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Physically Disabled Women: A Study of Perceptions of Social Support and Experiences Affecting the Transition Through Parenthood

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PHYSICALLY DISABLED WOMEN:
A STUDY OF PERCEPTIONS OF SOCIAL SUPPORT AND EXPERIENCES
AFFECTING THE TRANSITION THROUGH PARENTHOOD

by

BEVERLY KOPALA

A Dissertation Submitted to the Faculty of the Graduate
School of Loyola University of Chicago in Partial
Fulfillment of the Requirements for the Degree of
DOCTOR OF PHILOSOPHY

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1987

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VITA

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TABLE OF CONTENTS

	Page
ACKNOWLEDGMENTS	ii
VITA	iii
LIST OF TABLES	vi
CONTENTS OF APPENDICES	viii
 Chapter	
I. INTRODUCTION	1
Statement of the Problem	1
Significance of the Study	2
Purposes of the Study	3
Research Questions	3
Definition of Terms	4
Assumptions and Limitations	5
Procedure	5
Summary and Overview	7
II. REVIEW OF RELATED LITERATURE	9
Literature Related to the Physcially Disabled	9
Literature Related to Parenting and the Health-Care Institution	10
Literature and Studies Related to Decision-Making	12
Literature and Studies Related to Social Support and Support Networks	14
Two Models for the Determinants of Parenting.	18
Rationale for Studying Handicapped Parent Families.	20
III. RESEARCH METHODOLOGY.	21
Design and Research Questions	21
Instrumentation.	22
Pilot Study.	28
Research Sample	29
Selection of Research Participants	29
Description of Research Respondents.	30
Participants Included in the Analysis of Social Support	37
Participants Selected for Interviews	39
Research Procedures	42
Methods of Data Collection	42
Analysis of Research Data.	50
Summary	53

IV. RESULTS	55
Analysis of Data	55
Findings Relating to the Research Questions	64
Summary	75
V. DISCUSSION.	77
Discussion of Research Questions.	81
Implications.	146
Suggestions for Further Research.	152
Summary	154
VI. SUMMARY	157
BIBLIOGRAPHY	165
APPENDIX A	171
APPENDIX B	189
APPENDIX C	195
APPENDIX D	198
APPENDIX E	206
APPENDIX F	228

LIST OF TABLES

Table	Page
1. Summary of Demographic Data for Research Participants	31
2. Summary of Data Pertaining to Childbearing	33
3. Summary of Data Pertaining to Children of Research Participants	35
4. Geographic Distribution of the Sample.	43
5. Summary of Statistics for Total Number of Respondents Included in the Analysis of Social Support	56
6. Summary of Statistics for Subgroups of Respondents Included in the Analysis of Social Support	58
7. Summary Data of t-Tests Between Groups on Measures of Ideological Support Perceived to be Provided by Support Persons.	61
8. Summary Data of t-Tests Between Groups on Measures of Information, Emotional Support, and Instrumental Assistance Received.	62
9. Summary Data of t-Tests Between Groups on Measures of Perceived Influence of Information, Emotional Support, and Instrumental Assistance.	63
10. Analysis of Variance (Repeated Measures) for Perceptions of Social Support Provided by Selected Persons	65
11. Tukey's Test (Honestly Significant Difference) for Support Variables.	67
12. Tukey's Test (HSD) for Combined Support Variables.	70
13. Pearson Correlation Coefficients for Perceived Influence of Information on the Decision to Become a Parent.	72
14. Pearson Correlation Coefficients for Perceived Influence of Emotional Support on the Decision to Become a Parent	73
15. Pearson Correlation Coefficients for Perceived Influence of Instrumental Assistance on the Decision to Become a Parent .	74

LIST OF TABLES

Table	Page
16. Perceptions of the Adoption Experience	98
17. Responses to the Suggestion to Adopt a Special-Needs Child .	101
18. Perceived Differences in Childhood Experiences From Children Who Were Not Disabled	104
19. Two Biggest Problems Perceived to be Encountered When Making the Decision to Become a Parent	106
20. Health Problems Reported During Pregnancy/Pregnancies. . . .	110
21. Perceived Effect of Disability on Nurse's Response to the new Mother.	115
22. Reasons for Hospitalization of Children Following the Newborn Period	120
23. Adaptations Made in the Daily Physical Care of Children As a Result of the Disability.	121
24. Precautions Taken By Mothers to Ensure Child's Safety. . . .	124
25. Perceived Effects of Maternal Disability on Children	126
26. Greatest Satisfactions in Parenting.	131
27. Greatest Satisfactions in Parenting That Are Perceived to be a Direct Result of Having a Disability	133
28. Advice to Medical Professionals Assisting a Disabled Person.	137
29. Advice to Other Physically Disabled Women Who Are Considering Becoming a Parent.	143

CONTENTS OF APPENDICES

	Page
APPENDIX A	171
Survey Questionnaire.	172
APPENDIX B	189
Interview Questions	190
APPENDIX C	195
Consent Forms	196
APPENDIX D	198
Questionnaire Codebook Categories	199
APPENDIX E	206
Interview Coding Categories	207
APPENDIX F	228
Data Related to Question 1 - t-Tests for Combinations of Person Variables	229

CHAPTER I

INTRODUCTION

Medical care and technology have improved the survival rates for persons with various disabilities. Women, whether disabled from birth or from an injury later in life, are now able to bear children with less likelihood of problems. Thus, as the population of disabled persons has increased, the population of disabled parents has increased as well. Review of the literature has revealed a lack of research on the perceptions of physically disabled women during their transition through parenthood.

This chapter is an introduction to the exploratory study of childbearing and childrearing experiences of physically disabled women. Specifically, the focus is on: (a) their perceptions of social support from family, friends, and professionals, and (b) health care experiences of physically disabled women during the transition through parenthood.

Statement of the Problem

Society's attitudes toward the disabled have been found to be rather negative (Vash, 1982; Tate & Weston, 1982). In spite of increased social awareness due to legislative changes--such as Section 504 of the Vocational Rehabilitation Act of 1974, the Education For All Handicapped Children Act, PL 94-142--and an increasingly vocal disabled population in general, certain members of society still consider the

handicapped as asexual (Thurer, 1982; Task Force on the Concerns of Physically Disabled Women, 1978), and they also tend to doubt whether the disabled could, would, or even should consider bearing and raising children. The impact of these negative attitudes is increased when they are held by those who constitute the closest support persons available to the disabled--their family, friends, and health care providers (Dimond & Jones, 1983). These attitudes have resulted in the lack of knowledge of the needs and numbers of disabled mothers. The population of disabled parents is in the unique position of being socialized as disabled and having to socialize their children to the perspective of the non-disabled. A disabled mother may have difficulty understanding the behavior of her non-disabled child.

The exploratory study specifically addresses the problem of limited data relating to the physically disabled woman's perception of social support, needs, and experiences during the transition through parenthood. It is assumed that these perceptions reflect essential aspects of parenting and may complicate, or at least alter, the parenting experiences of the disabled woman.

Significance of the Study

It is essential that the problems and experiences of the population in the study be explored. The information gained from this research will be used to identify needs, to evaluate the perceived degree of support available to these women, and to provide insight into how these services may be improved to meet presently unmet needs. The findings will also generate ideas for future research. Ultimate

benefits will extend beyond the disabled woman herself, to her children, and to the community as a whole.

Purposes of the Study

The overall purposes of this exploratory study were: to identify the extent to which her support network influences the disabled woman's decision regarding parenthood; and to describe some of the perceived needs, concerns, and experiences of physically disabled women contemplating pregnancy, anticipating birth, and raising a child/children.

Because of the exploratory nature of this study, no directional hypotheses were tested. Rather, the intent of the research was to generate a data base and hypotheses that could guide future research.

Research Questions

Specifically, this descriptive study was designed to explore the following questions:

1. Does the physically disabled woman perceive differences in the support provided by family, friends, and professionals when she is making the decision to become a parent? and
2. Is there a relationship between the emotional support, information, and instrumental assistance received from the social network of family, friends, and professionals and the disabled woman's decision to become a parent?
3. What are some of the health care experiences of disabled women contemplating, anticipating, and raising a child/children?.

Definition of Terms

Physically disabled Woman: a woman, over 18 years of age, with a neurosensory or neuromuscular deficit that has existed prior to the birth or adoption of one or more children.

Neurosensory deficit: a severe visual or hearing impairment.

Neuromuscular deficit: a condition involving nerve and muscle impairment, such as cerebral palsy, meningomyelocele, and spinal cord injury.

Social support: the extent to which the physically disabled woman perceives that ideological support, information, emotional support, or instrumental assistance has been received.

ideological support: support for a person's role decisions and behavior in accord with role ideology (Power & Parke, 1984); also referred to as support for one's social expectations.

information: provision of knowledge about plans for the future (Cochran & Brassard, 1979) and assistance in locating resources and aid (Unger & Powell, 1980).

emotional support: that which results in the awareness of being loved and valued as well as obligated to one's social network (Cobb, 1976).

instrumental assistance: support characterized by material goods or services designed to reduce financial or economic hardship (Unger & Powell, 1980).

Assumptions and Limitations

The assumptions and limitations in research design affecting internal and external validity affect the credibility of the investigators findings. The basic assumptions upon which the study is based were: that the conceptual framework was sound; that the scales used were accurate measures of social support; that the criteria for subject selection aided in increasing the homogeneity of the sample; and that the types of disability--neurosensory and neuromuscular--were different enough to establish categories for comparison.

Findings of this reseach are limited to the physically disabled women participating in the study. Lack of a random sample and use of volunteers was expected to affect the external validity, and thus the generalizability, of the study. Diverse methods of data collection also increased the variance. Additionally, there is a paucity of research on physically disabled women who choose, or choose not, to become parents. The lack of available data limits the validation of findings.

Procedure

Fifty women over eighteen years of age, who have been physically disabled prior to the birth or adoption of one or more of their children, comprised the sample for the study. Subjects were divided into two groups, with the type of physical disability determining group membership. Subjects in Group 1 had visual or hearing impairments, and subjects in Group 2 had meningomyelocoele, spinal cord injury, and other similar severe neuromuscular disabilities. Since no comprehensive list or sampling frame existed from which subjects could be drawn, a sample

of convenience was used. Subjects were not deceived in any way, no information was withheld from them, and informed consent was obtained. Confidentiality of the research data was assured.

The research was designed to be performed in two phases. The first phase sought to answer the first two research questions, focusing on support systems, through the distribution and analysis of a questionnaire. The survey format was chosen for its appropriateness in collecting facts, opinions, and attitudes when that information does not presently exist. The questionnaire used in the study was constructed and content validity sought on the basis of existing literature on physical disabilities, parenting, and support systems. Knowledgeable persons examined the items for relevance. Reliability of the questionnaire was increased through question pretesting and a Cronbach alpha was performed to determine the internal consistency of the scales.

Administration of the questionnaire was done through distribution and retrieval of the instrument by mail, meeting with one small group of hearing impaired mothers, and over the phone with several visually impaired mothers who requested the researcher's assistance. Descriptive statistics, ANOVA (repeated measures), and Pearson correlation analysis were used to analyze the data.

The second phase of the research involved the administration of a nonschedule standardized interview to selected questionnaire respondents for the purpose of exploring the third research question. The interview was designed to permit physically disabled women to answer questions regarding their perceptions of needs and experiences during their transition through parenthood and to validate questions relating to

social support in the questionnaire. Content analysis was used to examine the interview data and direct quotations of respondents used to supplement the quantitative analysis.

Summary and Overview

The first chapter introduced the present study. The purpose of the study was to identify the extent to which the physically disabled woman's support network influences her decision regarding parenthood; and to describe some of the perceived needs, concerns, and experiences of physically disabled women contemplating, anticipating, and raising a child/children.

The following research questions were investigated:

1. Does the physically disabled woman perceive differences in the support provided by family, friends, and professionals when she is making the decision to become a parent?

2. Is there a relationship between the emotional support, information, and instrumental assistance received from the social network of family, friends, and professionals and the disabled woman's decision to become a parent? and

3. What are some of the health care experiences of disabled women contemplating, anticipating, and raising a child/children?.

A study exploring these questions can yield significant information and contribute to the limited amount of information in this area.

Chapter II contains a review of the literature relating to social support, parenting, and physical disability, while Chapter III describes

methods for data collection and analysis. In Chapter IV, the results of the study are presented, and Chapter V provides a discussion of the results. A recapitulation of the study is found in Chapter VI with a discussion of implications of the findings and suggestions for future research.

CHAPTER II

REVIEW OF RELATED LITERATURE

The Physically Disabled

"Literature dealing specifically with individuals having disabilities in the context of developmentally normal relationships, such as dating and marriage, is embryonic and virtually non-existent"(Bernardo, 1981,p.214). Information and statistics on the disabled are fragmented and unsystematic. Consensus on an operational definition of disability is lacking. As a result, discrepancies are noted in numbers reported.

A 1979 National Health Survey conducted by the National Center for Health Statistics found the following: almost 44 million people, over one fifth of the non-institutionalized civilian population, was estimated to have one or more impairments, while 9.9 million experienced two or more impairments; about 48% of the 44 million had chronic activity limitations, and women in this group between 17 and 44 years of age have between 70 and 100% more physician visits than men; deformities and orthopedic impairments account for 14.4% of the limitations reported; and, women between 17 and 44 years with chronic activity limitations are less likely to be wives than women without limitations, and more likely to live alone (National Institute of Handicapped Research, 1984). However, Vash (1982), when seeking disabled women who were successful in non-traditional areas, found "a preponderance of

candidates who were married and whose spouses were emotionally and materially supportive of their careers" (p.201).

Biological, psychological, sociocultural, and interpersonal factors affect how the individual deals with her condition. Adaptation involves ongoing, creative interactions between the individual and her environment, with available options limited by the specific disability and body systems affected.

According to Dimond (1983), "adaptation is evaluated from many perspectives and by many persons. The client, his/her family, friends, employers, health care providers, and funding agencies... may each have different sets of criteria for measuring different sets of expectations"(p.638). These differences in perspectives and expectations can create multiple and varied responses toward the disabled individual, ultimately provoking considerable stress.

Non-disabled persons interacting with persons who have some apparent physical deviation from the norm--some stigma--may experience some embarrassment or discomfort, and seek to avoid personal contact (Gelman, 1959).

Parenting and the Health-Care Institution

The health care system is the institution assuming primary responsibility for assisting individuals in their access to and transition through parenthood. It is a system that uses expert, legitimate, and even coercive power as a mechanism of control over who should parent and how they should parent. As such, the health care system is a major determinant in the quality of parenting. If parenthood

is determined to be problematic, health care professionals may use measures to decrease available choices and, in some sense, attempt to deny the prospective parent this opportunity. In fact, family and friends, in addition to health care providers, discourage most disabled women from considering parenthood, voicing concerns regarding the potential for inheritability of the disability as well as the safety of the infant (Asrael, 1982).

Horowitz, Hughes, and Perdue (1982) have identified four phases of parenting: (1) Birth control phase, when issues such as birth control, sexuality, and sex education arise, and the individual has few alternatives to the services of the health care system; (2) Anticipatory phase, when the decision whether or not to become a parent is made, often in the context of the family, and when, according to Prochaska and Coyle (1979), little help is available for persons trying to make this decision; (3) Birth phase, when health care institutions are often concerned with physiological indices and have been primarily responsive to the middle class nuclear family, and (4) Childrearing phase, with its emphasis on medical and nonmedical preventive care such as assessment, health education, consultation, and referrals.

Health has traditionally been viewed as the absence of disease, with mortality and morbidity statistics used as outcome measures. At present, while success measured as "parental adjustment to pregnancy, satisfaction with the birth experience, and health adaptations to the demands of early parenthood are usually not considered as important or significant"(Choi, 1984, p.14), the broadening concept of health will incorporate concern for individual well-being and quality of life, and

focus on the individual rather than the problem or the disease. Dimond (1983) confirms that health care provider's goals are often in conflict with or incompatible with those of patients--the former showing increased concern about physiological deviations while the latter are concerned with quality of life and social functioning.

Women are seeking increased accessibility to health care, more sensitivity to what it means to be a woman in today's society, thorough and honest communication, ability to participate in decision-making, and information on availability of alternatives to standardized care (Martin, 1978). However, health care providers do not always have the answers to questions about outcomes; the lack of information can create confusion and interfere with communication. In fact, many women have expressed feelings of "gross insensitivity on the part of medical staff regarding important aspects of female sexuality"(Task Force on Concerns of Physically Disabled Women, 1978, in Thurer).

Decision-Making

Janis developed a five stage schema of the decision-making process based on studies of individuals who were vigilant in reaching a personal decision they ultimately acted upon (Janis & Mann, 1977). While the decision-making process is applicable to a wide variety of personal decisions, it is influenced by a multitude of psychological factors including the coping pattern used. The process may proceed sequentially or may vacillate between stages.

In the first stage, one surveys the threat or opportunity; the need for changing one's course of action is then considered. One fears

possible loss of self-esteem, family and/or friends for refusing to acknowledge the need for change. Anticipation of social and self-disapproval for not maintaining the status quo may develop. In the second stage, the individual usually becomes more open to and seeks advice and information from others, especially knowledgeable associates. Depending upon the coping pattern used, alternative choices sought may be biased or unbiased. Stage three finds the vigilant decision-maker considering the advantages and disadvantages until selecting the course that is most in accord with his goals. If not satisfied with the alternatives, the individual may experience stress and return to stage two, seeking a more acceptable course of action. The covert decision is made in stage four. While concerned with the approval or disapproval of others in the social network, and possibly again considering the risks before making a final commitment, the individual chooses to inform others. Unless necessary for implementing the decision, he can usually convince others that his choice is correct. In the fifth and final stage, the individual maintains his decision until he becomes dissatisfied with the choice of action he has chosen, due to the negative feedback he receives from self and others, and his capacity to tolerate that feedback.

Situations require a target of influence, source of influence, and means of communicating a signal through threats, promises, recommendations, and warnings (Tedeschi, Bonoma & Schlenker, 1972). According to Tedeschi and Bonoma (1972), the source may (a) intentionally attempt to influence attitudes or actions of the target through use of information, threats of punishment or force, and promises of ultimate provision of reward when attitudes are changed; (b)

unintentionally influence the target through modeling or social contagion; or (c) adopt manipulative strategies to keep the target unaware of the source's intentions. The social status of physicians and other health care professionals also conveys a considerable degree of social influence on adherence to professional recommendations in the form of legitimate and expert power, and sometimes reward and coercive power (Janis, 1982).

