. My child gets into fights.	0.8	35

Although most parents did not rate the statement, "I wish my spouse would take more interest in our children," highly, this was rated as being often a problem for a greater percentage of the mothers (18, 14%) than for fathers (34, 1%).

Mothers level of education. Mothers were grouped into four levels of education: (1) no high school diploma, (< HS, n = 20) (2) high school diploma or GED (HS, n = 63) (3) some college or specialized post-secondary training (> HS, n = 102) and (4) college degree (CD, n = 80).

Mothers who had not completed their high school education were somewhat more likely to rate the statements as being often a problem than were mothers with more education, although the mothers with college degrees more closely resembled them in this respect than did the other two groups. The number of statements highly rated by 20 or more percent of the group were: < HS 16; HS 7; > HS 11; CD 13.

The statements which were rated as often a problem by 20% of the lowest educational group, but not by that great a percentage of the other three groups were the statements regarding child behavior (items 14, 15, and 17 in Table 4) and the statement about getting advice from family and friends (item 22). The four educational groups were similar in expressing a relatively high level of concern regarding their children's legal rights, preparing and planning for the future and difficult times, helping their children develop their potential, their children's speech, and the acceptance of their children by others.

Although having enough time for themselves was also a highly rated concern for all four groups, having enough emotional energy was not rated as being often a problem by as many mothers without any post-secondary education (< HS 26.5, 10%; HS 23, 8%) as by mothers with some post-secondary education (> HS 13, 19%; CD 11, 23%).

Mothers' race. The mothers were divided into two groups by race, white (W, n = 229) and nonwhite (NW, n = 30). A similar number of statements were rated as being often a problem by 20% or more of the mothers in the two groups (W 11; N 9). A greater percentage of nonwhite mothers than white mothers expressed concern over getting their babies on a regular sleeping schedule (W 30, 8%; NW 12.5, 19%), spoiling their children (W 27.5, 9%; NW 12.5, 19%), wondering what their babies want when they cry (W 23, 10%; NW 12.5, 16%), and their children's tantrums (W 14.5, 17%; NW 6, 32%).

White mothers, on the other hand, expressed more concerns about their children's acceptance in the community (W 3, 32%; NW 17.5, 16%) and finding time to address treatment goals (W 9, 25%; NW 21.5, 13%).

<u>Mothers' marital status</u>. Oddly enough, one of the statements rated as being often a problem by a greater percentage of single mothers (S, n = 52) than of married mothers (M, n = 212) was "I wish my spouse would take more



## Preferred Sources of Information

Parents were asked to indicate their first, second, and third choices regarding where they would <u>like</u> to get information about seven areas of childrearing. The sources and childrearing topics were presented in a matrix as demonstrated in Table 5. Results will be presented for fathers and mothers and for four educational levels of mothers.

Mothers versus fathers. This section of the questionnaire was not completed by 29 of the parents (8% of the fathers and 8% of the mothers). Not all of those who did respond indicated a first choice for all of the topics and many of the parents did not indicate second and third choices. Results are presented in Table 5 for mothers and fathers.

Mothers and fathers were similar in their first choices for sources of information for most of the topics. Interventionists/teachers was the first choice for information on teaching children, family and friends for information on coping with family problems, and reading materials for information on living areas and on finances. Interventionists/teachers and helping agencies split the vote for both mothers and fathers as first choices for information on finding and using community agencies.

Mothers and fathers differed in their first choices for information sources on two of the seven topics. The medical profession was the first choice for 37% of the mothers but only 12% of the fathers was for formation on child development. A higher percentage of fathers (36%) than of mothers (28%) selected reading materials as their first choice for information on this topic. For information on coping with child problems, 24% of the mothers would attend parenting courses while 25% of the fathers would turn to reading materials.

Mothers educational levels. Results were summarized for four educational levels of the mothers (1) no high school diploma (<HS, n = 20), (2) high school diploma or GED (HS, n = 63); (3) some college or specialized training after high school (>HS, n = 102); and (4) college degree (CD, n = 80). (Results are presented in Table 6.)

Medical professionals were chosen as the first choice for information on child development by over one-third of the mothers in each educational group. Reading materials was also a popular first choice for information on this topic for mothers in the top three educational levels whereas mothers with less than a high school education were more apt to choose family and friends.