Social Support and Support Networks

There are several different types of support or aid provided by social networks: instrumental support, emotional support, and information (Unger & Powell, 1980; Crnic, Greenberg, Ragozin, Robinson & Basham, 1984). Unger and Powell (1980) have characterized instrumental support as the material goods and services that can reduce financial or economic hardship. Lindblad-Goldberg and Dukes (1985) expanded the functional definition to include various types of concrete assistance provided to a person as needed. Physical support (Power & Parke, 1984) and the provision of goods and services (Cochran & Brassard, 1979) can be included in this category. Emotional support, as a form of information, results in the awareness on the part of the individual that she is loved and valued, as well as obligated to her network (Cobb, 1976). Sympathy, advice and the release of frustration are components of emotional or relational support (Cochran & Brassard, 1979). Affective functions can also be characterized by the frequency, quality and degree of emotional interchange (Lindblad-Goldberg & Dukes, 1985). With the third type of support, individuals are provided with information about

future plans, jobs, and so forth (Cochran & Brassard, 1979); individuals are also assisted in locating resources and aid (Unger & Powell, 1980).

A fourth type of support, ideological support, is provided to the woman with regard to the ideology of her role decisions (Power & Parke, 1984). According to Power and Parke (1984), ideological support provided by the support network influences the extent of adaptation to the maternal role.

According to Caplan (1974), individuals have a variety of needs for love, intimacy, validation of personal identity, help, control of emotions, and so forth. To meet these needs, a broad range of relationships are developed. Included in the support system are spouse, family, friends, neighbors, colleagues at work, and various service providers. Intermittent helping relationships are also formed with professionals such as lawyers, social workers, doctors, and nurses.

Various types of social support are available from members of the health care system during an individual's transition through parenthood. For example, genetic counseling is recommended for anyone with a chronic illness, disability, or condition that may be inherited by offspring (Asrael, 1982; Anderson, 1981; Task Force on Concerns of Physically Disabled Women, 1978). It provides prospective parents with the information upon which to base an informed decision about parenthood. Some disabilities with the potential for inheritance include: spina bifida, certain types of deafness and blindness, some muscle diseases, and osteogenesis imperfecta.

The importance of childbirth education classes has also been well-documented in the literature. These classes provide the childbearing

couple with the opportunity to be given information and to ask questions about physical changes and feelings experienced during pregnancy, as well as to learn the skills needed during labor, delivery, and the early postpartum period (Dzurec, 1981). This information can reduce the stress of pregnancy and early parenting.

Parents with disabilities may require certain adaptations in the content and format of the classes. Baranowski (1983) has discussed the effects of communication barriers experienced by the deaf in the traditional childbirth education class. She identified problems with the use and translation of some English words into Ameslan (a sign-language of the deaf), difficulty understanding sound films, and potential for decreased interaction with the hearing participants.

Health care providers do not have frequent contact with disabled women. Therefore, information may be unavailable or fragmentary with regard to the necessity of adaptations in the management of certain conditions, such as dysreflexia in a quadriplegic woman during labor and delivery, or complications of pregnancy or delivery due to muscle disease (Asrael, 1982).

Individuals may attempt to decrease the ambiguity that results from lack of information by comparing themselves with others in similar situations, and this interaction is probably very useful (Mechanic, 1977). Self-help and support groups provide the opportunity for sharing common experiences, giving and receiving help and support from one another, and obtaining information, solutions, and alternatives (Dimond, 1983, p.642). Once the childbearing decision is made, support is often sought from family, friends, and health care providers. While the

support of all family and friends is not considered essential, the support of health care providers is considered mandatory and can engender feelings of control, respect, and dignity in the disabled woman (Asrael, 1982). Other disabled parents are an additional resource.

Wandersman, Wandersman and Kahn (1980) studied the differences in social support, including emotional and instrumental, influencing the adjustment of parents during the first year following the birth of their child. They found social support to be a multidimensional concept and suggested that specific types of support be clarified, rather than considering social support in general. Specific types of support were also related to adjustment and found to help in the process of coping during the postpartum period.

Power and Parke's (1984) tentative model of the four types of social network support influencing the transition through parenthood, from the last trimester of pregnancy through the late postpartum period, suggests that the type that seems most important varies with the point in time in the transition. Further, they suggest that intervention programs would probably be most effective if they focused on 1) the provision of ideological support and information during pregnancy, and 2) information and physical support during the postpartum period.

Social support appears to be an important factor: influencing adaptation to parenthood, behavior, and attitudes (Crnic et al., 1984); mediating the effects of stress (Haggerty, 1980); improving physical and psychological well-being (Pilisuk, 1982); and protecting the individual in crisis from numerous pathologic conditions (Cobb, 1976).

Hogue (1977) has defined support systems as " a defined set of persons consisting of a focal or anchor person, all the family, all the friends and all the helping persons who stand ready to serve the anchor person, and the linkages or relationships among those people " (Friedman, 1982, p.68). Thus, the social network is formed as a result of the person's relationships with family, friends, neighbors, co-workers, and others with whom some form of interaction occurs. Service providers and professionals can also be part of the network (Halevy-Martini, Hemley-Van Der Velden, Ruhf, & Schoenfeld, 1984). The average size of the personal network expected includes 25 - 40 persons and falls into four to five clusters of friends, colleagues, relatives, social companions, and co-workers (Erickson, 1984). However, there is most likely no one universally supportive network.

Two Models for Parenting

Belsky (1984) developed a theoretical model identifying the determinants of healthy parental function based upon theory and research on dysfunctional parents and child abuse. The model has three major subsystems: (a) the personality and psychological well-being of the parents that is, in part, a result of their childhood experiences; and (b) the characteristics of the child, including the ease or difficulty caring for the child and parent/child "goodness of fit"; and (c) sources of stress and support that promote psychological and physical health. The hypothesis is that each subsystem provides some degree of stress or support for parental function. Functioning is most effective when each subsystem is weighted in favor of the supportive mode and the least effective when functioning is weighted in favor of the stressful mode.

While Belsky suggests that there are multiple factors influencing parental function, the model is not based on the presumptions that the characteristics of the child, parent, and social context equally influence parenting. Belsky hypothesizes that the personal resource system is most facilitative of parental function. Of the three subsystems, child characteristics alone is least able to facilitate functioning. The parent's own personality and developmental history exert an indirect influence on parenting through their affect on the environment in which the parent-child relations exist.

Greer (1985) proposed a research paradigm for the study of the physically disabled parent and family, a subject about which there is little research. The paradigm is designed to guide investigators in the development of a comprehensive body of knowledge. He identifies three major categories of variables in the model: (a) Parent, (b) Child, and (c) Family Situation variables. Parent and child categories include both independent and dependent variables. Independent parent variables include factors such as: type and severity of disability, age of onset, educational level, and socioeconomic status. Dependent parent variables focus on the adjustment levels and childrearing attitudes. Independent child variables encompass many factors including present age, age when the parent became disabled, sex, and birth order. Variables such as self-concept, level of adjustment, and attitudes towards parents and other disabled persons are identified as dependent variables.

*A Rationale for Studying
Handicapped Parent Families*

Thurman, Whaley and Weinraub (1985) have identified several rationales for studying handicapped parent families. These include: to provide data to policy-makers to permit the making of informed decisions; to allow for development and maintenance of appropriate and sufficient services and to clarify basic questions regarding the family system and child development.

This research provides an opportunity to examine a little-studied parent characteristic; parental disability.

CHAPTER III

METHODOLOGY

The overall purpose of this study was: to identify whether the physically disabled woman perceives differences in support provided by various members of her support system; to examine the extent her decision regarding parenthood is perceived to be influenced by various support persons; and to describe some of her perceptions with regard to health care experiences during childbearing and childrearing. This was done through use of a questionnaire and a nonschedule standardized interview. Identifying these factors could suggest areas of satisfaction as well as assist in need identification. This chapter includes a discussion of the design, sample, data collection, and analysis procedures used in the study.

Design and Research Questions

The descriptive investigation was designed to permit exploration of relationships without manipulation of variables. While this design has its limitations, it allows the researcher to collect a large amount of data relating to the research questions. It can also generate hypotheses for future experimental and quasi-experimental research. The following research questions were explored:

1. Does the physically disabled woman perceive differences in support provided by family, friends, and professionals when making the decision to become a parent?

2. Is there a relationship between the emotional support, information, and instrumental assistance received from the social network of family, friends, and professionals and the disabled woman's decision to become a parent? and

3. What are some of the health care experiences of disabled women contemplating, anticipating, and raising a child/children?

The questionnaire (see Appendix A) and interview (see Appendix B) used to examine these questions are discussed in the following section.

Instrumentation

The social support variables of information, emotional support, and instrumental assistance were measured by three scales contained in the survey (Questions 5, 6, and 7). Question 4 attempted to explore the ideological support provided by the social network, and the remaining questions provided demographic information. The survey format is appropriate for collecting facts, opinions, and attitudes when that information presently does not exist. The relationship between these sociological and psychological variables may then be examined.

The variable of physical disability was studied by including women with neurosensory and neuromuscular limitations. Perceptions of childbearing and childrearing experiences were obtained using interview questions developed by the researcher.

Bokemeier and Monroe (1983) performed a content analysis of 80 research articles on conjugal and family decision-making published in 48 professional journals. The majority of articles used questionnaires and interviews as techniques for data collection. Of these, approximately

19% used scales and 35% used nonparametric descriptive statistics. Likert-type scales have also been used in the analysis of attitude development about shared decision-making by medical and surgical residents (Eisenberg, Kitz & Webber, 1983). They also have been used to examine the relationship between the search for information in the childbearing decision and satisfaction with life (Holahan, 1983), as well as to evaluate a decision-making workshop for women who were having difficulty deciding whether or not to become a parent (Daniluk & Herman, 1983).

Scales have been used in the investigation of social support as well. Dhooper (1984) examined the type, source, and degree of support received by family members of persons experiencing heart attacks. Hirsch (1979) used a self-report questionnaire to investigate college student's overall satisfaction with persons and with their interactions. Scales have also been used to examine maternal stress and social support (Crnic et al., 1984), and to study the effects of social support in the adjustment to parenthood (Wandersman, Wandersman & Kahn, 1980).

The questionnaire in this study is designed to be a self-administered instrument that requires approximately 30 minutes to complete. It is constructed to elicit demographic data from the respondents and to assess the extent to which subjects perceived and were influenced by social support from a network of support persons.

The questionnaire was constructed and content validity sought on the basis of existing literature on physical disabilities, parenting, and support systems. Knowledgeable persons also examined items for relevance. Reliability of the survey questionnaire was increased

through question pretesting in order to decrease ambiguity and provide clear instructions to the respondents, and also through construction of a questionnaire of adequate length.

In the directions for completing the questionnaire, respondents are asked to circle the number matching their response to each question; space is provided to allow subjects to add responses that are not pre-specified. This format permits the researcher to gather data on numerous facets of parenthood and physical disability through the use of scales as well as fixed-alternative and open-ended items.

In response to the four questions pertaining to social support, participants are asked to rate each of 14 potential support persons (including 2 'other' categories - other family members and other) on a Likert scale. This 7 point intensity scale yields ratings from most supportive (7) to least supportive (1).

Due to the amount of missing data, the support persons were collapsed into 7 categories: spouse, mother, father, sibling (combined brothers and sisters), in-laws, friends, and medical professionals (doctors and nurses). On the measure of ideological support (Question 4), examination of internal consistency revealed a Cronbach alpha coefficient of .6013 and a standardized item alpha .6399. The researcher found the following internal consistency scores for each of the scales of information (Question 5a), emotional support (Question 6a), and instrumental assistance (Question 7a) provided respectively: (a) Cronbach alpha coefficient = .7170, .8072, and .7198, and (b) a standardized item alpha = .7222, .8067, and .7345. Measures of the influence of information (Question 5b), emotional support (Question 6b),

and instrumental assistance (Question 7b) received the following scores of internal consistency respectively: (a) Cronbach alpha coefficient = .7041, .6535, and .8011; and a standardized item alpha of .7201, .6716, and .8315. The researcher concluded that these scales demonstrated satisfactory consistency among items.

Responses to social support scales were found to have an 83% reliability rating. Consistency of 11 participant's responses was verified through answers to questions in the interview.

The interview was designed to permit physically disabled women to answer questions regarding their needs, perceptions, and experiences during their transition through parenthood. Proposed interview questions were examined by mothers with neurosensory and neuromuscular disabilities as well as by two psychologists. Their input aided in question development and revision. Validity of the interview was improved through attempts to eliminate potential interviewer bias and limit the number of interviewers to two. Interviewer experience gained through question pretesting also increased reliability. A retrospective approach was used since prospective parents might not have been able to anticipate needs and experiences.

The specific types of items used in both the interview and questionnaire have certain advantages. Fixed-alternative items provide for greater uniformity of response and reliability and are easier to code. The items are often superficial, however, and preconceived categories may irritate some of the respondents. Open-ended items place no constraints on the respondents reaction and provide for greater depth of response. When used in the interview, they are helpful in developing

rapport and can be used to assess the respondents knowledge of a subject. The major disadvantages with open-ended items are in increased time requirements for responding and coding; in the interview, there is potential for increased bias. Finally, the scale serves as an interval measure of a variable. When the responses to the Likert-type format items are summed, it is possible to obtain an individual attitude score. Another advantage of the scale is in the variance obtainable.

More general limitations of the questionnaire format include problems with generalization as a result of the usually slow and low response rate (50-60%), inability to control the respondents understanding of the questions, and the potential for obtaining misleading or incomplete responses. Respondents must also be literate and certain responses may be affected by over or under-rater bias.

The questionnaire format has several advantages for this research. Since it can guarantee confidentiality and can be self-administered, it is more likely to elicit honest responses and will not be affected by interviewer bias. It also covers a broad scope, is less expensive, and can reach a larger number of persons than the interview technique. Furthermore, pretesting helps eliminate ambiguity and bias, and improves the questionnaire design.

The nonschedule standardized interview is intended to elicit specific information, but the way the questions are phrased and ordered are geared to the characteristics of the respondent. While Maccoby and Maccoby (1954, p. 499) suggest that this format is best-suited for exploratory studies, the format has also been used by Lindesmith and Becker to extend beyond exploration to affirmation of conclusions (Denzin, 1978).

The main disadvantages to the interview format are of: potential bias on the part of the respondent attempting to please the interviewer or on the part of the interviewer seeking answers that support her preconcieved hypotheses; misunderstanding of the meanings or symbols of the physically disabled women; reluctance on the part of the respondent to reveal the requested information; time; cost; and the respondent's interpretation or possible misinterpretation of a group's values. To control for these, the investigator--aware of the information desired and able to clarify to the respondent the precise intent of the question--performed all interviews except one. A second interviewer, trained by the researcher as to how the interview was to proceed, performed one face-to-face interview out of state.

The rationale for use of the nonschedule standardized interview lies in its numerous advantages for this type of research. Specifically, questions can be rephrased, as needed, to assure understanding. The sequence of the questions may be altered to reflect the respondent's readiness to discuss a topic as it arises, thus maintaining interest and motivation. In addition, the respondent can bring up important information or issues that might not otherwise be addressed in the schedule, and the interviewer can challenge or clarify the respondent's reply as needed. Since interviews provide for in-depth understanding of responses and permit the gathering of more detailed and complex information, certain interview questions were used to validate the questionnaire.

Pilot Study

The pilot study was performed in order to develop an appropriate questionnaire and procedure needed for the data collection process. Because the intended sample of physically disabled women is limited in number and accessibility, the questionnaire was piloted on a non-disabled parent population. Fifteen surveys were distributed. The participants were asked to mail the completed questionnaire in the stamped, return envelope provided. Thirteen questionnaires were returned; all were usable. Responses were coded by the investigator in an attempt to assure reliability. Because problems with sampling included the lack of a prepared sampling frame, a non-probability sample, and small sample size, both bias and random error must be acknowledged.

A copy of the questionnaire was also given to five experts in the area of maternal child health for review and suggestions. Following this review and examination of the results of the pilot, the original questionnaire was modified. Some open-ended questions were changed to closed-question format, and additional options were made available to several questions. Four new questions were added and several deleted. Other minor format changes were made to eliminate ambiguities in questions.

A pilot interview was also performed to give the interviewer experience in the interview approach and to provide the opportunity to add, delete, and revise questions as needed.

Research Sample

In an attempt to control certain extraneous sources of variance and enhance the homogeneity of the physically disabled persons participating in the study, specific criteria were established for selecting research subjects. Sex was controlled by including only women as participants. This decision was made because a major focus of the study was on childbearing, and women with or without spouses/partners may experience this process.

Additional selection criteria specified the type of physical disability. Only women with neurosensory (NS) deficits, visual or hearing impairments, or neuromuscular (NM) deficits, such as cerebral palsy or spinal cord injury, would be included. It was felt that the women in the neuromuscular group would experience greater difficulty with mobility, while the women in the neurosensory group would have greater communication deficits. Selection criteria required that the woman be over 18 years of age and physically disabled prior to the birth, or adoption, of one or more of her children.

Selection of Research Respondents

Subjects were sought through personal contacts and referrals, community agencies, organizations, institutions, support groups, and agency newsletters. Contacts were made with many facilities, such as the Visiting Nurse Association of Chicago, Department of Rehabilitative Services of Illinois, HOW (Handicapped Organized Women), Guild for the Blind, Catholic Office for the Deaf, and Lighthouse for the Blind.

While the sample was expected to be small and somewhat inaccessible, a minimum number of 30 subjects was sought. Use of volunteers was necessary because of the lack of an existing sampling frame. However, use of volunteers was a limitation in the study because their characteristics may be different from a randomly sampled population.

Although the participants are not expected to benefit directly from this study, the researcher feels that the information obtained could serve to benefit others. If a respondent indicated an interest in a report, a brief summary of the research findings will be available.

Description of Research Respondents

The research population is best described by examining the characteristics of: (1) the entire sample of questionnaire respondents (n=50), and (2) each of the two subsets of the sample, (a) those participants whose responses were included in the analysis of social support (n=34), and (b) those interviewed (n=11). A comparison of demographic data from respondents participating in all phases of the research is found in Table 1. Further comparisons are provided in Table 2, A Summary of Data Pertaining to Childbearing Characteristics and in Table 3, A Summary of Data Relating to the Children of Respondents.

A total of 51 respondents completed and returned the questionnaire; one questionnaire was excluded due to an alleged history of mental illness. Of the respondents, 34% (n=17) were in the neurosensory group (NS) and 66% (n=33) in the neuromuscular group (NM). Of the total sample, 68% (n=34) were married, 14% (n=7) divorced, 8% (n=4) separated, 8% (n=4) single, and one was widowed.

Table 1

Summary of Demographic Data for Research Participants

Category	Questionnaire Respondents (N=50)	Social Support Participants* (N=34)		Interviewees (N=11)	
		NS(N=12)	NM(N=22)	NS(N=4)	NM(N=7)
Age					
22 - 29 years	7	1	3	1	2
30 - 39 years	28	4	16	2	4
40 - 49 years	10	4	3	1	1
50 - 55 years	5	3	0	0	0
Mean age in years	36.9	36.7		33.7	
Standard deviation	7.7	7.5		6.7	
Type of Impairment:					
Neurosensory					
Visual Impairment	11	8		3	
Hearing Impairment	6	4		1	
Neuromuscular					
Spina bifida	7		6		2
Spinal cord injury	6		5		1
Multiple sclerosis	6		4		2
Dystonia musculorum deformans	6		2		0
Post polio	5		4		2
Cerebral palsy	1		0		0
Charcot Marie syndrome	1		1		0
Rheumatoid arthritis	1		1		0
Age Disabled					
Birth	16	6	5	2	2
Before 1 year	2	1	1	0	0
2 - 39 years	31	5	16	2	5
Missing	1	0	0	0	0
Age of Decision to become a parent					
13 - 19 years	2	1	1	1	0
20 - 26 years	19	8	11	1	2
27 - 33 years	9	1	8	0	5
Don't remember	3	1	2	1	0
Missing	1	1	0	0	0

Table 1 continued

Summary of Demographic Data for Research Participants

Category	Questionnaire Respondents (N=50)	Social Support Participants* (N=34)		Interviewees (N=11)	
		NS(N=12)	NM(N=22)	NS(N=4)	NM(N=7)
Mean age first pregnancy	25.6	26.5		27.1	
Standard deviation	4.6	4.3		5.0	
Marital Status					
Married	34	5	20	4	6
Single	4	0	1	0	0
Widowed	1	0	0	0	0
Divorced	7	3	0	0	1
Separated	4	4	1	0	0
Race					
Black	6	2	1	2	0
Caucasian	43	9	21	2	7
Hispanic	1	1	0	0	0
Years of Education					
12	12	3	2	2	1
13 - 16	27	8	13	1	4
17+	10	0	7	1	2
Missing	1	1	0	0	0
Educational Degrees					
Diploma	24	7	9	2	4
Associate	3	0	2	0	1
Baccalaureate	13	5	5	1	1
Masters	8	0	5	1	1
Doctoral	1	0	1	0	0
Other	1	0	0	0	0
Employed					
Yes	25	7	10	2	2
No	25	7	12	2	5

Note: * Only respondents who perceived that they had made a decision to have a child were included in the analysis of social support.

Table 2

Summary of Data Pertaining to Childbearing



Category	Questionnaire Respondents (N=50)	Social Support Participants* (N=34)		Interviewees (N=11)	
		NS(N=12)	NM(N=22)	NS(N=4)	NM(N=7)
Pregnancy decision					
Planned	34	12	22	3	5
Unplanned	12	0	0	1	0
Other	4	0	0	2	
Genetic counseling					
No	41	11	16	4	5
Yes, before pregnancy	4	0	3	0	1
Yes, after pregnancy	4	1	3	0	1
Missing	1	0	0	0	0
Person suggesting counseling					
Self	8	1	6	0	3
Physician	4	0	4	0	2
Family member	3	2	1	0	1
Other	1	0	0	0	0
Obstetrician experience with disabled women					
Yes	14	2	7	1	2
Unknown	18	5	7	2	1
No	12	4	7	1	3
Does not apply	6	1	1	0	1
Reasons cited for child-birth class non-attendance					
Inconvenient location	3	1	0	1	0
No desire	2	0	1	0	0
No need	3	0	1	0	0
Did not meet needs	2	0	1	0	0
Disinterested spouse	1	1	0	0	0
Too early in pregnancy	1	0	1	0	1
Too late in pregnancy	1	0	1	0	0
Unaware of class	6	3	0	1	0
Other	8	3	3	0	1

Note: * Only respondents who perceived that they had made a decision to have a child were included in the analysis of social support.

Table 2 continued

Summary of Data Pertaining to Childbearing

Category	Questionnaire Respondents (N=50)	Social Support Participants* (N=34)		Interviewees (N=11)	
		NS(N=12)	NM(N=22)	NS(N=4)	NM(N=7)
Childbirth education class					
Group classes	24	5	13	3	5
Private classes	1	1	0	0	0
Adaptations made in content presented					
Yes	4	2	1	2	1
No	17	1	10	1	3
Don't know	4	0	4	0	0
Does not apply	27	0	0	1	3
Adaptations desired in information presented					
Yes	12	1	7	0	4
No	7	4	2	1	0
Don't know	4	0	4	0	0
Does not apply	27	0	9	1	3
Special arrangements made for delivery					
Yes	15	4	10	1	3
No	20	7	6	3	2
Don't know	2	1	0	0	0
Does not apply	11	0	6	0	2
Special arrangements desired for delivery					
Yes	14	5	6	0	2
No	18	6	5	4	1
Don't know	4	0	3	0	1
Does not apply	14	1	8	0	3

Note: * Only respondents who perceived that they had made a decision to have a child were included in the analysis of social support.

Table 3

Summary of Data Pertaining to Children of Research Participants

Category	Questionnaire Respondents (N=50)	Social Support Participants* (N=34)		Interviewees (N=11)	
		NS(N=12)	NM(N=22)	NS(N=4)	NM(N=7)
Number of Children					
Natural children					
None, pregnant	1				
One	16	2	9	1	3
Two	18	4	9	1	1
Three	10	4	3	1	0
Four	2	1	0	0	0
Five	2	0	1	0	1
Six	0	0	0	0	0
Seven	1	1	0	1	0
Adopted					
One	5	1	3	1	2
Two	1	0	1	0	0
Born with physical disability					
One	4	2	1	1	0
Unsure	4	0	1	0	1
Premature					
One	13	4	2	1	1
Two	3	1	1		
Three	1	0	1	0	3
Stillborn					
One	0	0	0	0	0
Two	1	0	1	0	0
Miscarried					
One	9	2	5	1	3
Two	2	1	0	0	0
Five	1	0	0	0	0
Unsure	1	0	1	0	0

Note: * Only respondents who perceived that they had made a decision to have a child were included in the analysis of social support.

Years of education ranged from 12 to over 17, with 48% (n=24) having completed high school and 52% (n=26) with education beyond high school. Respondents ranged in age from 22 to 55 years, with a mean age of 36.9 years (SD = 7.7). One half (n=25) were employed. Most were Caucasian (86%, n=43), six (12%) Black, and one Hispanic.

For 66% (n=33), the age at which the decision to become a parent was made ranged between 13 and 33 years; 24% (n=12) had unplanned pregnancies; 16% (n=8) sought genetic counseling; and 28% (n=14) had an obstetrician or health care provider who had experience with women with physical disabilities. The mean age at the birth of the first child was 25.6 years (SD = 4.6). One half (n=25) of the respondents attended childbirth education classes, with 'other' and lack of awareness of the classes as the reasons most often cited for non-attendance. Of the mothers attending the classes, one had planned an adoption and another knew in advance that she would be having a Cesarean section. Four women (8%) indicated that some adaptations were made in the content of the childbirth education classes, and 24% (n=12) wished that some information would have been included in the class. As shown, 30% (n=15) negotiated special arrangements in the hospital at the time of delivery, while 28% (n=14) wished that some special arrangements would have been made.

The majority of women had one (n=16), two (n=18), or three (n=10) children. Six (12%) had adopted children. Four mothers (8%) reported children with physical disabilities and 34% (n=17) indicated having premature infants. Twelve (24%) listed from one to five miscarriages, and one woman reported two stillborn infants.

A typical questionnaire respondent then was 36.9 years of age (SD = 7.7), Caucasian, married, had two natural children, a college or advanced degree, attended childbirth education classes, and was as likely as not to be employed.

Participants Included in the Analysis of Social Support

Summary data for the 34 participants whose responses qualified for inclusion in the analysis of questions pertaining to social support are found in column two of Tables 1 through 3. Only respondents who perceived that they had made a decision to have a child were included. Thus, women with unplanned pregnancies were excluded from the analysis.

The responses from these participants--68% of all the women completing the questionnaire--were included in the analyses of the data relating to (a) ideological support, information, emotional support, and instrumental assistance perceived to be provided by various support persons, and (b) the perceived influence of that support on the woman's decision to become a parent. In this group, 35% (n=12) had neurosensory impairments and 65% (n=22) had neuromuscular impairments. The majority were married (73%, n=25), 9% (n=3) divorced, 15% (n=5) separated, and one was single.

Educational preparation varied from 12 to 17 years, with 47% (n=16) having completed high school and most having some college education. This included two respondents with associate degrees (6%) and ten (29%) with baccalaureate degrees. Graduate degrees were held by 18% (n=6) of the respondents--five prepared at the masters level and one at the doctoral level.

The age at which the decision to become a parent was made was between 13 and 33 years for 88% (n=30) of the respondents. Three (9%) did not remember the age the decision was made and one respondent indicated that she had always wanted children. In this group, 21.2% (n=7) sought genetic counseling--42.9% (n=3) before the pregnancy and 57.1% (n=4) after the pregnancy. The first pregnancy occurred at the mean age of 26.5 years (SD = 4.3). Nine women (26%) had an obstetrician experienced with women with physical disabilities, and 56% (n=19) attended childbirth education classes. "Other" and lack of awareness were cited most often as the reasons for non-attendance at the classes. Adaptations were made in the content of the childbirth education classes for 9% (n=3), and 24% (n=8) would have desired adaptations in the classes. Approximately 41% (n=14) of the women acknowledged that special arrangements were made in the hospital at the time of delivery, while 33% (n=11) stated that they would have liked to have had some special arrangements made at that time.

The women had from one to seven children, with 32% (n=11) having one child, the majority (38%, n=13) two children, and 21% (N=7) three children. Four mothers, 12%, had adopted one child while one mother had two adopted children. Premature infants were reported by 26% (n=9) of the women and 9% (n=3) reported children with physical disabilities. Eight women (24%) indicated one or two miscarriages, and one mother reported two stillborn infants.

The mean age for the typical subject in this group was 36.7 years (SD = 7.5) and, as with the entire group of survey respondents, was Caucasian, married, had two natural children, a college or graduate

degree, attended childbirth education classes, and was as likely as not to be employed.

Participants Selected for Interviews

Characteristics of respondents selected to participate in the nonschedule standardized interviews are described in column three of Tables 1 through 3. Women with representative disabilities, who were currently raising young children in the home, were chosen. Eleven women, 22% of the total sample and approximately 30% of women whose responses qualified for inclusion in the analysis of social support, were interviewed.

The following is a brief description of each of the interview respondents. For purposes of confidentiality, certain information has been withheld in the individual descriptions.

Respondent 1 is a mid-thirties mother of one pre-school child who is confined to a wheelchair because of spina bifida.

Respondent 2 is a mother in her mid-thirties with spina bifida, clubfeet, and skeletal deformity of the ribcage and hips. She is raising one pre-school child.

Respondent 3 is a mother in her early thirties with post-polio and scoliosis who uses a cane or electric wheelchair. She has one infant.

Respondent 4 is a woman in her early forties who had polio as a child and is confined to a wheelchair. She has one school-age child.

Respondent 5 is a mother with multiple sclerosis who was diagnosed several years prior to the recent birth of her infant. She uses a cane for mobility.

Respondent 6 is a mid-thirties mother of two children under 5 years of age. She was diagnosed with multiple sclerosis and uses a wheelchair for mobility.

Respondent 7 is a woman who sustained a traumatic spinal cord injury. She is confined to a wheelchair and has several children under 8 years of age.

Respondent 8 is a mother of two children under 4 years of age who has been blind since birth due to retrolental fibroplasia.

Respondent 9 is a late forties mother of several grown children and one school-age child. She has been blind since school-age and uses a cane.

Respondent 10 is a mid-twenties mother of 2 children under 9 years of age. She has been visually impaired since school-age and uses a cane or guide-dog to assist mobility.

Respondent 11 is a profoundly deaf mother of three children under 6 years of age.

Four women (36%) had neurosensory impairments and seven women (64%) had neuromuscular disabilities. Ten (91%) were married and one was divorced. The four spouses of interviewees in the NS group had similar disabilities. In the NM group, none of the six spouses (one respondent was unmarried) were disabled. Two women with multiple

sclerosis had become disabled after marriage. Years of education ranged from 12 to 17 years, with 55% (n=6) completing high school and the remaining 45% (n=5) having an education beyond high school. One interviewee had an associate degree, one a baccalaureate degree, and 18% (n=2) held graduate degrees.

The decision to become a parent was made between 19 and 32 years for 82% (n=9) of the women; one did not remember the age at which her decision was made; and one pregnancy was unplanned. Two women (18.2%) sought genetic counseling--one before the pregnancy and one following the pregnancy. The first pregnancy occurred at the mean age of 27.1 years (SD = 5.0).

Of the women interviewed, 27% (n=3) had an obstetrician experienced with women with physical disabilities, 36% (n=4) did not, one did not know, and for one woman adopting a child this did not apply. Childbirth education classes were attended by the majority (73%, n=8) of the women and various reasons were cited by 27% (n=3) of the women for non-attendance. For 27%, (n=3) adaptations were made in the content of the childbirth education classes, and 36% (n=4)--all in the neuromuscular group--desired adaptations in the classes that were not made. Special arrangements were made in the hospital at the time of delivery for 36% (n=4); 18% (n=2) would have liked some special arrangements at that time.

The women interviewed had from one to seven children, with most (55%, n=6) having one child, 18% (n=2) two children, and three mothers having three, five, and seven children respectively. Three mothers had each adopted one child, 27% (n=3) reported premature infants, one had a

child with a physical disability, and one was unsure about the prognosis of her newborn infant. Four women (36%) reported one miscarriage.

The mean age for the typical subject in the interview group was 33.7 years (SD = 6.7). Most were Caucasian, married, had one natural child, a college or graduate degree, attended childbirth education classes, and were not employed. The educational level of the group was also slightly higher.

The subset of interviewees differed from the typical respondents to the questionnaire and those in the social support analysis group on several variables. Specifically, the mean age for those interviewed was approximately three years less and the mean age at the time of the first pregnancy from .6 to 1.5 years greater. The majority of women in this group had one child rather than two and was less likely to be employed.

The geographic distribution of all participants is presented in Table 4. The total sample population was drawn from 13 states. Responses of women from 12 states were used in the analysis of social support, and women from 6 states were interviewed.

Research Procedures

In this section, the methods for administering the research instruments and analyzing the research data are presented.

Methods of Data Collection

The research was performed in two phases. The first phase sought to answer the first two research questions and involved distribution and analysis of a survey questionnaire (see Appendix A). The second phase of this process involved the nonschedule standardized interview (see

Table 4

Geographic Distribution of Sample

State of Residence	Questionnaire Respondents (N=50)	Social Support Participants* (N=34)		Interviewees (N=11)	
		NS(N=12)	NM(N=22)	NS(N=4)	NM(N=7)
California	4	1	3	1	1
Colorado	2	1	0	0	0
Illinois	23	7	8	3	2
Indiana	1	0	0	0	0
Minnesota	4	0	2	0	1
Missouri	1	0	1	0	0
North Carolina	3	0	2	0	1
New Jersey	2	0	1	0	0
New York	2	0	2	0	0
Ohio	1	1	0	0	0
South Dakota	1	0	1	0	1
Wisconsin	3	0	1	0	1
Washington	1	0	1	0	0
Missing	1	0	0	0	0

Note: * Only respondents who perceived that they had made a decision to have a child were included in the analysis of social support.

Appendix B) of selected questionnaire respondents in an attempt to explore the third research question. Subjects were not deceived in any way, and no information was withheld from them.

Only physically disabled women who met the sample criteria were used as subjects after an appropriate consent (see Apperdix C for details) was obtained. The type of consent varied depending upon the phase of the research, questionnaire, or interview. Consent *Form A* was incorporated into and used for women completing the questionnaire. On the face sheet of the questionnaire, the subject is asked to read and sign the consent form located on the reverse side.

The questionnaire was given or mailed to a sample of physically disabled women meeting the criteria for subject selection. Subjects could receive assistance, as needed, in completing the form. The respondents were then asked to mail the completed form to the investigator in the self-addressed, stamped, return envelope, which was included with the questionnaire. There were no known physical or psychological risks to subjects asked to complete the questionnaire. Subjects could choose to complete and return the questionnaire or choose not to do so.

Subjects were sought for participation from June 1985 through January 1986. Data collection involved administration of the questionnaire either in person (on one occasion with an interpreter) and over the phone in the case of several visually impaired mothers. Other subjects self-administered the tool. Because of the need for confidentiality, representatives of organizations, such as the Dystonia Musculorum Research Foundation, agreed to mail the questionnaire with a

cover letter from the organization asking mothers to participate. In other cases, employees from organizations, such as the Lighthouse for the Blind and Visiting Nurse Association of Chicago, agreed to personally ask mothers if they would take part. The latter approach appeared to be the least effective method of obtaining subjects. One state organization, which initially appeared to be an excellent resource, was not. The counselors felt it would take too much time to both locate subjects who met the criteria and then to obtain their consent for release of information.

Eliciting participation involved contact with prospective subjects through phone calls, face-to-face communication, or by letter from an organization introducing the questionnaire. The researcher believed that some contact with the potential participants prior to the mailing of the questionnaire might increase what is generally a poor response rate to mailed questionnaires.

A cover letter, contained on the front page of the questionnaire, provided an explanation of the purpose of the research and an invitation to participate in the study. The letter also asked the participants to indicate whether they wished to receive a brief summary of the research findings and whether they wished to participate in a follow-up interview. In addition, the telephone number of the researcher was included in case any questions arose when the respondent was completing the questionnaire. Page 2 of the questionnaire contained the consent form. The survey was designed so that identifying information on the first two pages could be removed from the instrument itself to assure confidentiality. Accompanying the questionnaire was a self-addressed, stamped, return envelope.

Forty-two questionnaires were mailed to potential participants after personal contact with the researcher. The rate of return was 76% ($n = 32$), not including a group of five hearing impaired mothers completing the questionnaire in the researcher's presence. While eleven questionnaires were received as a result of agency cooperation, the rate of return could not be determined due to the agencies' need to preserve anonymity. Because identifying information was not included on the face sheet of the questionnaire of two respondents, the original source of contact could not be determined. A follow-up letter was not sent to any woman; potential subjects contacted by agencies were unknown to the researcher and a second contact of these persons would have required a considerable investment of time on the part of individuals in those organizations.

High response rate may have been the result of personal contact with the researcher, which allowed the potential participant to consent or refuse to participate before receiving the questionnaire. Also, personal contact provided the woman with an opportunity to ask questions after receiving an explanation of the purpose of the research. Many of the disabled women stated that the subject was understudied and wanted to share their experiences with other mothers. Two mothers asked how this research would be communicated to others. The researcher believes that personal contact was an important factor in increasing the response rate.

Alternate forms of collecting data may have introduced an extraneous source of variance into the study. An attempt was made to control for this variability by standardizing the format of the personal

contacts. The researcher contacted the individual, introduced herself, and informed the woman as to how her name came to be known to the researcher. The purpose of the research was revealed along with information about the questionnaire and the follow-up interview. The potential subject was then asked whether she would like to participate. If she consented, the survey was mailed to her home or office, completed in a small group with an interpreter and the researcher present, or completed over the phone at the woman's request. In the latter cases, the cover letter was read, informed consent obtained, and the entire questionnaire completed. In the case of a group of hearing impaired mothers, portions of the questionnaire were read aloud by the researcher while the interpreter used sign language.