For information on how to teach children, teachers and interventions were clearly the first choice of mothers in the top three educational levels. Mothers with less than a high school education were as \_pt to choose family and friends as teachers and interventionists for information on this topic.

Mothers with less than a high school education would turn to medical professionals, family and friends, and parenting courses to get info acion on



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Topic	Parent	Family & Friends	Books, Etc.	TV & Films	Parent Courses	Medical	Teachers & Interven.	Helping Agencies	
How children grow		9	28	4	8	37	11	2	
and develop	F	20	36	6	5	12	14	5	
How to teach	M	15	11	2	14	2	53	4	
children	F	14	25	5	9	0	43	4	
How to cope with	M	16	17	2	24	19	18	7	
children's problems	$\mathbf{F}$	19	25	4	9	7	16	19	
How to cope with	M	32	1.9	1	21	5	7	16	
family problems	F	40	22	8	11	2	9	9	
How to manage your	M	28	33	4	10	2	18	5	
child's living areas	F	19	42	6	11	2	19	2	
How to manage	M	22	47	6	8	1	4	12	
family finances	F	21	49	7	8	0	9	6	
How to find and	M	17	17	5	4	15	21	21	
use community agencies	F	13	16	5	4	10	27	24	
(Mean across topics)		20	25	3	13	12	19	10	22
- · ·	F	21	31	6	8	5	20	10	

Informational Needs

Table 6. Percentage of Mothers (M) by Educational Level Selecting Sources as First Choice for Information

	Sources										
<b>Topic</b>	Ed'l Level	Fam/Friends	Books	TV & Films	Parent Cou	rse Medical	Teach & Int	Help Ag			
low children grow	<hs< td=""><td>29</td><td>18</td><td>6</td><td>0</td><td>41</td><td></td><td>0</td></hs<>	29	18	6	0	41		0			
and develop	HS	7	28	3	8	38	12	3			
ilid develop	>HS	11	25	5	10	38	8	3			
	CD	5	34	3	8	34	14	3			
ow to teach	<hs< td=""><td>38</td><td>13</td><td>0</td><td>13</td><td>6</td><td>31</td><td>0</td></hs<>	38	13	0	13	6	31	0			
hildren	HS	14	7	0	19	2	55	3			
	>HS	17	14	2	16	1	46	3			
	CD	8	10	4	9	1	62	5			
ow to cope with	<hs< td=""><td>31</td><td>6</td><td>0</td><td>25</td><td>38</td><td>0</td><td>0</td></hs<>	31	6	0	25	38	0	0			
children's problems	HS	21	16	2	21	18	18	4			
"TATOL D PLODEOUR	>HS	17	12	0	26	20	17	9			
	CD	13	13	4	25	15	21	9			
ow to cope with	<hs< td=""><td>50</td><td>14</td><td>0</td><td>14</td><td>21</td><td>0</td><td>0</td></hs<>	50	14	0	14	21	0	0			
amily problems	HS	37	25	0	21	2	5	11			
umily producemb	ZK<	39	12	1	20	6	3	18			
	CD	17	21	0	23	5	13	21			
ow to manage your	<hs< td=""><td>21</td><td>29</td><td>0</td><td>29</td><td>14</td><td>7</td><td>0</td></hs<>	21	29	0	29	14	7	0			
hild's living areas		33	29	6	17	2	10	4			
	>HS	33	30	1	8	1	17	9			
	CD	22	39	8	3	1	26	1			
low to manage	<hs< td=""><td>33</td><td>20</td><td>13</td><td>20</td><td>0</td><td>13</td><td>0</td></hs<>	33	20	13	20	0	13	0			
amily finances	HS	27	42	4	9	0	2	16			
	>HS	23	47	4	6	1	4	14			
	CD	14	58	7	7	1	4	9			
low to find and	<hs< td=""><td>20</td><td>13</td><td>13</td><td>0</td><td>13</td><td>20</td><td>20</td></hs<>	20	13	13	0	13	20	20			
ise community	HS	31	11	6	6	9	20	18			
gencies	>HS	15	15	6	4	17	21	22			
.601.0100	CD	7	23	1	4	19	22	23			
Mean across topics)	<hs< td=""><td>32</td><td>16</td><td>5</td><td>14</td><td>19</td><td>11</td><td>3</td></hs<>	32	16	5	14	19	11	3			
(	HS	24	23	3	15	10	17	9			
	>HS	22	22	3	13	12	17	11			
	CD	12	28	4	11	11	23	10			

Informational Needs

coping with children's problems. There were no clear choices for information on this topic for the other three educational groups although parenting courses was the first choice for 20-35% of the mothers in these groups.

For information on coping with family problems, one half of the mothers with less than a high school education and over one-third of the mothers in the next two educational levels would turn to family and friends. Mothers with college degrees, however, would gain this information from reading materials, parenting courses, or helping agencies. Medical professionals were selected as first choice for information on this topic by 22% of the mothers with less than a high school education but by a very low percentage of mothers in the other groups.

Family/friends and reading materials were selected as first choices for information on how to manage the child's living area by all four educational groups. Mothers with less than a high school education also selected parenting courses, whereas mothers with college degrees also chose teachers and interventionists. As educational level increased, family/friends decreased and reading materials increased as first choices for information on family finances.

Although no clear choices emerged for information on how to find and use community agencies, teachers/interventionists and helping agencies were the first choices for 18-23% of the mothers in all four educational groups. Similar percentages of mothers at the two lower educational levels chose family and friends, and 23% of the mothers with college degrees again opted for reading materials for information on this topic.

Overall, as the level of education increased, family and friends decreased and reading materials increased in percentage of mothers in each educational group selecting these as their first choice for sources of information on child and family matters.

## <u>Titles versus Problems</u>

A few topics were addressed by both titles and problems. For instance, one of the titles is "How can I tell what my baby wants when she or he is crying?" and one of the problem statements is "I wonder what my baby wants when she or he is crying." Results for this and other topics are discussed below. The reader is referred to the data presented in Tables 2 and 4. In comparing data for titles and problems it is important to remember that there are almost twice as many titles as problems, so a rank of 60 for a title is comparable to a rank of 35 for a problem. Also, high ratings were given by more parents to titles than to problems.

Both the title (Title 5 in Table 2) and the problem statement (Problem 1 in Table 4) which dealt with their children's development were rated highly by parents. On the other hand, parents indicated a high degree of interest in reading about building their child's self confidence (Title 2), but did not



express a great deal of concern about their child's self-confidence (Problem 23). Similar results regarding this topic were found by Sparling et al. (1979). Moderate levels of interest were exhibited for both the titles and problem statements regarding their infant's crying (Title 48, Problem 19), spoiling their children (Title 35, Problem 24), and a child's anger and tantrums (Title 28, Problem 12).

The title about the emotional highs and lows often experienced by parents of children with special needs (Title 3) was rated highly by 58% of the parents. Although none of the problem statements dealt specifically with this issue, several of them addressed related topics. The statement, "I wish I had more time for myself," (Problem 5) was rated as "often a problem" by 28% of the parents (34% of the mothers; 13% of the fathers). The other statements regarding having time and emotional energy (Problem 11 and Problem 18), and the statements about being worn out by their child's activity (Problem 17) and being made nervous by their child's crying (Problem 32), did not rank as highly. Although the titles regarding financial management (Title 21) and the cost of raising a child (Title 49) were not highly rated by many parents, the problem statements concerning planning for the child's long term needs (Problem 2) and preparing for difficult times (Problem 6) were.

## Comparison with Results from Previous Study

All of the titles and problem statements which were in the questionnaire used by Sparling et al. (1979) to survey informational needs of mothers from the general population were included in the questionnaire used in the present study. In addition, the present study included 10 titles and 10 problem statements which addressed topics of possible interest to parents of children with special needs. The inclusion of these topics may account for the findings that greater percentages of mothers in the present study than in the previous study, gave high ratings to both titles and problems. In the present study, 15 titles were rated 90-100 by 50% or more of the mothers whereas only 3 titles were as highly rated by that great a percentage of mothers in the Sparling et al. (1979) study. Similar differences were found for problem statements; the number of statements rated "often a problem" by 20% or more of the mothers was 11 in the present study compared with only 3 statements in the Sparling et al. (1979) study.

<u>Titles</u>. Mothers of children with special needs expressed much greater interest in reading, using, and knowing about community resources and services (Title 7 and 23) than did mothers in the general population. These two titles ranked 7 and 23 out of 60 in the present study and both ranked 41.5 out of 50 in the previous study. The mothers of special needs children also expressed more interest in reading about stuttering and other speech problems (Title 14), putting together their own playground (Title 16), and establishing a partnership with their child's preschool (Title 26).