The personal encounters of the researcher with the respondents and the use of an interpreter with the hearing impaired mothers may have injected variability into the study. Also, the completion of the questionnaire in a group may have had some affect. However, in all the cases, the mothers responded individually to the questions/instructions. None of the mothers receiving a mailed questionnaire or contacted directly by organizations asked for an interpretation of the questions/instructions or telephoned the researcher for clarification. Three of the mothers in the hearing impaired group did require additional information to clarify some questions after they began completing the questionnaire. However, the remaining mothers in the group completed the questionnaire without asking for assistance.

In the second phase of the research, several mothers with representative physical disabilities were interviewed. Those

respondents who had indicated on the face sheet of the completed questionnaire that they were interested in participating in a follow-up interview served as the sample from which these subjects were drawn. Interview data were collected between June and August, 1986 with interview questions based, in part, on data generated from the questionnaire. Consent *Form B* was used for these subjects.

These nonschedule standardized interviews were conducted over the phone, with the exception of three participants. Because they lived in various areas of the country, the telephone was determined to be the desired method of interviewing participants. However, an attempt was made to accommodate the needs of the respondents. In the case of one hearing impaired mother, the telephone was not feasible. Given the option of a long-distance teletelephonic device (TTD) interview or completing the interview by mail, this mother chose the mail. A visually impaired mother requested that she be interviewed at her place of employment to lessen the distractions created by the children in the home. Another mother was interviewed in her home, out of state, by a second interviewer, as this mother did not supply her telephone number on the questionnaire. In the latter case, the second interviewer was briefed by the researcher as to the purpose of the research and protocol to follow during the interview. This interviewer had had prior experience with the interview technique.

In all cases, the subject was contacted by the researcher to determine her continued interest in participating in the follow-up interview. Once that determination was made, the investigator then arranged a time suitable for the respondent to complete the interview.

All subjects contacted agreed to participate. One mother could not be reached due to a disconnected telephone. An attempt to contact this respondent by mail also yielded no response. A second hearing impaired mother was contacted by mail. While she was willing to participate, she was not available during the time parameters established for data collection.

Upon initiation of the telephone interviews and one face-to-face interview, the researcher obtained the subject's consent to audio-taping. Consent *Form B* was then read to the subject. If the participant refused to consent to audiotaping of the interview, the researcher planned to use extensive note-taking. No refusals were received. Therefore, after verbal consent was obtained, the researcher replaced the audiotape containing the subjects name and consent with a new tape. In this way, confidentiality was maintained. In the case of two remaining interviews, the subjects were given consent *Form B* to read and sign.

After the consent was obtained, the interview began and continued until all the questions had been fully explored. There was a planned attempt to complete the interview in one session. However, if the respondent seemed to show any psychological or physiological stress as a result of the questions or interview length, the interview would be stopped and rescheduled. Respondents were also informed that they should inform the researcher if, for any reason, they needed to terminate the interview.

There was no known physical or psychological risk for participants in the interview. Only subjects indicating an interest in the follow-up

interview, as determined on the face sheet of the questionnaire, were asked to participate.

The combined interview and questionnaire techniques are complementary and served to augment and validate one another.

Analysis of the Research Data

Upon receipt of the questionnaire, identifying information on the face sheet was removed and stored separately from the questionnaire and interview data. A code number was assigned to both the questionnaire and the face sheet to preserve confidentiality and facilitate contact of some of the respondents at a later date. In addition, the investigator was the only individual receiving completed questionnaires.

Responses were coded by the investigator according to categories identified in the codebook (see Appendix D). Reliability of the coding procedures was established using the test-retest technique. Approximately three weeks after the questionnaire was coded, the investigator repeated the coding process. The results of the second coding were compared with the initial coding. A final decision regarding any discrepancies was made by the investigator.

Data obtained from the research instrument were prepared for computer analysis. One questionnaire was excluded from the analysis because of the mother's alleged history of mental illness. However, none of the questionnaires was discarded from analysis because of large amounts of missing data. When responses to one or more of the items of the scales were missing, they were coded as missing.

Following coding of the responses and exclusion of the one questionnaire, data from the 50 questionnaires were entered into an SPSS-X computer program. The program is designed to provide descriptive statistics about respondents and their scores on the survey scales, and to generate information about the study's research questions.

Frequencies were obtained for all categorical variables on the questionnaire. This yielded a description of the respondents as a whole and of each subgroup. It also allowed the researcher to identify the responses of women with unplanned pregnancies or pregnancies prior to their diagnosis of physical disability so they could be excluded from the analysis of scales of social support. Sixteen questionnaires were excluded because of these factors.

The mean and standard deviation were used to reduce the data for continuous variables; a t-test was performed to determine whether a difference existed between the two subgroups, neurosensory and neuromuscular.

To examine the first research question, analysis of variance (ANOVA) (repeated measures) was performed for each of the scales of social support. Using this procedure, each of the respondent's ratings of the amount of support received by the first support person, the spouse/partner, is compared to her rating of each of the remaining support persons. In cases of missing values for any of the support persons, that subject's responses were automatically excluded from the analysis.

An additional *a posteriori* test--Tukey's HSD (honestly significant difference)--was performed to make multiple comparisons of all the

differences between the means. Without this test, it would not be possible to locate the source of significant effects of the person variables.

Pearson correlation analyses were performed to examine the second research question. This procedure permitted the researcher to determine whether a significant relationship existed between the type of support received from various persons and the influence of that support on the decision to become a parent.

The final research question was examined through a content analysis of interview data (see Appendix E). Tape recorded interviews and the one handwritten response to the interview questions by a hearing impaired mother were professionally transcribed. Responses to questions were coded by the researcher into mutually exclusive and exhaustive categories for the purpose of summarizing the data. The investigator then reread each interview and identified the categories included in each response.

A second reader, who had been trained in the categorization process on one interview, then independently read and categorized responses from five additional interviews. Overall inter-rater reliability on content analysis of the interviews was 81.7%. Because the minimal level of 80% reliability, or percentage of agreement, exceeded 80%, the researcher proceeded to report the findings.

When the same category of response to a question was selected by both coders, agreement was defined to have occurred. The percentage of agreement was calculated using the standard formula:

n of agreements

(n of agreements + n of disagreements)

Summary

The researcher mailed questionnaires to potential subjects following a preliminary telephone call to assess the woman's interest in participating or in response to a woman's self-initiated request to participate. Some participants heard about the research through friends or by seeing a request for research participants. In other instances, a cover letter and questionnaire were sent from national organizations requesting the participation of potential subjects. Respondents received assistance, as needed, in completing the questionnaire. Several visually impaired mothers requested assistance from the researcher in completing the instrument, and five hearing impaired mothers received the assistance of the researcher and an interpreter.

Standardized procedures were used to administer the questionnaire, whether the communication was personal or by mail. The one exception was with the group of hearing impaired mothers. Several members of this group needed further explanation, through definition and example, of the types of support since this abstract terminology was unfamiliar to them.


Data from the questionnaires were coded in preparation for statistical analysis and an SPSS-X computer program applied that was appropriate to the study's research questions. A variety of data reduction techniques was used to summarize the data and seek meaningful

relationships. A descriptive analysis of categorical variables was done using proportions and frequency distributions across all variables for the total population and for each subgroup. For continuous variables, the mean and standard deviation were used to reduce the data.

Interrelations for continuous variables were sought using correlation coefficients. The t-test was used to determine whether differences existed between groups.

Interview data were analyzed through content analysis; data was examined to determine whether either subgroup reported more problems or unmet needs. Exact quotations of respondents were used to supplement the quantitative analysis and to further explore perceptions of health care experiences during childbearing and childrearing.

Chapter IV contains the results from the analysis of the research data. Findings pertinent to the study's research questions are described.



CHAPTER IV

RESULTS

The results of the data analysis are presented in this chapter. A description of the responses of the participants to survey Questions 4 through 7 is followed by a discussion of findings as they relate to the first two research questions. The results of the content analysis of interview data are included in Chapter V.

A Description of Respondent's Scores on Four Scales of the Questionnaire

Social support participants rated 13 support persons across 4 categories of social support--ideological support (social expectations), information, emotional support, and instrumental assistance. The descriptive statistics for their responses are presented in Table 5. The mean and standard deviation for Selected Person Variables (family, friends, and professionals) providing these types of support have been computed. For the total group, the spouse received the highest mean for all categories of social support with the exception of ideological support (social expectations), where sisters received a .018 greater mean rating. In-laws received the lowest mean rating among all support persons in all categories of support with the exception of instrumental assistance, where brothers received a lower rating. All 50 respondents could not be included in this analysis due to factors such as unplanned

Table 5

Summary of Descriptive Statistics For Participants Included in the Analysis of Social Support (N=34)

Selected Person Variables	Social Support Variables											
	Ideological Support			Information			Emotional Support			Instrumental Assistance		
	n	Mean	Standard deviation	n	Mean	Standard deviation	n	Mean	Standard deviation	n	Mean	Standard deviation
Spouse	33	6.030	1.334	28	4.821	2.038	32	5.810	1.731	30	4.800	2.250
Mother	28	5.000	1.678	28	3.428	2.116	28	4.321	2.056	27	3.296	2.163
Father	25	5.360	1.150	26	2.923	2.038	26	4.192	2.117	23	2.913	2.314
Brothers	20	5.450	1.191	19	2.474	2.170	21	3.333	2.033	17	1.765	1.393
Sisters	21	6.048	1.071	21	3.286	2.327	23	4.069	1.777	19	3.158	2.192
In-laws	29	4.965	1.592	26	2.346	1.765	29	3.207	2.128	24	2.042	1.732
Friends	32	5.843	1.081	25	4.080	2.080	31	4.548	1.912	26	3.038	2.218
Doctors	32	5.000	1.704	28	4.500	2.203	27	3.889	2.259	24	2.792	2.395
Nurses	23	5.087	1.379	21	2.810	2.089	22	3.682	2.169	18	2.167	2.036

pregnancies, the birth of children prior to the diagnosis of physical disability, and missing data for some of the person variables. Thus, the n for each type of support and for each person providing support varied. The highest incidence of missing data related to the instrumental assistance category of support and for professional persons across all types of support. As a result, only Selected Person Variables are presented in the tables. With regard to the validity of the research, loss of these data caused concern.

The descriptive statistics for each of the subgroups of respondents--women with neurosensory (NS) and neuromuscular (NM) disabilities--to the four categories of support provided by Selected Person Variables, are contained in Table 6. Data revealed that women in the neuromuscular group consistently rated the spouse and mother higher than women in the neurosensory group across all categories, with spouse receiving the highest mean rating among all support persons. Women with neurosensory impairments gave the highest mean rating to sisters in all categories of emotional support with the exception of emotional support. In the latter category, the spouse was rated highest among support persons. In every case, the n of responses of the neuromuscular group was greater for every person rated.

Subgroup Differences

A t-test was performed to determine whether a difference existed between the two subgroups. The difference between the two sample means was considered in relation to the sample variances and size. Because different subjects comprised the groups, the subjects were presumed to

Table 6

Summary of Descriptive Statistics For Subgroups of Participants Included in the Analysis of Social Support

Selected Person Variables	Social Support Variables												
	Ideological Support			Information			Emotional Support			Instrumental Assistance			
	n	Mean	Standard deviation	n	Mean	Standard deviation	n	Mean	Standard deviation	n	Mean	Standard deviation	
Spouse	NM	21	6.286	1.056	19	5.158	1.951	21	6.333	1.065	21	5.095	2.189
	NS	12	5.583	1.676	9	4.111	2.147	11	4.818	2.316	9	4.111	2.369
Mother	NM	18	5.222	1.309	19	3.789	2.097	18	4.833	1.948	20	3.500	2.283
	NS	10	4.600	2.221	9	2.667	2.062	10	3.400	2.011	7	2.714	1.799
Father	NM	16	5.430	.814	17	2.647	1.869	17	4.000	2.208	17	2.647	2.206
	NS	9	5.223	1.641	9	3.444	2.351	9	4.556	2.007	6	3.667	2.658
Brothers	NM	15	5.267	1.163	14	2.643	2.205	15	3.400	2.098	15	1.846	1.159
	NS	5	6.000	1.225	5	2.000	2.236	6	3.167	2.041	4	1.500	1.000
Sisters	NM	13	6.000	1.155	19	2.714	2.301	14	4.571	1.910	12	2.500	2.236
	NS	8	6.125	.991	7	4.429	2.070	9	4.667	1.658	7	4.286	1.704

Table 6 continued

Summary of Descriptive Statistics For Subgroups of Participants Included in the Analysis of Social Support

Selected Person Variables	Social Support Variables											
	Ideological Support			Information			Emotional Support			Instrumental Assistance		
	n	Mean	Standard deviation	n	Mean	Standard deviation	n	Mean	Standard deviation	n	Mean	Standard deviation
In-laws												
NM	19	4.895	1.524	19	2.421	1.644	20	3.350	1.927	18	1.889	1.530
NS	10	5.100	1.792	7	2.143	2.193	9	2.889	2.619	6	2.500	2.345
Friends												
NM	21	5.857	1.153	18	4.000	2.249	21	4.762	1.895	18	2.720	2.244
NS	11	5.818	.982	7	4.286	1.704	10	4.100	1.969	8	3.750	2.121
Doctors												
NM	22	4.545	1.738	21	4.714	2.028	21	3.952	2.202	18	2.556	2.307
NS	10	6.000	1.155	7	3.857	2.734	6	3.667	2.658	6	3.500	2.739
Nurses												
NM	15	5.067	1.033	14	2.214	1.762	15	3.367	2.134	13	1.846	1.725
NS	8	5.125	1.959	7	4.000	2.309	7	3.286	2.360	5	3.000	2.739

be independent. However, the lack of random sampling and the small samples of unequal size have the potential for bias.

Prior to analysis, several person variables were deleted because of a large amount of missing data. These variables included other family members, teachers, clergy, and the 'other' category. Table 7 presents a summary of data and t values for perceived ideological support. Table 8 contains the t values for the perception of support provided by the remaining support variables. Values for information, emotional support, and instrumental assistance received from person variables (spouse, mother, father, brothers, sisters, in-laws, friends, doctors, nurses, and social workers) were not significant. The t values pertaining to the *influence* of information, emotional support, and instrumental assistance, using the same person variables, also were not significant (see Table 9). Because there were no significant differences between groups on the measures of support provided, the combining of the two groups for the ANOVA (repeated measures) for perception of support provided by Selected Person Variables was justified.

Multiple t-tests were run for various person variables (see Appendix F) for all types of perceived support. The t value for the influence of emotional support provided by the spouse was significant $t = -3.17, p < .01$. The influence of emotional support provided by the combined person variables of spouse, mother, and father was significant $t = -2.29, p < .05$. However, when the spouse variable was removed from the computation, there was no significant difference in the influence of emotional support provided.

Table 7

*Summary Data of t-Tests Between Groups on Measures of Ideological
Perceived to be Provided by Support Persons*

Type of Support Provided	N	Mean	Standard Deviation	t	Level of Significance
Ideological Support					
Group 1 (NS)	12	5.0191	.749	.16	.878(ns)
Group 2 (NM)	22	4.9779	.719		

Note: (ns) denotes no significance.

Table 8

*Summary Data of t-Tests Between Groups on Measures of Information,
Emotional Support, and Instrumental Assistance Received*

Type of Support Provided	N	Mean	Standard Deviation	t	Level of Significance
Information					
Group 1 (NS)	10	3.8288	1.632	.19	.853(ns)
Group 2 (NM)	22	3.7105	1.674		
Emotional support					
Group 1 (NS)	11	3.9789	1.461	-0.81	.430(ns)
Group 2 (NM)	22	4.4062	1.383		
Instrumental assistance					
Group 1 (NS)	9	3.7712	1.505	1.24	.233(ns)
Group 2 (NM)	22	3.0228	1.567		

Note: (ns) denotes no significance.

Table 9

Summary Data of t-Tests Between Groups on Measures of Perceived Influence of Information, Emotional Support, and Instrumental Assistance

Perceived Influence of Support Provided	N	Mean	Standard Deviation	t	Level of Significance
Information					
Group 1 (NS)	7	3.5357	1.305	.12	.893(ns)
Group 2 (NM)	22	3.4498	1.821		
Emotional support					
Group 1 (NS)	11	2.9284	1.081	-0.76	.401(ns)
Group 2 (NM)	22	3.3187	1.508		
Instrumental assistance					
Group 1 (NS)	9	2.8119	1.495	.16	.874(ns)
Group 2 (NM)	22	2.7146	1.580		

Note: (ns) denotes no significance.

Findings Relating to the Research Questions

In this section, the findings relating to each of the research questions are presented. The first question explored whether the disabled woman perceived differences in support received from family, friends, and professionals when making the decision to become a parent. The second question examined the relationship between the types of social support received and the woman's decision to become a parent. The last research question, concerned with identifying some of the health care experiences of disabled women when bearing and rearing children, will be discussed in Chapter V.

Question 1: Does the physically disabled woman perceive differences in the support provided by family, friends, and professionals when making the decision to become a parent?

An ANOVA (repeated measures) was performed for the four types of support (see Table 10). The person variables entered into the ANOVA included: spouse, mother, father, siblings, in-laws, friends, and medical professionals. Other family members, social workers, teachers, clergy, and 'other' variables were excluded from this analysis due to an $n < 10$. Also, due to variability in n 's across all categories of support, brothers and sisters were combined for analysis into a 'sibling' variable and doctors and nurses combined into a 'medical professional' variable.

The ratings of these person variables across all categories of support, both individually and in combination, were significant at .05.

Table 10

Analysis of Variance (Repeated Measures) for Perceptions of Social Support Provided by Selected Persons

Type of Support: Information

Source	DF	Sum of Squares	Mean Square	F
Between persons	17	165.4464	9.7321	
Between Measures	6	66.8849	11.1475	4.0478 (.05)
Residual	102	280.9008	2.7539	

Type of Support: Emotional support

Source	DF	Sum of Squares	Mean Square	F
Between persons	16	209.1842	11.6213	
Between Measures	6	102.5451	17.0909	7.6264 (.05)
Residual	108	242.0263	2.2410	

Type of Support: Instrumental assistance

Source	DF	Sum of Squares	Mean Square	F
Between persons	15	146.3371	9.7558	
Between Measures	6	84.7634	14.1272	5.1679 (.05)
Residual	90	246.0223	2.7336	

Type of Support: Information/Emotional support/ Instrumental assistance

Source	DF	Sum of Squares	Mean Square	F
Between persons	22	135.9075	6.1776	
Between Measures	6	103.8388	17.3056	10.7668 (.05)
Residual	132	212.1660	1.6073	

Since the ANOVA did not specify where the differences between the person variables lay, Tukey's HSD (honestly significant difference) was used to make multiple *a posteriori* comparisons of all the differences between means. This was done to determine where the sources of significant effects of person variables were located and to permit exploration of their meanings. A summary of the findings of Tukey's HSD test pertaining to Question 1 is found in Table 11.