The mothers of children with special needs also expressed considerably less interest than did mothers from the general population in reading about



the difference between loving and spoiling (Title 35), and when punishment becomes abuse (Title 47).

Childrearing problems. The two highest ranking concerns were the same for both the mothers of children with special needs and mothers from the general population (Problem 1 and Problem 5). Concern over helping their children develop their full potential was rated highly by 41% of the mothers in this study and 40% of the mothers in the Sparling et al. (1979) study. Having enough time for themselves was also of major concern to mothers in both groups (special needs group, 34%; general population, 27%). Also rated as "often a problem" by more than 20% of the mothers in both groups was concern about finding a good babysitter (Problem 7).

More than 20% of the mothers of children with special needs rated highly their concerns over their childrens' speech, whining, and toilet training (Problems 8, 9, and 10). These statements were not rated as "often a problem" by as great a percentage of mothers from the general population. As reported above, mothers in this study also rated highly items related to having a child with special needs (Problems 2, 3, 4, 6, and 11). These items were not in the Sparling et al. (1979) study.

## Discussion

A national sample of parents of children, age: birth to eight years, who have developmental delays and disabilities indicated 2 need for information regarding various aspects of child development. Over half of the parents expressed a strong concern over whether they could help their young children with special needs reach their full potential. High readership ratings were given to titles about helping their special needs child adjust, building their child's self-confidence, enhancing learning and academic skills, developing imagination, and discipline. The parents recognized that play is important for development (Gowen, Hussey, Goldman, & Johnson-Martin, 1989) and that children with disabilities often need adapted toys in order to play (Musselwhite, 1986) by rating highly the title, "Toys and Games for Special Children."

Results of this study also attest to the fact that parents of special needs children have special needs of their own. Strong interest was expressed in learning how to deal with the emotional highs and lows of parenting a child with special needs. Children with disabilities sometimes require unusual caregiving such as tube feeding and physical therapy (Beckman, 1983). Although the unusual caregiving demands sometimes associated with caring for a handicapped child were, at times, significantly related with feelings of distress, mothers of handicapped infants and toddlers did not differ significantly from mothers of same-age children without disabilities in a longitudinal study of middle-class mothers and their children (Gowen, Johnson-Martin, Goldman, & Appelbaum, 1989). Numerous studies have demonstrated that the effects of stress, whether stemming from child characteristics or other factors, can be ameliorated by adequate social support systems (Crnic, GreenJerg, Ragozin, Robinson, & Basham, 1983; Cutrona



& Troutman, 1986; Levitt, Weber, & Clark, 1986). These findings have been replicated in studies of mothers with children with disabilities (Dunst, Trivette, & Cross, 1986; Peterson, 1984). These results suggest that parents of children with special needs may benefit from information on how to strengthen their social support systems.

Mothers in this study also indicated that they often had a problem finding time for themselves which may be related to the problem they indicated they have in finding good babysitters. Obtaining adequate child care/respite care is a persistent problem for parents of children with disabilities (Salisbury, 1986). Higher levels of distress have been reported by mothers of special needs children who wanted to go out more than they did (Bradshaw & Lawton, 1978) and who had few or no holidays and social outings (Chetwynd, 1985). These results suggest a need for information on how to mobilize resources to obtain more childcare/ respite care.

Parents also expressed a need for information about their community's resources and concerns regarding their children's legal rights and how to plan for their children's long term needs. Books such as <u>Disability and the family: A guide to decisions for adulthood</u> by Turnbull, Turnbull, Bronicki, Summers, and Roeder-Gordon (1989) address this need.

Group differences. For the most part, parents' informational needs did not vary much as a function of the characteristics of the parents and the children. There were a few differences, however, which are worth noting. Results of this study agreed with those from the earlier study of mothers from the general population (Sparling et al. 1979) in finding that mothers with low levels of education were more interested than better-educated mothers in acquiring information about their children's physical health. Also, interest was indicated by white mothers in learning about socio-emotional development and by non-white mothers in reading about child learning.

As might be expected, mothers of more than one child were more interested than mothers of only one child in gaining information about sibling relationships. Other differences which seemed predictable were the higher ratings given by single mothers, as compared with married mothers, to the topics of single parenthood, explaining divorce to children, and the cost of raising a child. Somewhat surprisingly, single mothers were also more apt, than married mothers, to view getting their spouses to take an interest in their children as a problem. Presumably, the single mothers were referring to their ex-spouses.

Some group differences in informational needs were related to the age of the child. More interest was expressed by mothers of infants and toddlers in baby exercises and infant games, by mothers of preschoolers in speech problems, and by mothers of school-aged children in preparing their children for learning.

<u>Information channels</u>. Parents preferred different sources for information on different parenting topics. Many parents would turn to reading



materials or medical professionals for information on child development, to teacher and interventionists to learn about teaching their children, and to family and friends for advice on coping with family problems. They would seek information on managing family finances and their children's living areas from reading materials. There were no clear choices for sources of information on coping with children's problems and using community agencies.

Mothers with less than a high school education differed from the other groups in where they preferred to get childrearing information. They indicated that they would turn to family and friends for information on most childrearing topics. These results present a challenge to professionals who are interested in addressing the informational needs of this group. For information on most childrearing topics, under-educated mothers would turn to their families and friends. Early interventionists can become a part of parents' informal social support networks through being proactive and supportive during regular home visits. They may then become trustworthy sources of parenting information in the eyes of the under-educated mothers.

<u>Conclusion</u>. This study identified some of the informational needs and preferred information channels of parents of young children with special needs. The next step for professionals is to mobilize information to meet these needs and to provide this information in ways that parents have indicated would be most helpful.



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# Appendix A

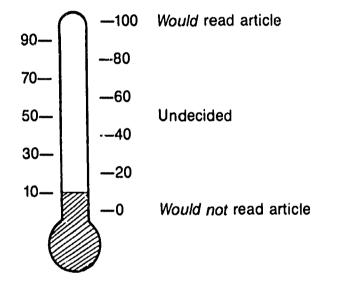
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REL (11)
ASSIST (12)
DATE//(13–18))  mm

# PARENT QUESTIONNAIRE

Below and on the facing page are some titles of articles on parenting and child development. As a parent of a special needs child, please indicate how interested you would be in reading each article based on its title.

To show the degree of your interest, please give each title a score between 0 and 100. If you are completely sure you **would** want to read the article, score it 100. If you are completely sure that you would **not** want to read the article, score it 0. If you are not completely sure, use the number between 0 and 100 that best shows the degree of your interest in reading the article. You may use any score as many times as you wish.

#### DEGREE OF INTEREST



then is you; infant ready for

baby sitter? . . . .

# **EXAMPLE**

Does my child hear as well as s/he should?... 10

A score of 10 shows that you have little interest in reading the article.

and spoiling	youngsters
Parents discuss discipline and the	Build your
special child	What do o
When it comes to your baby, does your mother really know best?	do about i
When does punishment become	Technique
child abuse?	Caring for
How do babies learn trust?	Pregnancy to report t
When a child is angry	Prevent co
Boy or girl: how different are they— how alike?	A guide to
What to do with angry feelings	The sick
toward your baby	Immunize
Independence: how much, how soon?	

Being different is O.K.: parents help youngsters with special needs adjust
Build your child's self-confidence
What do other parents do about naps?
Techniques for baby's bath
Caring for the premature baby (61-63)
Pregnancy disorders: 8 symptoms to report to your doctor
Prevent common childhood illnesses
A guide to birth defects
The sick child: what to do
Immunize your child