The formula:

$$\text{HSD} = q_{\alpha} \sqrt{\text{MS error}/n}$$

was used to determine the honestly significant difference. Because the n 's for each of the sample means were not of equal size, the formula $2n_1n_2/(n_1 + n_2)$ was used to determine the n used in the computation of Tukey's HSD. In this formula, n_1 is the size of the sample with the largest mean, and n_2 is the size of the sample with the smallest mean.

The difference between all pairs of means was then computed. In all cases where the difference between any pair of means was equal to or exceeded the $q_{.05}$ HSD, the hypothesis that the means of the person variables represented by the sample were equal was rejected.

Tukey's HSD test revealed that, on the measure of social expectations, medical persons were perceived as significantly less supportive ($\text{HSD} \geq .9281$) than spouse and friends; mother as significantly less supportive than spouse and friends; and in-laws and father as providing significantly less ideological support for the woman's role decision to become a parent than friends. While friend's

Table 11

Tukey's Test (Honestly Significant Difference) for Support Variables

Type of Support Received	Differences Between Means for Person Variables						
Ideological Support (Social Expectations)	I Medical Persons 4.944	II Mother 5.037	III In-Laws 5.316	IV Father 5.435	V Sibling 5.795	VI Spouse 6.030	VII Friend 6.611
I	-	.093	.372	.491	.851	1.086*	1.667*
II		-	.279	.398	.758	.993*	1.574*
III			-	.119	.479	.714	1.295*
IV				-	.360	.595	1.176*
V					-	.235	.816
VI						-	.581
VII							-

HSD \geq .9281

Information	I In-laws 2.263	II Father 2.773	III Sibling 2.976	IV Mother 3.400	V Medical Persons 3.611	VI Friend 3.889	VII Spouse 4.821
I	-	.510	.713	1.137	1.348	1.626*	2.558*
II		-	.203	.627	.838	1.116	2.048*
III			-	.424	.635	.913	1.845*
IV				-	.211	.489	1.421
V					-	.278	1.210
VI						-	.932
VII							-

HSD \geq 1.503

Note: * denotes significance

Table 11 continued

Tukey's Test (Honestly Significant Difference) for Support Variables

Type of Support Received	Differences Between Means for Person Variables						
Emotional Support	I In-laws	II Medical Persons	III Sibling	IV Father	V Mother	VI Friend	VII Spouse
	3.428	3.710	4.109	4.167	4.259	4.952	5.810
I	-	.282	.681	.739	.831	1.524*	2.382*
II		-	.399	.457	.549	1.242	2.100*
III			-	.058	.150	.843	1.701*
IV				-	.092	.785	1.643*
V					-	.693	1.551*
VI						-	.858
VII							-
HSD \geq 1.299							
Instrumental Assistance	I In-laws	II Sibling	III Medical Persons	IV Friend	V Father	VI Mother	VII Spouse
	1.944	2.350	2.469	2.625	2.727	3.154	4.800
I	-	.406	.525	.681	.783	1.210	2.856*
II		-	.119	.275	.377	.804	2.450*
III			-	.156	.258	.685	2.331*
IV				-	.102	.529	2.175*
V					-	.427	2.073*
VI						-	1.646*
VII							-
HSD \geq 1.534							

Note: * denotes significance

support was significantly different from the previous person variables, homogeneity existed between siblings, spouse, and friends on this measure.

On the measure of information provided by the person variables, significantly less ($HSD \geq 1.503$) information was perceived to be provided by in-laws than friends and spouse. Father and siblings were also perceived to provide significantly less information than the spouse. Homogeneity existed among all other person variables including mother, medical persons, friends, and spouse.

The person variables for the measure of emotional support revealed the perception of significantly less support ($HSD \geq 1.299$) from in-laws than friends and spouse. Significantly less emotional support was perceived to be provided by medical persons, siblings, father, and mother than the spouse. Homogeneity existed between friends and spouse in this category. The last scale, rating instrumental assistance, also revealed significant differences ($HSD \geq 1.534$) between the spouse and all other person variables who were perceived to provide less support. All other comparisons for this category were homogeneous.

When responses to social support scales of information, emotional support, and instrumental assistance were combined (see Table 12) in-laws were perceived to provide significantly less support ($HSD \geq 1.032$) than friends and spouse. All remaining person variables were perceived to provide significantly less support than the spouse. Analysis of all 4 scales of support, using Tukey's HSD ($HSD \geq .9097$), showed significantly less support perceived to be provided by in-laws than friends and spouse. All remaining person variables were perceived as

Table 12

Tukey's Test (HSD) For Combined Support Variables

Type of Support Received	Differences Between Means for Person Variables						
Information							
Emotional support	I	II	III	IV	V	VI	VII
Instrumental assistance	In-laws	Father	Sibling	Medical Persons	Mother	Friend	Spouse
	2.736	3.334	3.498	3.527	3.600	3.819	5.263
I	-	.598	.762	.791	.864	1.083*	2.527*
II		-	.164	.193	.266	.485	1.929*
III			-	.029	.102	.321	1.765*
IV				-	.073	.292	1.736*
V					-	.219	1.663*
VI						-	1.444*
VII							-
HSD \geq 1.032							
Social expectations							
Information							
Emotional support	I	II	III	IV	V	VI	VII
Instrumental assistance	In-laws	Father	Medical	Sibling	Mother	Friend	Spouse
	3.271	3.753	3.815	3.879	3.936	4.448	5.464
I	-	.482	.544	.608	.665	1.177*	2.193*
II		-	.062	.126	.183	.695	1.711*
III			-	.064	.121	.633	1.649*
IV				-	.057	.569	1.585*
V					-	.512	1.528*
VI						-	1.016*
VII							-
HSD \geq .9097							

Note: * denotes significance

providing significantly less support than the spouse. Across all categories of support, the spouse received the highest mean scores with the exception of ideological support (social expectations) where friends received the highest mean scores. In-laws received the lowest mean scores among all person variables rated in all categories except ideological support. In this category, medical persons were rated lowest.

Analyses of the data suggest that physically disabled women did perceive differences in support provided by family, friends, and professionals when making the decision to become a parent.

Tukey's test for non-additivity was not significant for any of the cases analyzed.

Question 2: Is there a relationship between the emotional support, information, and instrumental assistance received from the social network of family, friends, and professionals and the disabled woman's decision to become a parent?

Pearson correlation analyses were performed in order to explore possible relationships between types of support received from various persons and the influence of that support on the decision to become a parent. The data for the perceived influence of information are presented in Table 13. Pearson correlation analyses for the perceived influence of emotional support are found in Table 14 and Table 15 presents the analyses for the perceived influence of instrumental

Table 13

*Pearson Correlation Coefficients for Perceived Influence of Information
on the Decision to Become a Parent*

Person Variable	N	Correlation Coefficient	P-Value
Spouse (T)	26	.7134	.000
(NM)	19	.7468	.000
(NS)	7	.5892	.164(ns)
Mother (T)	25	.7608	.000
(NM)	19	.8536	.000
(NS)	6	.5395	.269(ns)
Father (T)	23	.6824	.000
(NM)	17	.8686	.000
(NS)	6	.4108	.418(ns)
Brother(T)	15	.9157	.000
(NM)	13	.9275	.000
(NS)	2	1.0000	-
Sister (T)	19	.7320	.000
(NM)	14	.7428	.002
(NS)	5	-.6864	.201(ns)
In-laws(T)	23	.5634	.005
(NM)	19	.7750	.000
(NS)	4	-.1741	.826(ns)
Friends(T)	22	.9035	.000
(NM)	18	.9311	.000
(NS)	4	.3333	.667(ns)
Doctors(T)	25	.6133	.001
(NM)	21	.6414	.002
(NS)	4	.4685	.531(ns)
Nurses (T)	18	.7347	.001
(NM)	14	.9109	.000
(NS)	4	.4706	.529(ns)

Note: (ns) denotes no significance

Table 14

Pearson Correlation Coefficients for Perceived Influence of Emotional Support on the Decision to Become a Parent

Person Variable	N	Correlation Coefficient	P-Value
Spouse (T)	32	.8136	.000
(NM)	21	.8069	.000
(NS)	11	.7539	.007
Mother (T)	28	.5059	.006
(NM)	18	.5438	.020
(NS)	10	.3815	.277(ns)
Father (T)	26	.5203	.006
(NM)	17	.5575	.020
(NS)	9	.4572	.216(ns)
Brother(T)	21	.7314	.000
(NM)	15	.8422	.000
(NS)	6	.2683	.607(ns)
Sister (T)	23	.5105	.013
(NM)	14	.4232	.132(ns)
(NS)	9	.7161	.030
In-laws (T)	28	.4338	.021
(NM)	19	.4348	.063(ns)
(NS)	9	.4136	.268(ns)
Friends (T)	29	.6107	.000
(NM)	21	.6483	.001
(NS)	8	.5404	.167(ns)
Doctors (T)	27	.7253	.000
(NM)	21	.6455	.002
(NS)	6	.9904	.000
Nurses (T)	21	.5078	.019
(NM)	15	.4130	.126(ns)
(NS)	6	.9405	.005

Note: (ns) denotes no significance

Table 15

Pearson Correlation Coefficients for Perceived Influence of Instrumental Assistance on the Decision to Become a Parent

Person Variable	N	Correlation Coefficient	P-Value
Spouse (T)	30	.7793	.000
(NM)	21	.8759	.000
(NS)	9	.5062	.164(ns)
Mother (T)	27	.8698	.000
(NM)	20	.8720	.000
(NS)	7	.8408	.018
Father (T)	23	.7518	.000
(NM)	17	.8636	.000
(NS)	6	.5125	.299(ns)
Brother(T)	17	.9213	.000
(NM)	13	.9122	.000
(NS)	4	1.0000	.000
Sister (T)	19	.7258	.000
(NM)	12	.8538	.000
(NS)	7	.3084	.501(ns)
In-laws(T)	23	.6004	.002
(NM)	17	.8835	.000
(NS)	6	-.1044	.844(ns)
Friends(T)	26	.7338	.000
(NM)	18	.8141	.000
(NS)	8	.5750	.136(ns)
Doctors(T)	23	.8361	.000
(NM)	18	.9493	.000
(NS)	5	.6163	.268(ns)
Nurses (T)	16	.8717	.000
(NM)	12	.9865	.000
(NS)	4	.7276	.272(ns)

Note: (ns) denotes no significance

assistance provided regarding the decision to become a parent. The analyses was done for the total group (T) and for each subgroup--women with neuromuscular disabilities (NM) and women with neurosensory disabilities (NS). When the $n < 10$ for both subgroups of any person variable, that person variable was excluded from the Table.

Results of a Pearson correlation between the support received and the influence of that support revealed multiple significant p-values. The great majority of instances of non-significance were found in the NS group when the n of responses was 10 or less. The only exception was found in the correlation for perceived influence of emotional support from nurses on the decision of the woman with a neuromuscular impairment to become a parent. This tended to support a relationship between the information, emotional support, and instrumental assistance received from the social network of family, friends, and medical professionals and the disabled woman's decision to become a parent.

Summary

The fourth chapter focused on presentation of the results of the data analyses. The subjects' responses to the research instrument were described, followed by the findings that resulted from examining the study's first two research questions and performing additional analyses.

Examination of mean scores of the total group of social support participants showed that the spouse received the highest scores across the social support variables of information, emotional support, and instrumental assistance with the exception of ideological support. Examination of the mean scores for both subgroups of respondents

revealed that the NM group gave a higher mean rating for support, across all four categories, to the spouse and mother than the NS group. The NS group rated sisters higher than the NM group across all four categories of support. Other person variables showed mixed results in ratings.

T-tests between subgroups on the information, emotional support, and instrumental assistance received from person variables were not significant. When a t-test was performed to analyze the *influence* of information, emotional support, and instrumental assistance--using the same person variables--no significant difference was found. When t-tests were performed for all types of support perceived to be provided and for the perceived influence of that support, a significant difference was found only for the influence of emotional support from the spouse at .007 and from the spouse, mother, and father combined at .031.

An ANOVA (repeated measures) for the four types of support, followed by Tukey's HSD, showed significant differences between person variables entered into the analysis. This finding suggested that the physically disabled woman did perceive differences in support provided by family, friends, and medical professionals when making the decision to become a parent.

Multiple Pearson correlation analyses yielded numerous instances of significant p-values. These findings tended to confirm a relationship between social support received and the physically disabled woman's decision to become a parent.

The results of the content analysis of interviews of eleven respondents are included in Chapter V.

CHAPTER V

DISCUSSION

An interpretation of the results of the study are presented in Chapter V. A content analysis of interview data is presented, with quotations of respondents supplementing the descriptive analysis. Ways in which the results of the study can be utilized and recommendations for future research are discussed.

A Discussion of the Respondent's

Mean Scores on the Scales of Social Support

Social support participants (n=34) used a Likert scale to rate 13 support persons across four categories of social support. As noted in Chapter IV, Table 5, the spouse received the highest mean rating in all categories, with the exception of the category relating to ideological support (social expectations). In this category, sisters received a slightly higher (.018) mean rating. Among all categories of support, in-laws received the lowest mean rating with the exception of instrumental assistance. In this category, brothers received a lower rating.

As can be seen in Table 6, women in the neuromuscular (NM) group (n=22) gave a higher mean rating to spouse and mother across all types of support than the NS group. Women in the neurosensory (NS) group (n=12) gave a higher mean rating to sisters than the NM group across all

categories of support with the exception for the spouse who received a higher mean rating (.151) in the emotional support category. Other person variables showed mixed results in ratings by the groups.

A Discussion of t-test Results

T-tests to determine whether significant differences existed between groups revealed no significant differences when all support person variables were entered into the computation. When t-tests were performed for various combinations of support persons, only the value for the *influence* of emotional support provided by the spouse was significant at .01, and the value for the combined person variables of spouse, mother and father at .05. However, when the spouse was removed from the computation, results of the t-test for mother and father were not significant. This led the researcher to conclude that the significance found when the three variables were combined was due to the influence of the spouse.

The responses of all participants included in the analysis of social support (n=34) were used in the analysis of subgroup differences. However, the presence of similar impairments in the spouses of interviewees in the NS group and absence of disabilities in spouses of interviewees in the NM group may suggest a reason for the significant difference in the influence of emotional support received from the spouse. This is especially true if the sample of interviewees is representative of the larger sample from which it was drawn.

It is possible that the influence of communication played a role in the selection of similarly impaired spouses by women in the NS group

and the choice of able-bodied spouses by women the the NM group.

Persons with hearing or vision loss are more isolated in some ways than persons with intact sensory systems. In a social situation, a visually impaired person does not "see" someone with whom she would like to converse. Rather, she would more likely speak with someone standing nearby, someone to whom she has been introduced, or someone of whom she has knowledge and would like to meet. This is also likely in the case of a visually impaired male.

A sighted person may actively seek the attention of a visually impaired person, but the social opportunities are likely to be less frequent than social situations where all participants are sighted. Thus, a sighted person may feel more comfortable with a sighted companion.

A similar situation exists for the hearing impaired. They have a unique culture, a language that is not understood by most hearing persons, and an inability to understand abstractions. They also must deal with the difficulties of lipreading. Communication with hearing persons is limited. Hearing impaired persons would share these commonalities in a social situation. A hearing person may not have the interest, or patience, to communicate in writing, to speak slowly while facing the individual, or to learn sign-language. The deaf usually attend special school or classes with other hearing impaired persons, so one opportunity for social contact with hearing persons is eliminated.

A person with a disability may feel more comfortable with another who understands and has experienced a similar loss. There is a more keen awareness of the other's needs and limitations, as well as strengths. There is a mutual dependency.

It would seem, though undocumented by statistics, that few couples have two partners with neuromuscular disabilities. In a post-interview conversation with four respondents, two mentioned that, from their experience, it was rare to find this occur; although it has been reported in occasional articles.

Of the six married interviewees in the NM group, all had able-bodied husbands. For two with multiple sclerosis, the onset of their condition occurred after marriage.

Communication is unaffected by most neuromuscular disabilities. While mobility is impaired, it can be accomplished by alternative means such as a wheelchair or specially equipped van. Persons with a NM disability are more likely to be educated with non-disabled children because, often, (a) they do not need the special communication devices necessitated by sensory losses, and (b) the upper body is unaffected by the disability, so the individual has full use of the upper extremities.

In social situations, women with neuromuscular disabilities do not experience the same difficulties as others with sensory deficits. They have more opportunity to "select out" persons from a group. In addition, women in the group are more likely to receive ongoing treatment because of their disability or associated medical conditions. Persons with permanent vision or hearing impairments do not usually require such treatment.

A disabled woman may attract an able-bodied man for a variety of reasons including her intelligence, wit, beauty, sensitivity, and overall personality. Some may be attracted to a disabled person because of the opportunity it offers to "rescue" the disabled person from a

difficult situation. Indeed, a couple with one disabled partner may find that their abilities are complementary and together they may overcome any limitations in either.

A Discussion of Findings Relevant to the Research Questions

In this section, interpretation of the findings from the study's research questions are presented. Questions are raised and conclusions proposed based on the results.

Question 1: Does the physically disabled woman perceive differences in the support provided by family, friends, and professionals when she is making the decision to become a parent?

Examination of the statistical analyses revealed that a physically disabled woman does perceive differences in support provided by family, friends, and professionals when making the decision to become a parent.

Ideological support

On the measure of ideological support (social expectations) as it relates to the woman's role decision to become a parent: (a) the spouse ($M = 6.030$) was perceived to be significantly more supportive than medical persons ($M = 4.944$) and mothers ($M = 5.037$); and (b) friends ($M = 6.611$) perceived as significantly more supportive than medical persons, mothers, in-laws ($M = 5.316$) and fathers ($M = 5.435$). Statistical analyses revealed that there were no significant differences between siblings, spouse, and friends on the measure of ideological support.

References to perceptions of support were made by several mothers during the interviews. The lack of support for the woman's decision to become a parent as well as the lack of available information were recurring themes when the women discussed the experience of seeking genetic counseling or medical information. When asked whether anyone tried to discourage her from having children, one woman remarked, "No. But I wouldn't give them the chance. I know a lot of disabled women who have been.... that's one reason why [sic] didn't ask doctors." Another commented, "The more highly trained, the less likely they were to encourage me.... Basically, because I've gotten so many negative reactions, probably, people's first inclination is to say 'you can't' or 'shouldn't', rather than 'if you want to, give it a try'."

There are a variety of possible reasons for the significant differences in perceived ideological support. Medical persons may be concerned with the lack of available information on pregnancy and childrearing among the disabled. A specialist in the treatment of neuromuscular or neurosensory disabilities, or an obstetrician who most frequently deals with able-bodied women, may also be inexperienced in dealing with the special needs and concerns of a pregnant and disabled woman. In fact, only 3 of the 11 women interviewed (27.3%), and 14 (31.8%) of the 44 questionnaire respondents having obstetricians, knew that their physician had experience with disabled women. Moreover, that experience may have been with other types of disabilities.