How well does your Child See? (12-14)	when s/he's crying		
Protect your child's teeth	•		
How your child's diet changes as s/he grows	Using community resources for your baby:  Do you know how?		
Choose a balanced diet from the grocer's baby shelves	FOR FPG USE ONLY  CARD (1-2)  DUPLICATE COLS (3-11)		
Parents of special children discuss the emotional highs and lows of parenting	Getting your church or synagogue to include your special needs child (12-14)		
Learning in the first year of life: how can parents raise smarter kids?	What does it cost to raise a child these days?		
A reading list for story time	Financial management: dealing with the costs of raising a special needs child		
Prepare your child for learning			
Baby exe: cises to develop motor skills	Knowing your community's special resources		
What infant movements mean — arm waving has a purpose	Stares and stairs: A parent's tips for getting out in public with a special		
Developmental cues and signals: your special child	needs child		
How mental abilities develop in children	the working mother(27-29)		
Parent-Infant games that can help	Fathers of special needs children describe their role in parenting		
a baby learn	Explaining divorce to children		
A child's imagination: activities for growth	Be a successful stepparent		
Identify mental handicaps	Raising a family as a single parent		
in preschoolers	The challenge of being a teenage parent		
Active learning: games to enhance academic skills	Family changes that come		
Establish a partnership with your child's preschool	with adding children		
Impact of TV on today's children	with each other		
Teach your child to talk	Vacationing and travelling with a child with special needs		
When does an infant begin	Toys and games for special children		
to understand speech?	For kid's sake, think toy safety (57-59)		
How to respond to stuttering and other speech problems in children	Put together your own playground 60-62		



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DUPLICATE COLS	(3–11)

# THINGS THAT TROUBLE ME

Listed below and on the next page are some problems parents face. As a parent of a child with special needs, have any of these troubled you lately? For each problem, circle the letter that shows whether you have been troubled by it often, sometimes, or not at all. Use "Does Not Apply" only if it is impossible for you to have this problem.

### EXTENT TO WHICH THIS HAS BEEN A PROBLEM FOR YOU -

STATEMENTS	OFTEN A PROBLEM	SOMETIMES A PROBLEM	NOT AT ALL A PROBLEM	DOES NOT	
I wonder what my baby wants when s/he is crying.	0	S	N	D	(12)
I wish I had more time for myself.	0	S	N	D	
My child throws tantrums.	0	s	N	D	
I have trouble getting my baby on a regular sleeping schedule.	0	S	N	D	
It's hard to find a good babysitter.	0	S	N	D	
I wonder when I should call the doctor.	0	S	N	D	(17)
My child seems to lack self-confidence — I wish I could help.	0_	s	N	D	
I wonder if my child is eating enough.	O	S	N	D	Ш
My child resists what I ask him/her to do.	0	S	N	D	
My baby is hungry at times when I can't stop to feed him/her.	0	S	N	D	
My child is impatient and demanding.	0	S	N	D	(22)
It's hard to get my child to ask for what s/he wants instead of whining.	0	S	N	D	
I wonder how I can help my child develop her/his full potential.	0	S	N	D	
I have trouble getting my child to respond to toilet training.	0	s	N	D	
It worries me that others can't understand my child's speech.	0	s	N	D	
My baby's crying makes me nervous.	0	S	N	D	(27)
My child's activity wears me out.	0	S	N	D	Ш
It bothers me that my child tries to do things alone before s/he is really able.	0	s	N	D	
I get advice I don't want from family and friends.	0	S	N	D	Ш
My child gets into fights.	0	S	<u> </u>	D	(31)



# EXTENT TO WHICH THIS HAS BEEN A PROBLEM FOR YOU —

STATEMENTS	OFTEN A PROBLEM	SOMETIMES A PROBLEM	NOT AT ALL A PROBLEM	DOES NOT	
I worry that my child will get hurt				_	H
around the house.	0	S	N	D	(32)
wonder if I am spoiling my child.	0	S S	N	D	Ц
Punishing my child seems to make the situation worse.	0	S	N	D	
l wish my spouse would take more interest in our children.	0	S	 	D	
My older children think I love the baby more than them.	0	S	N	D	
Because of the demands of caring for my child, I have little or no emotional energy to deal with other areas of my life.	0	S	N	D	(37)
The other people in my family need some help with adjusting to having a special needs child in the family.	0	s	N	D	
I'd like to be better prepared for the difficult times that face me and my family.	0	S	N	D	
The fact that our child has a problem has strained our marriage.	0	S	N	D	
It is hard for me to find enough time in the day to follow through with all of my child's treatment goals.	0_	S	N	D	
I'd like ( w how to train a good babysitter for my s, al needs child.	0	s	N	D	(42)
There is always so much concern for my child's condition that I worry s/he does not have a chance to be "just 1 kid."	0	S	N	פ	
! wonder how to plan for my child's long term needs.	0	s	N	D	
I wonder whether my child will be accepted by his/her peers and the community.	0	S	N	D	
I wish I knew more about my child's legal rights to services and aid.	0	s	N	D	(46



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DUPLICATE COLS	(3–11)

# **PARENTING ATTITUDES**

Listed below are some qualities that parents like their children to have. Thinking of parenting in general, which of these qualities do you like most for all children, especially as they get older?