With a parenting decision, medical persons, mothers, fathers, and in-laws may have additional concerns revolving around: potential inheritance of the disability by the offspring; threat to the woman's

physical health; a possible decrease in life expectancy; whether the woman can provide for the child's developmental needs and meet the demands of parenting; and the potential drain on the family's financial resources. Bogle and Shaul (1979) note that "Many congenitally disabled women report that their parents programmed them to be 'super career women' in the belief that they would never be considered marriage material." (p. 40)

One respondent noted that her parent's response to her decision to become pregnant was a "definite negative," as they were concerned about her physical health. The parents' attitude changed only after they were told that the couple had decided to adopt a child. Among the other comments that reflect the tentative support were: "They knew that I wanted a baby... but at the same time they were scared." "Are you sure it won't make your condition worse?" and, "They were essentially supportive... except they wish I had chosen natural birth over adoption."

One visually impaired woman stated at the onset that she could not remember any particular concerns her family had with regard to her decision to to become a parent. However, by the end of the interview she mentioned an incident that, she felt, reflected her parents' concern for her ability in the parenting role. The couple had taken their child out for the first time. When they returned home it was late in the evening, and the child was crying. They received a phone call from the respondent's mother asking, "What had we been doing, and how come the baby was crying?" She also informed the respondent that "They [the grandparents] had called the police because they were afraid something

had happened to me." She reported that her husband was "concerned that they might keep interfering with us, and if this kind of thing continued, might try to imply that we couldn't take care of our kids."

Lack of support for the parenting decision may stem from a family's initial negative response to a marital relationship. Most parents do not want their child to marry someone with a disability. Some parents are concerned with the reactions of friends and neighbors, or that their child's life will be jeopardized because the relationship will bring unanticipated problems. Some may feel that their expectations for their child must be lowered as a result. However, parental interference in their child's choice of a marriage partner may be enough to resolve any doubts about the decision to marry. (DeLoach & Greer, 1981)

Another participant commented that her father-in-law and grandfather-in-law did not seem too happy about her pregnancy decision "because they thought I couldn't take care of a child." A visually impaired mother mentioned that her mother-in-law had informed her:

Because I was visually impaired I couldn't handle a child, and I wouldn't know whether or not if [*sic*] anything was wrong with the child. I wouldn't know what to do if the child was crying. I wouldn't know whether or not if [*sic*] the child had anything in its mouth or not. Just anything. She told me I wouldn't know how to feed the child because I wouldn't be able to find the child's mouth.

In-laws who have initially opposed the marriage of their son to a physically disabled woman may be less likely to offer support at a later

date. Parents who have been unable to influence a marital decision may estrange themselves from the couple, not attend the marriage ceremony, and disinherit their own child, the spouse, and grandchildren (DeLoach & Greer, 1981). This was acknowledged by one respondent who commented that her mother-in-law opposed her son's fathering a child with her, as well as the couple's eventual decision to adopt. "She [the mother-in-law] basically told us they would not be her grandchildren. She felt that it would not work. She all along didn't feel I would live very long."

The finding that the spouse was perceived as significantly more supportive is not surprising since he would typically be expected to be most closely involved in the parenting decision. The reason was clearly expressed by one respondent who said, "He encouraged me because both of us wanted children." The relationship with the spouse is one of choice, commitment, and mutual goals.

Friends, who were also perceived as significantly more supportive, may have been sought for advice in the parenting decision. Usually of the same generation and similar or shared experiences, views, and values friends are generally a supportive and available resource. Some friends themselves may be disabled parents.

Information

On the scale measuring the amount of information perceived to be provided by various support persons: (a) friends ($M = 3.889$) were perceived as providing significantly more information than in-laws ($M = 2.263$); and (c) spouse ($M = 4.821$) perceived as providing significantly

more information than in-laws, father ($M = 2.773$), and siblings ($M = 2.976$).

It is less likely that the woman would discuss details of her parenting decision with or seek information from her in-laws than from her more immediate family members. This is especially true if in-laws are not perceived as supportive of the parenting decision. In addition, in-laws who are unfamiliar with the specific needs of a woman with a physical disability may simply lack the practical information sought. Also, fathers and brothers may not be seen by the woman as sources of childbearing information based on gender.

The spouse is generally involved in the pregnancy decision and more consistently available than members of the immediate family whose involvement with the couple usually increases after the birth of a child. An additional source of information was cited by six of the eleven interviewees: they acknowledged that, before becoming pregnant, they had known, or sought to contact, one or more disabled parents. Some of the disabled parents were friends. Indeed, "disabled women often need more information and advice related to their disability" (Shaul, Dowling and Laden, 1981, p. 366).

Statistical analyses revealed homogeneity of responses among mothers, medical persons, friends, and spouse. Mothers and sisters, while perceived as better sources of information, could still be limited as to the amount of childbearing information they could provide to a pregnant family member with a disability. Yet they are still likely to be perceived as better sources of such information than a father or brother. Medical persons might provide some information on the effect

of a pregnancy on the woman's short- or long-term health or the potential for genetic transmission of the disability.

Emotional Support

Friends received a mean rating of 4.952 on the measure of emotional support and were perceived as significantly more supportive than in-laws ($M = 3.428$). The spouse ($M = 5.810$) was perceived as providing significantly more emotional support than in-laws, medical persons ($M = 3.710$), siblings ($M = 4.109$), father ($M = 4.167$), and mother ($M = 4.259$). There was no significant difference between friends and spouse in this category.

Of the eight women responding to the interview question, "Who would you say was the one person who provided you with the greatest amount of emotional support in your decision to become a parent?" 75.0% ($n=6$) identified the spouse as most supportive. One woman elaborated saying, "He knew that I could take care of them, and he had faith in me." Only two interviewees identified friends or sister as more supportive than the spouse.

The perception of the spouse as providing the greatest amount of emotional support is probably due to his active part in the decision-making process and his investment in the family. The spouse and friends are generally selected as participants in significant, mutually chosen, reciprocal relationships. Friends provide the social and emotional support of interaction with those in similar situations. Thus, they understand one's problems and concerns (Caplan, 1974). These persons are important to one other. A friend, who is also disabled and/or a

parent, may be able to provide more meaningful support. In-laws cannot be selected in this manner.

Instrumental Assistance

Finally, analysis of responses to the scale rating instrumental assistance (goods and services) revealed that the spouse ($M = 4.800$) was perceived as providing significantly more support than all remaining person variables. In-laws again received the lowest rating among support persons ($M = 1.944$) for instrumental assistance provided.

It may be perceived as the traditional role of the spouse to provide, or at least contribute to, goods and services with regard to the decision to become a parent. It is also possible that respondents may have found the determination of goods and services as difficult or felt some personal responsibility for independence in this area. Other support persons may not perceive this type of support as their responsibility. Unsolicited offers of assistance may also be considered interference in the lives of the couple. One respondent commented on the actions of some friends after she became pregnant: "The invitations became more infrequent, we saw less and less of a number of our friends." She continued, "I really think they perceived... 'I am going to have to assist that woman every day.' My husband [*sic*] I never ever said anything to lead them to believe that."

Social support networks appear to interact to influence the woman's adaptation to a first birth (Power & Parke, 1984). Thus if a woman receives one type of support from a particular support person--friends or spouse--she may request it less from other persons in

the support network. This factor may account for some of the consistency with which in-laws were rated significantly less supportive, and spouse and friends as significantly more supportive in the various support categories.

When the scales of: (a) information, emotional support, and instrumental assistance and (b) ideological support, information, emotional support, and instrumental assistance were combined for analysis, Tukey's HSD revealed that in-laws, again, were perceived to provide significantly less support than friends and spouse. All remaining person variables were perceived as providing significantly less support than the spouse.

These findings lead to the conclusion that the physically disabled woman does perceive significant differences in the various types of support provided by family, friends, and professionals when making the decision to become a parent. However, this interpretation must be made cautiously because of the small sample size, the use of volunteers as subjects, and the level of internal reliability of the scale measuring ideological support (Cronbach alpha coefficient = .6013).

Question 2: Is there a relationship between the emotional support, information, and instrumental assistance received from the social network of family, friends, and professionals and the disabled woman's decision to become a parent?

A Pearson correlation analysis was performed to explore the possible relationships between emotional support, information, and instrumental assistance *received* from the social network of family,

friends, and professionals and the *influence* of that support on the disabled woman's decision to become a parent. The findings supported such relationships. Examination of the analyses revealed that, for the total group (n=34) and across all categories of support, there was a significant correlation between the perceptions of support received from various persons and the influence of that support. These findings would suggest that physically disabled women who choose to become parents have a support system available to them influencing their decision. Whether physically disabled women who choose not to become parents are influenced by their support system is an interesting question. Because all respondents in the study had chosen to become parents, the relationship between the support system and the decision to remain childless could not be examined.

When these same analyses were performed for the NM group, there was a significant correlation across all categories of support with the exception of perceived influence of emotional support. In this category, only sisters, in-laws, and nurses were *not* found to be significantly correlated.

Examination of these analyses for respondents in the NS group revealed that, across all categories and person variables, there were few significant correlations. In the emotional support category, spouse, sisters, doctors, and nurses were significantly correlated, and for instrumental assistance only brothers and mother were significant. However, in all cases, the number of responses was less than ten, with the exception of spouse (n=11) and mother (n=10) in the emotional support category. This fact, alone, may affect the validity of the findings.

Several other factors may have influenced the outcome of these analyses and must be considered in relation to these findings. Respondents may have been unable to distinguish between the perception of social support provided and the influence of that support on the decision to become a parent. Indeed, there may not be a difference between the support received and the influence of that support. Thus, a high degree of correlation would be expected. It is also possible that the respondents could not distinguish between support received and the influence of that support.

When many coefficients are computed, it is likely that some would appear statistically significant by chance alone. Also, the extent of the relationship between support received and the influence of that support may differ depending on factors such as how support is measured, the age at which the woman made the decision to become a parent, the extent and type of physical disability, culture, and circumstances present when the woman was completing the questionnaire. It is also possible that, over time, the nature of the decision making process and increasing independence of women may have altered the influence of support persons on the decision-making process.

The analyses provided statistical support for the conclusion that there is a relationship between the emotional support, information and instrumental assistance *received* and the *influence* of that support on the decision to become a parent. However, these findings must be considered in light of the multiple factors potentially affecting the results.

Question 3: What are some of the health care experiences of disabled women contemplating, anticipating, and raising a child/children?

Eleven respondents answered a series of interview questions on a variety of topics related to the experience of parenthood. While the third research question focused on health care experiences of disabled women during their transition through parenthood, additional experiences have been incorporated into the discussion. This has been done to provide a more comprehensive picture of the physically disabled woman's perception of parenthood. Because the sample was not representative of the larger population, the findings are not conclusive. The researcher also acknowledges that there may have been more important issues affecting the disabled mothers than those about which they were questioned.

Genetic counseling

Genetic counseling is a non-directive process. It provides information on diagnosis, risks, prognosis, and management. Counsel and support is also provided to the family in its choice of action. Though the husband of one visually impaired woman sought genetic counseling, none of the women in the NS group sought counseling or any information about how a pregnancy might affect her health. The deaf respondent reported that her impairment might have been hereditary because she had a hearing impaired sibling. None of her children were affected, however. One visually impaired woman did have a hereditary condition of which she was unaware until after the birth of two visually impaired

children. While relating her feelings about the experience, she stated, "I was quite upset... it's very hard to handle... because me having a visual impairment myself, I don't want my children to have to go through that. But I just have to make the best of the situation."

Another visually impaired woman reflected on how she might have felt if one of her children was born with a visual impairment. While she also acknowledged that she would do her best in the situation, she recognized that the "degree of the vision impairment" would make a difference. She related concern about whether she could adequately care for a disabled child and speculated that, in that case, "I don't know if we would have wanted another child."

In the NM group, two respondents sought genetic counseling. One, who was pregnant at the time of consultation, felt that she had received no understandable opinion and that her sense of privacy was violated due to the manner in which the session was handled. (spina bifida)

A woman with spina bifida was informed that she was at increased risk for having a child with the same defect and that the pregnancy would be a high risk for her. The information received affected her decision regarding pregnancy. Because she did not wish to risk a child's inheritance of her medical problem, she had a tubal ligation and decided to adopt.

Four others in the NM group sought information other than through genetic counseling as to how a pregnancy might affect their health. A woman with multiple sclerosis (MS) was told by her physician that her condition was not inheritable and that there was limited information available on the potential effects of pregnancy on her condition.

However, she felt that her physician had a positive attitude toward her desire to become pregnant. She was told, "If you want children, have them. There's no data... to say it's hereditary. There's no way to predict how it will influence your MS. It's a gamble."

Another woman was told that her condition was not hereditary and received both positive and negative feedback from her physicians. She stated, "Because of my one 'gynie', I decided it's worth the chance." A mother with post-polio paraplegia reported that she received only negative feedback from her physician about a pregnancy: "My back was crooked, my age was against me. I would spend most of my time in bed. It would increase my disability's progression." Rather than asking specific questions of a physician, one mother sought information from her friend's medical texts, from medical journals, and from letters from other disabled mothers.

None of the women in the NS group sought genetic counseling. Neither did they seek medical information on the potential effects of pregnancy on their disabilities. Two of four mothers with NS impairments, who might have benefitted from genetic counseling, did not receive it. The visually impaired mother was not informed of the potential heritability of her condition and has two affected children. The hearing impaired mother, who did not seek genetic counseling, has no affected children.

Perhaps, the women with NS impairments felt that there was little likelihood of transmitting their conditions to their offspring; two of the four women had incurred visual impairment from the effects of medical treatment for prematurity. While sight was permanently

affected, their remaining body functions were not impaired. During the interviews, none of the respondents reported current treatment for their neurosensory conditions.

Six of seven women in the NM group sought genetic counseling or information about the effects of pregnancy on their health. None of the NM impairments occurred as a result of medical treatment of a pre-existing condition. Two women were born with spina bifida. Two developed multiple sclerosis as adults. These respondents were concerned whether their condition could be transmitted to their offspring. These women and the others in the group also wondered whether their physical condition might be affected by a pregnancy. Because many disabilities predispose the person to a variety of associated medical conditions, this was a legitimate concern.

One could hypothesize that the reason women in the NM group were more likely to seek or obtain information about genetic counseling or the effects of pregnancy on their health and the women in the NS group were not, lay in the continuing contact of the former group with medical professionals. The women with multiple sclerosis were receiving treatment for a progressive disease. The others were likely to require treatment for conditions associated with their disability. Thus, the women had more opportunity to ask questions of, or be given information from, their physicians.

Genetic counseling probably could not have prevented fetal distress resulting from the prolonged labor and "failure to progress" of one mother planning a home birth. There was initial concern that the newborn might have incurred brain damage. When asked to share her

feelings about the possibility of having a child with a disability, she related several:

It had been very restimulating [*sic*] of my own experiences, and I felt it would be very hard. That I, in a sense, [*sic*] so much in common with, and to watch a child go through the same struggles I went through.... and I did a lot of saying 'Epilepsy's okay, if he's a genius too.' 'Epilepsy's okay as long as he doesn't have a seizure every day.'

In addition, the mother mentioned feeling "guilt", "responsibility", and "even more abnormal."

A mother with multiple sclerosis speculated about her response to the birth of a child with a disability. She identified fear and concern about her ability to care for the child, but said that she would attempt to make the best of the situation.

With the actual or expected birth of an infant with one or more defects, the parents experience feelings of loss, guilt, and frustration. They also experience what Olshansky (1962) has labeled "chronic sorrow", a persistent grief that is resolved only upon the death of the child or the parents. It does not imply maladaptation. While Olshansky originally applied the term to the experience of parents of children with a mental impairment, it has been more broadly applied (Young, 1977) to any parents who experience the loss of the "perfect child." The respondents comments suggest that the feeling of "chronic sorrow" is experienced by the disabled child/adult as well as his or her parent.

Adoption

Three of the interviewees had, for various reasons, chosen to adopt children. One mother chose to have a tubal ligation and attempt adoption after receiving genetic counseling. She was told that, given her family history, she had a 33% higher risk for having a child with spina bifida. Another, who consulted a physician for advice on pregnancy, feared that she would be bedridden for much of the pregnancy and that her disability would progress creating additional problems. Her desire for a child and inability to conceive led her to adopt. A visually impaired mother of six who was still raising her own family and wanted another baby decided to become a foster parent and then, later, to adopt. Because of regulations in force at the time, her first foster child was adopted by another family. The second foster child was successfully adopted by the family.

The experience of adopting appeared to be emotionally difficult (see Table 16). Two mothers reported being initially rejected by one or more agencies. One woman with spina bifida and her able-bodied spouse were refused by several agencies for various reasons--a long waiting list; the couple was unacceptable as adoptive parents; there is a shortened life expectancy for a person with spina bifida; the couple's refusal to adopt a special-needs child.

The prospective foster parent, who eventually adopted, also met resistance in the process. In spite of the fact that she had raised several children, she perceived that:

They didn't want to give me any child at all because they felt, that with my handicap, I could not take care of them. And I told

Table 16

Perceptions of the Adoption Experience

Coding Category	Number in NS group Mentioning Category (N=1)	Number in NM group Mentioning Category (N=2)
<hr/>		
Encouraged adoption of child		
with special needs	1	2
Initially refused by agency	1	1
Intrusive/asked many questions	0	1
Increased communication with spouse	0	1
Inaccessible office	0	1
Much paperwork/yearly reviews	0	1

them that was silly because I had already reared six children, and with no help at all, and that I could do it. But it just didn't seem to matter to them. I just couldn't convince them.

After much discussion, agency personnel suggested that she accept a special-needs child but, later, placed a non-handicapped child in her care. Buck and Hohmann (1983) in their review of research, theory, and myths about parenting included a reference to a personal communication by Hohmann. He stated: "The limitations that disabled persons encounter in engaging in physically oriented activities and sports are presumed to be so important that adoption agencies cite them as a primary reason for precluding the adoption of children by individuals with disabilities" (p. 209).

While agency personnel seemed to assume that parental disability would increase openness to adopting a handicapped child, this was not the case in this study. The presence of a disability in one or both parents did not seem to diminish the desire for a non-disabled child. One mother commented: "And she proceeded for an hour to try to convince me that I would be the best kind of parent for unadoptable children" (post-polio paraplegic). In fact, two mothers emphatically stated that they felt unable to provide for a disabled child's needs. Comments included "But I would probably handle a baby or a child with a defect incorrectly" (spina bifida), and

I'd never taken care of any handicapped children, and I wouldn't, and I felt that I was unable or incapable of taking care of one because, if they had special needs, then I wouldn't know what to do even though I was handicapped myself. (blind)

The threat of legal action seemed to assist the couples in obtaining a healthy child. One respondent reported telling agency personnel that "I was fully aware of what my civil rights were, and that our lawyer would be contacting the agency" (post-polio), and another commented that her sister contacted the agency to "tell them it was discrimination" (blind). In both cases, the matter was resolved without any legal proceedings.

One mother with spina bifida felt that she would be "too strict a parent for a person with a disability" and would have unrealistic expectations for a disabled child based upon what she felt was her "competitive" and "compulsive" nature. Another noted that there was too much disability in the couple's life to take on the rearing of a disabled child. A summary of responses to the suggestion to adopt a child with special needs is found in Table 17.

As a result of social changes beginning in the 1960's, there has been a decreasing number of healthy infants available for adoption due to an increase in single-parent families, independent adoptions, availability of abortion, and increased availability and distribution of birth control information and methods.

The caseworker's concern for placing a handicapped child with disabled parents may be based on several additional factors. Both adoption agencies and parents consider heredity an important developmental factor. As a result, a "double genetic screening" occurs: (1) to consider whether or not the child is readily adoptable in light of family history and/or condition; and, if adoptable, (2) to determine which family environment would be most suitably matched to the child's background (Clarke, 1981).

Table 17

Responses to the Suggestion to Adopt a Special-Needs Child

Coding Category	Number in NS group Mentioning Category (N=1)	Number in NM group Mentioning Category (N=2)
Felt unable to provide for child's needs	1	1
Threatened legal action/ charges of discrimination	1	1
Feared having unrealistic goals for the child	0	1
Felt too much disability in couple's life	0	1

Coyne and Brown (1986) examined developmentally disabled children in thirteen foster-care and adoption agencies in the United States and described their adoptive parents. Parental characteristics that adoption workers considered most ideal for adopting disabled children included:

maturity, flexibility, lower-middle class status, high school education, blue-collar employment, family centered life, religious orientation, previous parenting experience, experience with stress (such as divorce or another handicapped or troubled child), and a desire to adopt a developmentally disabled child.... A number of the adoptive parents were themselves handicapped to some degree.

(p. 192)

While the particular characteristics were viewed as strengths by adoption workers, they were often seen as limitations by foster-care workers who were likely to refuse potential adoptive parents because of their desire to secure the correct placement for the child (Coyne & Brown, 1986). While disabled woman may have a greater knowledge of the needs of the disabled child as a result of her personal experience, she may also better understand the time, money, and special care the child may require. One may hypothesize that her knowledge may cause her to question whether she has the stamina or the desire to meet the potentially greater needs of a disabled child than a non-disabled child. The mother may also be reflecting on her personal experiences as a child and prefer not to have to "relive" these experiences through her child.

Reflections on Childhood Experiences

Seven of the women interviewed felt that their childhood experiences were different from children who did not have a disability (see Table 18). Of the remaining respondents, three were not disabled as children and one was unsure of her response.

Six of the eight women reflected on the social isolation and lack of acceptance they experienced. In fact, elementary school children have been found to favor able-bodied children over their handicapped peers. This results in the disabled child being less often chosen as a friend or workmate (Hedahl, 1981). Respondents commented: "I felt a real sense of loneliness and differentness... I always felt much older than the other kids.... I also had a precocious puberty which is common to disabled girls and that made me feel very different" (post polio); "I was taken off the playground because the principal thought I might get hurt... I would always be left in the room" (spina bifida); "Most of the time I didn't know any other blind kids until I was in high school"; "Other children had never been taught to communicate or socialize with deaf children like me."

Two visually impaired mothers spoke about their overprotective parents who "wanted to do everything for me and wanted people to do everything for me." It is not unusual, however, for maternal care to intensify for a child with a severe illness or deformity (Levy, 1970). One disabled mother spoke about experiencing harassment, "the name calling, the pointing behind your back, the strange looks" (spina bifida). The issue of harassment was mentioned by other mothers in the course of the interview.

Table 18

Perceived Differences in Childhood Experiences From Children Who Were Not Disabled

Coding Category	Number in NS group Mentioning Category (N=4)	Number in NM group Mentioning Category (N=4)	% of Total Responses* (n=13)
Social isolation/ lack of acceptance	3	3	46.2
Attendance at schools	3	1	30.8
Overprotective parents	2	0	15.4
Experienced harrassment	0	1	7.7
Unsure	1	0	0.0

Note: *Percentage error due to rounding.

Four mothers, 50%, mentioned their attendance at special schools as an experience that improved "self-esteem" (deaf), and provided a sense of safety through association with other handicapped students (blind). One respondent mentioned participating in a resource program that provided her with increased contact with sighted children (blind).

While these are perceptions of experiences that occurred approximately 20 years ago, they were vividly remembered.

Problems Encountered in the Parenting Decision

The women were asked to identify the two biggest problems a woman with a disability faced when making the decision to become a parent (see Table 19). Seven mothers were concerned for their ability to physically care for their children. Respondents worried about: "How am I going to manage... just the day-to-day routine" of childcare (spina bifida); "not being aware... when the child might have something wrong, and you might not be sure whether or not you're handling the situation properly" (blind); and wondered "if I'm capable of taking care of him" (multiple sclerosis). Four women cited insufficient information and resources. One stated, "nobody knows anything" (post-polio). Another reported difficulties finding "a doctor that will be familiar with your condition, know how to handle it" (multiple sclerosis).

Two women cited several problems: dealing with misconceptions and misunderstandings as a result of the disability; concern that the child might be disabled; and the effects of restricted mobility on daily parenting activities. Others mentioned concern about the physical effects of pregnancy, being able to stimulate and physically challenge the child, and the lack of a role model.

Table 19

Two Biggest Problems Perceived to Be Encountered When Making the Decision to Become a Parent

Coding Category	Number in NS group Mentioning Category (N=4)	Number in NM group Mentioning Category (N=7)	% of Total Responses* (n=22)
Ability to care for the child/ perform physical care	3	4	31.8
Insufficient information/resources	1	3	18.2
Dealing with misconceptions/ misunderstandings	1	1	9.1
Concern for child's health	2	0	9.1
Child's safety	1	1	9.1
Restricted mobility	0	2	9.1
Effects of pregnancy	0	1	4.5
Lack of confidence to stimulate and physically challenge the child	0	1	4.5
Lack of a role model	0	1	4.5

Note: *Percentage error due to rounding.

The respondents identified concerns that are experienced by many women considering pregnancy. The demands of parenting, sometimes coupled with a career, are well known. A person's physical limitations can complicate the decision. Anticipating potential problems provides an opportunity to consider options for overcoming them.

An increase in information and resources, perceived by some to be lacking, may serve to broaden one's options. Locating health professionals experienced with both pregnancy and one's specific disability was problematic. Even interested professionals have limited information to offer.

Childbirth Education

Five mothers in the NM group--with the exception of two that adopted--were questioned about their experiences in childbirth education classes. They were asked whether they had received any information about the possibility that their disability might affect their delivery. Four women received no such information. One woman elaborated saying that she found the classes to be an "alienating experience" because she felt her "disability was ignored" (post-polio). Another said, "I tried to do the best I can [s/c] and follow along, and more or less she [the childbirth educator] said 'whatever you could do, you do. When you can't, you can't'" (multiple sclerosis). All five in the NM group indicated that they wished they could have attended special classes for disabled women or could have had the option of participating in one class specifically addressing the needs of a pregnant woman with a disability. Although it has been minimal, recent issues of professional

journals address the childbirth education needs of the disabled. The literature seems to have had little effect on childbirth education classes for the majority of disabled women participating in the interview portion of the research.

Three of the five women denied receiving any special suggestions during the class regarding what they could do ahead of time to make the hospitalization easier; one did not respond; and one remembered only that her obstetrician had made all the arrangements.

However, one mother was quite positive about the experience. (spina bifida) She felt that the childbirth educator always tried to provide facts that she "could directly relate to that I know other people couldn't relate to. And she was really trying to do her homework... to make sure there was some piece of information that I could take home every single night." She added that the disabled woman "is not going to find the sensitivity" needed in the usual childbirth class. "And I think they are going to sit there and go... this doesn't sound familiar. And I think that would bring apprehension, possibly fright and confusion."

In the NS group, three mothers were asked whether they had received any suggestions in their childbirth education classes that were intended to make their hospitalization easier. Two mothers reported that they were treated as all the others in the class. One woman remarked, "I never even thought about it" (blind). The other visually impaired mother received some individual attention. A film was explained before it was shown to the class, and she was assisted in assuming various positions and performing breathing exercises. The hearing impaired

mother wrote, "An interpreter was provided," and "the nurse was willing to write down some important information." She also said that, through their attitudes and responses, the other couples in the childbirth class showed acceptance. She followed through on the suggestion to have an interpreter present during the delivery, and made arrangements made for installation of a TTD in her room following the delivery enabling her to communicate with friends.

Effects of NM disabilities vary greatly based on factors such as cause, severity of the condition, and number of associated medical problems. In certain cases, such as multiple sclerosis, there can be rapid fluctuation in one's physical status. Thus, needs may vary greatly in women with the same condition and in the same woman at a different time.

Based on the reports of interviewees, women with NS impairments seem to have had more positive experiences with childbirth education classes than women with NM disabilities. Perhaps, these educators were more aware of interventions to overcome the limitations of visual or hearing impairments, such as describing the content of a film to a blind client or having an interpreter assist a hearing impaired client.

Health Problems During Pregnancy

Health problems encountered by the interview respondents during their pregnancies are listed in Table 20. While all four mothers in the NS group reported common effects of pregnancy, three visually impaired mothers had experienced some additional health problems during their pregnancies and immediate post-partal periods. Two mothers reported an

Table 20

Health Problems Reported During Pregnancy/Pregnancies

Coding Category	Number in NS group Mentioning Category (N=3)	Number in NM group Mentioning Category (N=5)
Urinary tract infections	0	3
Decreased mobility	0	2
Elevated blood pressure	2	0
Eclampsia	1	1
Loss of vision	0	1
Hemorrhage	0	1
Epistaxis	0	1
Disseminated intravascular coagulation	1	0
Ulcer	1	0
Hiatal hernia	0	1
Urinary incontinence	1	0
Hyperventilation/fainting	0	1
Loss of sensation	0	1
Joint problems	0	1

elevated blood pressure, while the other identified problems with an ulcer, urinary incontinence, eclampsia, and disseminated intravascular coagulation.

All women in the NM group reported health problems in addition to those usually associated with pregnancy. Few problems were reported by Shaul et al. (1981) in a study of 10 women with neuromuscular or musculoskeletal disabilities. The women reported only three complications, and these complications were related to the pregnancy rather than the disability. In this study, however, one mother with multiple sclerosis reported a loss of vision and decreased mobility, adding "I'm worse now than before the pregnancy, so it's really not important at this point." Another mother with multiple sclerosis reported decreased mobility, episodes of hyperventilation and fainting, and urinary tract infections. She also reported the need for oxygen and an epidural anesthetic due to bronchitis during her second delivery. She experienced a gradual deterioration of her condition during her pregnancy but stated: "I don't blame the baby on any worsening of my condition. I don't feel it got any better, but I don't feel I got any worse because of being pregnant." A woman with spina bifida experienced urinary tract infections, progressive loss of sensation, epistaxis, hemorrhage, and eclampsia. One mother with spinal cord injury (SCI) identified multiple problems that included: an increase in urinary tract infections, decreased blood pressure during delivery as a result of autonomic dysreflexia, need for anesthesia, and a forceps delivery because she was unable to help expel the baby. A woman with the effects of post-polio experienced joint problems and the discomfort of a hiatal

hernia. Some reported health problems were extensions of existing disabilities, such as decreased mobility in the mother with multiple sclerosis. Others noted an increase in frequency of problems often associated with conditions, such as urinary tract infections in the spinal cord injured mother.

Certain problems mentioned are common causes of maternal mortality. According to Williams (1980), "Hemorrhage, hypertension that is either induced or aggravated by pregnancy, and infection still account for half of the maternal deaths in the United States." (p. 4) Williams (1980) notes that there are multiple causes of hemorrhage in the obstetric patients. Hypertension occurs in approximately 6-7% of pregnant women and is accompanied by preeclampsia (edema and proteinuria) and sometimes by eclampsia (convulsions and coma).

Fortunately, in spite of medical complications, the pregnancies and deliveries of all interviewees resulted in viable infants. However, since little research has been done on the pregnant, disabled woman there is little information to offer on the effects of pregnancy on disability.

Childbirth Experience

Of the 10 pregnancies of the 5 mothers in the NM group, two women had a total of five premature births; the birth of an infant prior to 38 weeks gestation. This is a higher proportion of premature births than noted by Shaul et al. (1981). Only one premature birth was reported. In the present study, of the 13 pregnancies of 4 mothers in the NS group, one reported one premature birth.

Only two of five women in the NS group and two of three in the NM group experiencing labor reported that special plans were made for one or both of the couple at the time of delivery. Three appreciated that information regarding their disability was communicated to others by the doctor, themselves, or an interpreter. Only one mother stated that she did not want the staff--other than her physician--to know about her disability and actively attempted to protect this information. (multiple sclerosis) She said, "What good would it have done? They would have just kept me there longer."

Because her mother would be with her, another woman with multiple sclerosis said that she did not plan to inform the staff ahead of time. She thought the doctors would respond, "We've never dealt with this. Now what do we do?" One woman related a nurse's distress at not being informed in advance that the woman was blind: "I think she expected that I was going to be very incapable."

Two of five mothers in the NM group discussed the extent to which their pregnancy was treated as high risk and included a special team of doctors and nurses. In the NS group, the hearing impaired mother seemed to have the most extensive planning to deal with the effects of her disability. However, her disability was not expected to affect her pregnancy and risk during delivery.

Several mothers discussed the value of having a private room while in the hospital. In addition to affording privacy, a private room served to accomodate wheelchairs and other assistive devices.

All the women reported that they were allowed to make some decisions about their care while hospitalized for the birth of their

child/children. However, several mothers mentioned specific experiences where, they felt, their desires were not respected. In one case, the mother felt the nurses "didn't pay any attention" to her request to have her baby in a delivery room rather than in the more home-like birthing room. Instead, "they just kind of left me there" (multiple sclerosis). Another mentioned feeling that she was not respected for knowing herself and her limitations. Specifically, on the post-partum unit--less than 24 hours after a cesarean section--she was informed of the need to get out of bed. She protested, knowing that without the use of both arms (she was receiving intravenous fluids) she was "dead weight". She anticipated being "dropped" or "hurt in some way".

The mothers stated that the nurses on the postpartum unit encouraged them to spend time with their infants. Three mothers in the NM group reported that they perceived that their disability affected the nurses' response to them as new mothers. Of the three visually impaired mothers responding to this question, two felt their impairment affected the nurses' response, and one was unsure.

As shown in Table 21, the perceived effects of the disability on the nurses' response were mixed. Three women felt that the nurses were helpful. The hearing impaired mother, who felt that people in her community were better educated than most about the needs of deaf persons, stated that the nurses were as helpful as with any other mother. Two others commented that the nurses wanted to learn from them. "They always asked... if I needed this or that or if they were doing it right" (SCI). A woman with spina bifida reported that the nurses would say, "We want to help and you tell us what" to do.

Table 21

Perceived Effect of Disability on Nurses' Response to New Mother

Coding Category	Number in NS group Mentioning Category (N=4)	Number in NM group Mentioning Category (N=7)	% of Total Responses* (n=11)
Helpful	2	1	27.3
Concerned for ability to care for self/infant	2	1	27.3
Not truthful	1	1	18.2
Wanted to learn from her	0	2	18.2
Provided increased information	1	0	9.1

Note: *Percentage error due to rounding.

Three mothers noted concern on the part of the nurses for their ability to care for themselves and their infants.

At the beginning, the nurses were sort of hesitant. They'd bring the baby, and then they'd stand there and watch for awhile. They weren't sure as to [sic] 'if I should leave the child with this woman or not...' and I know they weren't doing this with other mothers. (blind)

Another commented: "I think they probably did a lot of questioning 'Oh, how are you going to do this' or 'How do you do it?' and then they'd just kind of hand the baby over and watch" (SCI).

Two respondents mentioned feeling that the nurses did not communicate truthfully. They "lied to me" (blind) and "they try to minimize everything because, I guess, they don't want you to get more upset" (blind). One felt that the nurses provided her with a greater than usual amount of information because of her disability.

The mothers recalled both positive and negative experiences surrounding the births of their infants. For example, a private room was valued by mothers in both groups. Mothers varied, however, on many other issues including: the extent of pre-planning felt necessary, the perceived responses of nurses to the disabled new mother, and whether the hospital staff should be informed of their disability. It is unlikely that the mother could "hide" her disability from the hospital staff because the physician would be expected to communicate this information. The fact that a mother would prefer that the staff remain unaware of her limitations is interesting. Perhaps the attitudes or behavior of health care providers in the past have influenced her decision.

Education for Family Life

All biologic mothers breast fed their infants or combined breast and bottle feeding except one mother with multiple sclerosis, who returned to taking her medication following delivery and feared for the health of her infant. All but one mother reported receiving information on infant feeding during her hospital stay from nurses or others. This mother obtained her information from books. (deaf) One of the mothers felt that the feeding information she received was minimal. It was only during her hospitalization after the birth of her last child that information was presented only on the selection of the most suitable breast pump. (SCI) Another commented that a lactation consultant gave her "one concrete" piece of information and "literally handed these sheets of paper" to her "and ran out of the room" (post-polio).

All mothers in the NS group responding to the question were taught about bathing their infants. However, only two of five mothers in the NM group reported such teaching. Of the three remaining mothers in this group, one commented that she has bathed her child only once. (spina bifida) She elaborated, "Nobody taught me. I bathed my child one time.... But since I ruined everything else in the process... I decided from that day on... I said 'I will never give my son a bath'." Another reported that, "We just kind of learned on our own." Because her first three children were premature and needed special care for several weeks, she stated, "We never learned till we got home" (SCI). Of the two mothers in this group who acknowledged such teaching, one reported receiving the information only with the birth of her second child.

Only one of four mothers in the NM group remembered being taught about family planning while in the hospital; that mother was taught by the midwife who was to deliver her child. Two of the mothers with NS impairments who responded to this question were taught about family planning, although they stated that they already knew. One visually impaired mother reported that her physician strongly suggested she consider a tubal ligation after the birth of twins, but she refused.

The responses suggest that the women in the NM group were more likely to experience a paucity of education about infant feeding and bathing, as well as family planning. While the type of hospitals, community or medical center, and the staffing patterns of the hospitals where the mothers delivered their infants were not determined, both may have affected the amount of teaching offered to the new mothers. The birth of an infant that required a prolonged hospital stay due to prematurity or complications during the perinatal period may also have contributed to the lack of information provided. These infants may have been transported to another hospital or to a special care unit in the hospital of birth. While the teaching should have occurred before discharge, it would not have been of immediate importance and may have been overlooked.