Please rank all items. Place a (1) beside the quality which you value most for children, and continue ranking through to the one which you value least, giving that quality a (6).

To obey parents	(12)
To think for themselves	
To be polite to adults	
To feel they are good persons	
To be curious about many things	
To keep themselves and their clothes clean	(17)

# WHERE I'D LIKE TO GET MY INFORMATION

Sometimes information isn't available when and where we'd like it to be. But for now assume you can get information wherever you wish. For each type of information listed, select the three most important sources of information you wish you could use.

Write a 1 for the most important, a 2 for the next most important, and a 3 for the third most important source for each of the types of information.

## **SOURCES**

Types of Information	Family and Friends	Books, Magazines, and Pamphiets	T.V. and Films	Parenting Courses	Medical- Nurses & Doctors	Teachers and Interventionists	Helping Agencies (Please Specify)	
(EXAMPLE) HOW TO DISCIPLINE CHILDREN.	1	3					Muntal Mandi Center	
How children grow and develop.								(18-24)
How to teach children								(25–31)
How to cope with children's problems.								(32-38)
How to cope with family problems.								(39–45)
How to manage your child's living areas.								(46~52)
How to manage family finances.								(53-59)
How to find and use community agencies.								(60-66)



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<b>DUPLICATE COLS</b>		(3-11)

# SURVEY OF INFORMATIONAL NEEDS

We would like to know what types of information different groups of parents are most interested in. In order for us to do this, we need to know about those who are answering the questionnaire. We would appreciate your answers to the following questions as they will enable us to describe the informational needs of different groups of parents so that professionals will be better prepared to meet those needs. Once again, all responses are confidential.

Your Relationship to Child: (circle one 1 = Mothe 2 = Fathe 3 = Other	er e e		(month/ day/ year) (13-18)
Your Sex: M = Male F = Female	(circle one) (19)		
Your Race: (circle one) (20)			
B = Black H = Hispar W = White N = Native	nic O = Or American X = Oth	iental ner <i>(pl</i> ease s <i>pecify)</i> .	
Your Marital Status: (circle one) (21)  M = Married S =  D = Divorced R =  or  Separated			
Child's Sex: M = Male F = Female	e (circle one) (22) C	hild's Date of Birth:	/(23-28) (month / day / year)
Child's Race: (circle one) (29)		0 0	
B = Black $H = HiW = White$ $N = Na$	spanic ative American	O = Oriental X = Other <i>(please sp</i>	pecify)
CHILD'S SPECIAL CONDITION: _			(30)
How many children do you have O	LDER than your spec	cial child?	(31)
How many children do you have Yo	DUNGER than your s	pecial child?	(32)
Is your special child a child of your	present marriage?	$y = yes \qquad n = ne$	o (circle one) (33)
Child lives with: (circle one) (34)			
1 = Mother and Father 2 = Mother only 3 = Father only	4 = Mother and spou 5 = Father and spou 6 = Shared Custody 7 = Adoptive parents	se 9 = Rel 0 = Oth	eter parents ative(s) ner; specify:
Your Education: (35) (circle the highest level completed)		Your Spouse's Ed	ducation: (38) nest level completed)
1 = Below 7th grade 2 = Jr. High School 3 = Some High School 4 = High School 5 = Specialized Training after High School 6 = Some College 7 = 4 year College Program 8 = Graduate or Professional School	chool	6 = Some Col 7 = 4 year Co	chool h School ool d Training after High School lege
Your Occupation:	(38)	Spouse's Occup	ation: (3s
Your Employment Status: (circle one) (37)  1 = Not Employed outside of home  2 = Part time  3 = Full time			yment Status: (circle one) (40)  byed outside of home
Total Annual Income for all memb	ers from all sources	: (circle one) (41-42)	
1 = Below 10,999 2 = 11,000-16,999 3 = 17,000-22,999	4 = 23,000-28,999 5 = 29,000-34,999 6 = 35,000-40,999	7 = 41, 8 = 47, 9 = 53	000-46,999 000-52,999 ,000-58,999 ,000 or above