Hospitalization of Infants and Children

Following delivery, four of nine biologic mothers reported that their children remained in the hospital for an extended period of time. Two mothers in the NS group identified problems with neonatal jaundice. A woman with spinal cord injury had three premature infants with apnea

and bradycardia. One discussed her newborn's hospitalization following meconium aspiration. (post-polio)

Five mothers in the NM group and three in the NS group noted 10 occasions on which a child had been hospitalized at some time following the newborn period. A list of conditions is included in Table 22. All mothers, except one, felt they received adequate information with regard to their child's hospitalization.

Physical Care of the Children

All of the woman, except the hearing impaired mother, were asked whether they had done anything because of their disability to make some aspect of the physical care of their children easier. All responded affirmatively. As shown in Table 23, ten mothers reported some type of environmental modification. One mother would place her child on a footstool with wheels and push him around the house. Another had a bassinette on wheels. Later, she found a stroller with a handle in the middle so she could maneuver her child and an electric wheelchair at the same time. The husband of one of the interviewees modified a desk into a changing table.

Seven women found that by using an atypical location or position, certain activities were more convenient than when using a traditional approach. For example, one chose to change her infant's diaper on the floor. (post-polio) Another chose to change the child in the crib; she also found it helpful to feed her child in the crib at night. A visually impaired mother, when her child grew too large for a stroller, positioned her child on her shoulders. The child would hold onto the

Table 22

Reasons for Hospitalization of Children Following the Newborn Period

Coding Category	Number in NS group Mentioning Category (N=3)	Number in NM group Mentioning Category (N=5)
Tearduct surgery	1	0
Tachycardia	0	1
Croup	0	1
Herniorraphy	0	1
Parainfluenza	0	1
Detached retina	1	0
Fractured arm	1	0
Pneumonia	1	0
Diagnostic testing	0	1
Fever of unspecified origin	0	1

Table 23

Adaptations Made in the Daily Physical Care of Children As a Result of the Disability

Coding Category	Number in NS group Mentioning Category (N=4)	Number in NM group Mentioning Category (N=7)	% of Total Responses* (n=26)
Modifies environment	3	7	38.5
Uses special position/ location	1	6	26.9
Avoids performing certain activities	1	3	15.4
Seeks/trains child to assist	1	2	11.5
Feeds by breast/bottle	0	2	7.7

Note: *Percentage error due to rounding.

mother's head while she held the child's legs with one hand; the other hand was free to hold her cane. When feeding her baby, one blind respondent positioned her child on her lap facing away from her. She placed a blanket around the child to catch any spills and keep the child from reaching for the spoon. Then she "would have one hand by the baby's mouth and the other with the spoon in it. And I could find the baby's mouth without getting the food anywhere else other than the mouth."

Four mothers avoided performing certain activities altogether. For example, several mothers never carried the child outside of the house because of poor balance and the fear of falling (multiple sclerosis) or stumbling (blind). They usually kept the child in a stroller or had someone else carry the child. Two others mentioned never putting the child in a position where they could not lift or reach her. One commented that she "held her for seven months," and "I put her down only to go to the bathroom" (post-polio). The mother who avoided bathing her child left this task to her spouse. Three reported teaching the child to assist them in some way. A visually impaired mother has her 3-year-old son pin his socks on hangars with his clothes. She also tried putting bells on his shoes to assist in locating him in the house, however, he kept removing them. One respondent noted that her child frequently--if not consistently--assisted her in lifting him. Starting at about 4 weeks of age she "would hold his hand and say 'hand'." By about 8 weeks of age "he would hold his hands up" in response to her request. The third said, "My baby knows now that he has to roll over on his stomach, get on my arm, and I just lift him up" (SCI). Another felt that because she was unable to carry her son she and her husband had

trained their child to walk at 8½ months of age. Two mothers noted that their selection of breast or bottle feeding was planned to make childcare easier.

With regard to the physical care of their child/children, one mother may have summarized the feeling of all when she said:

Just because you're handicapped that's not going to make you not a good mother. You just work around the inconveniences, not to be afraid to try different things. I mean, I came up with all kinds of thing because of my wanting a baby so bad. It was, more or less, I'm going to find different ways of making it easy for me.

While 7 of the 11 mothers had initial concerns about performing daily childcare activities, all interviewees reported success in these tasks. Physical limitations did not preclude performance of childcare activities. The parents devised creative approaches to circumvent physical limitations and accomplish their goals.

Child Safety

Some concern for their child's safety as a result of limitations due to the disability was mentioned by six of seven mothers in the NM group and all four in the NS group (see Table 24). Nine of eleven mothers reported restricting their children's mobility outside the home. Fencing in the yard was the most commonly mentioned precaution. Other actions included keeping the child indoors when no one was available to watch him outside (blind), and maintaining constant (blind) or close (spina bifida) physical contact with the child when outside. In the NS group, all reported increased monitoring/ watchfulness of the child,

Table 24

Precautions Taken by Mothers to Ensure Child's Safety

Coding Category	Number in NS group Mentioning Category (N=4)	Number in NM group Mentioning Category (N=7)	% of Total Responses* (n=16)
Restricted child's outside mobility	3	6	56.2
Increased monitoring/watchfulness of the child	4	2	37.5
Childproof home	0	1	6.3

Note: *Percentage error due to rounding.

while only two in the NM group did so. Three mothers noted that they would call to their children and listen for their responses. (blind) A hearing impaired respondent reported using her "eyes and legs to check more frequently" on the child.

Perceived Effects of Disability on Children

As noted by Buck and Hohmann (1983), "The prevailing opinion in the literature is that children's physical, emotional, interpersonal, and recreational well-being are at risk when a parent is disabled or chronically ill" (p. 209). They note that few articles distinguish between paternal and maternal disability and that these are speculations without empirical basis.

To assess the interviewees' perceptions about their children, the mothers were asked if they felt their disability had any effect on their children (see Table 25). Three women in the NM group indicated it had, while three anticipated effects when their children grew older. One commented: "This is the first year she has ever said she felt sorry for me" (post-polio). All four respondents in the NS group acknowledged some effects; the hearing impaired mother indicated only that it did not seem to have much effect. Newbrough (1985) writes that the effects of parental deafness on children are at the social and educational level; that the child who learns sign language often assumes a very responsible role, early in life, of intermediary and interpreter.

Four of the six mothers in the NM group with children beyond infancy reported that their children showed an increased sensitivity to others. "She [the child] gets really mad when someone stares at me" (post-polio).

Table 25

Perceived Effects of Maternal Disability on Children

Coding Category	Number in NS group Mentioning Category (N=4)	Number in NM group Mentioning Category (N=7)	% of Total Responses* (n=22)
Increased sensitivity to others	1	4	22.7
May feel embarrassed later/ sense of being different	2	3	22.7
Provides assistance to mother	1	3	18.2
Special fears for parents	0	2	9.1
Increased limit testing	1	1	9.1
Restricted mobility	0	2	9.1
Increased sensitivity to environment	1	1	9.1

Note: *Percentage error due to rounding.

One respondent noticed that her 4-year-old "would be playing with one little boy that's on braces and crutches one way, and... the sibling would come by, who was not disabled, and he would play with him in a completely different physical fashion" (spina bifida). While only one visually impaired mother identified increased sensitivity in her children as an effect of her disability, two other mothers with NS deficits mentioned their child's increased sensitivity in response to the question about parental satisfactions.

Three mothers--two from the NM group--related incidents where the child was embarrassed or had a sense of being different. A mother remarked: "Other children would tease them about their blind parents... and I know a lot of times I used to go out with my children. Sighted people would stare at them or stare at me." Her children would get upset but would say, "Well, Mommy, I just stared right back at them and made them turn their head." Two other mothers, one from each group, speculated that such feelings might be experienced by their young children when they grew older. In response to this question, four mothers noted that their children provided assistance to them. However, in the course of the interview, several other mothers mentioned ways in which their children assisted them. This assistance came in the form of reading the mail, writing checks, helping with the wheelchair, obtaining help in an emergency, notifying the mother when the telephone is ringing, and performing certain household tasks.

During the course of the interview, two mothers identified special fears experienced by their children as a result of their disabilities. One mother recounted an incident where she fell out of her wheelchair

and could not get up. She said that her 4-year-old daughter was "very, very concerned" (multiple sclerosis). Another commented about her four-year-old son's fears. When he was younger, she had fallen on two occasions and hit her back. She stated, "It had a very big impact on him. He was very afraid for Mom. I lose all feeling in my legs so I drop to the ground, and he didn't like to see that in his Mom at all" (spina bifida). Two women with neuromuscular impairments felt that their disability restricted their children's mobility. Two mentioned that limit-testing and sensitivity to the environment, as well as awareness of people in wheelchairs, with canes, on crutches, or with an unusual gait were increased in their children.

In the study by Shaul et al. (1981) women cited independence and "increased sensitivity to other stigmatized individuals" (p. 371), including their parents. Reported disadvantages included limited participation in certain family activities, prolonged separation from children due to medical needs, children's long adjustment to maternal disability that occurred after the birth of children, and social difficulties of children with peers because of a mother who is "different".

The respondents perceived that their disabilities had, or would have, some affect on their children. However, some of the perceived effects are experienced by children with able-bodied parents. For example, a child may be teased for having an obese parent or one that is "older" than most. Children who experience the loss of one parent through divorce or death may fear the loss of the other. Perhaps parental disability did make the children more sensitive to the disabled

and the surrounding environment. Whether their children might have evidenced some of these behaviors regardless of the parent's disability was not within the scope of the investigation.

Questions Asked By the Children

All of the women in the NM group with children over 2 years of age said that their children asked questions about their mother's disability. In the NS group, only two mothers indicated that their children had asked such questions. The remaining two reported that their children had not asked questions because the parent provided an explanation about the disability before the child asked.

Jones and Sisk (1967) studied young children's perceptions of physical disability. They found that awareness of limitations of a disability first occurs at 4 years of age. One interviewee reflected on the statements of her child before he was three years old. He urged her to "stand up" and she responded by moving from the couch to her wheelchair. In response to his continued request to her to stand, she informed him, "Mommy can't. Mommy does not stand. Mommy does not walk." He stated, "I help. I help." This type of interaction persisted for several months. This same child, at 5 years, was reported to have a keen awareness that "there's a difference in Mommy." Another interviewee commented that occasionally her 4-year-old would ask "Why can't you walk?" She went on to say, "but she knows.... I don't even know if she thinks of me as a handicapped person. This is what Mommy is. This is Mommy, a normal Mommy" (multiple sclerosis).

Several mothers mentioned that they imparted honest, developmentally appropriate information to their children. Some of the children, because of their mother's community involvement, were exposed to others with a wide range of disabilities.

Perceived Satisfactions in Parenting

Responses to the question about their greatest satisfactions in parenting fell into two major categories: parent-centered (n=12) and child-centered (n=12) satisfactions (see Table 26). In the parent-centered category all respondents (N=11) reported experiencing a sense of fulfillment. According to Benedek (1970), a mother introjects gratifying mothering experiences "and their object, the thriving child" (p. 117). A thriving infant is equated with good mothering and self-confidence. Two visually impaired mothers identified breast feeding as an experience that fostered a close bond between parent and child. One said, "I don't think its [s/c] anything as great in the world.... something that you really can't explain, you just have to do it." Some other comments included: "He's ten times more than we ever wanted" (multiple sclerosis); "It makes you feel more confident in yourself to know that you can take care of somebody else" (blind); "I never realized what another human being can do in terms of getting a mom and dad to completeness" (post-polio); and the joy of "seeing this miracle of life grow and respond and turn into a little bit of you and a little bit of your husband and a lot of himself" (spina bifida). One mother in the NM group also identified a feeling of control through this "sense of reliving my own childhood and, maybe, being able to do things differently than was done with me" (post-polio).

Table 26

Greatest Satisfactions in Parenting

Coding Category (N=24)	Number in NS group Mentioning Category (N=4)	Number in NM group Mentioning Category (N=7)	% of Total Responses*
Parent-Centered			
Sense of fulfillment	4	7	45.8
Sense of control	0	1	4.2
Child-Centered			
Normal growth and development	3	6	37.5
Success/achievements	1	0	4.2
Desire for mother's presence	0	1	4.2
Helpfulness	1	0	4.2

Note: *Percentage error due to rounding.

In the child-centered category, six of seven women in the NM group and three of four women in the NS group expressed great satisfaction in their children's normal growth and development. "Seeing them growing properly, stage by stage--mental, emotional, physical and spiritual development" (deaf), and having the opportunity "to watch, observe them, how they play" (SCI) were satisfying. One woman with a NM disability reported satisfaction in the fact that her 8-year-old daughter wanted her mother with her everywhere she went saying, "I do five times more with her and all the neighbor kids than their own parents do" (post-polio). One visually impaired mother identified a great satisfaction in her child's ability to succeed in school as well as tasks; another was especially pleased with her child's helpfulness. (blind)

Special joys or satisfactions in raising children that the mothers perceived were directly related to the disability also fell into two major categories: mother-centered and child-centered (see Table 27).

In the mother-centered category, a sense of normalcy was identified by three of the women in the NM group and one in the NS group. One respondent with post-polio felt that seeing her child's "ability to succeed in life be so much above my own, diminishes my disability."

Increased self-esteem/self-confidence was reported by three mothers in the NM group and one woman with a neurosensory impairment. Three of four women in the NS group identified their own increased awareness and sensitivity as did one woman in the NM group. One respondent noted that she was more comfortable with children now and they were more comfortable with her. She mentioned overhearing

Table 27

*Greatest Satisfactions in Parenting That Are Perceived To Be A
Direct Result of Having a Disability*

Coding Category	Number in NS group Mentioning Category (N=4)	Number in NM group Mentioning Category (N=7)	% of Total Responses* (n=31)
Mother-Centered			
Sense of normalcy	1	3	12.9
Increased self-esteem/ self-confidence	1	3	12.9
Increased awareness/ sensitivity	3	1	12.9
Sense of accomplishment	1	0	3.2
Increased number of children	0	1	3.2
Eligibility for benefits	0	1	3.2
Child-Centered			
Special abilities	4	1	16.1
Increased sensitivity	2	1	9.7
Normal growth/development	0	3	9.7
Absence of discrimination	1	1	6.5
Special opportunities	0	2	6.5
No response	0	1	6.5

Note: *Percentage error due to rounding.

disparaging remarks because, "I'm in a wheelchair, and when I'm out in a machine... they're naturally going to look at me" (spina bifida). Now that she had a child these remarks were less of a concern.

One hearing impaired mother reported a sense of accomplishment in being "able to teach and train our children the way the Lord wants us to do." The children were becoming socialized to bicultural settings--that of the hearing and the hearing impaired.

One respondent reported a special satisfaction in the hope that she would qualify for social security payments since she could no longer work, and would be able to stay home and take care of her child.

(multiple sclerosis) Another indicated that her disability motivated her to have more children than if she had been able-bodied and had probably made her more "sensitive" to them. (SCI)

Child-centered joys and satisfactions were divided into five categories. All four mothers in the NS group and one in the NM group reported satisfaction in their children's special abilities. Children of the hearing impaired mother were "able to communicate in sign language... their needs, wants, hurts, feelings, and are able to obey me or my husband." The 3-year-old son of a visually impaired woman would tell her "if he sees something" and "take my hand and put it on something when he wants to show me where it is." Another respondent noted that her children described things in much more detail than the average child. (blind) One child was considered "very protective" by her mother: "She knows how to put the wheelchair together.... knows if I spasm how to help me try to get my feet back on the chair.... she's not afraid." Three of the mothers responding to the question identified the

child's normal growth and development as important. One woman commented, "I love to look at his straight back. I love to see that he is so normal and so perfect" (spina bifida). Two visually impaired mothers identified their child's increased sensitivity as satisfying and one was pleased that her child was more accepting of others. The respondent said, "They see somebody that's maybe on crutches or in a wheelchair, and a lot of times, the average child will make fun of that other person.... my children... accept more... are more open-minded." Another remembered that when one son was fourteen, he said, "When I die, I want the doctors to take my eyes and give them to you." A mother with a NM impairment noted that her child would not be discriminated against in the way she was saying, "He will be able to grow up without the harrassment - the teasing.... I feel thankful that he won't have to go through a lot of the things that I did" (spina bifida). Two mothers in the NM group found joy in the special opportunities provided for their children and children's friends, such as riding in the wheelchair or specially equipped van.

The most frequently reported satisfactions in parenting, a sense of fulfillment and appreciation of the child's normal development and achievements, do not seem surprising. Some of the most frequently identified satisfactions in parenting perceived to be a direct result of having a disability appear noteworthy. Several mothers reported a sense of "normalcy". Perhaps, with the birth of a healthy child the disabled woman felt that her body was functioning as effectively as that of her able-bodied counterpart. Perhaps the sense of "normalcy" arose from the woman's ability to overcome her limitations and be a successful parent.

Increased self-confidence may have come from perceived success in parenting tasks. The increased sensitivity to her children may be the result of living with the limitations of a disability. Children had developed some special abilities that may not have occurred if the parent had been able-bodied.

Advice to Medical Professionals

When asked how medical professionals could more effectively assist a person with a disability, the responses fell into eight categories (see Table 28). The majority of respondents--three of four in the NS group and six of seven in the NM group--felt that medical persons needed to become better-informed. A hearing impaired mother suggested a sign-language course in medical terminology. Another respondent advised that health care professionals learn more because "nobody knew anything about what my pregnancy was going to be like for me." She further stated that it would be helpful if they also learned "something about how disabled people live their lives "in order to provide some concrete suggestions" (post-polio). This was echoed by another respondent with post-polio who further suggested that medical curriculums include some "hands on" experience on rehabilitation units. She stated:

We can't expect the world to know what our problems are. We can, but then we're disappointed and we're negative and resentful. But if we constantly try to teach people, either by our actions or our words or sending them a bit of information, then I can expect more of them because I've given them that information.

Table 28

Advice to Medical Professionals Assisting A Disabled Person

Coding Category	Number in NS group Mentioning Category (N=4)	Number in NM group Mentioning Category (N=7)	% of Total Responses* (n=32)
Seek information	3	6	28.1
Don't stereotype/make undocumented assumptions	3	3	18.8
Provide information/referral	0	5	15.6
Provide support	0	5	15.6
Use appropriate communication	1	2	9.4
Accept need for control during pregnancy	0	2	6.3
Improve accessibility/ modify environment	0	2	6.3

Note: *Percentage error due to rounding.

This woman indicated that she has spoken to various groups of health care providers but has never been invited to speak to nurses. She said, "I think that's some indication that they know it all, or that they don't need it." Another woman wrote on the questionnaire, "I found I taught my doctors how to deal with a disabled pregnant woman. Both my doctors were great and eager to learn" (multiple sclerosis).

Six women admonished health professionals for stereotyping and for making undocumented assumptions. As a woman with post-polio wrote on the questionnaire, "convincing doctors that disabled women have sex is a monumental obstacle in 1985 as it was in 1895.... physicians over age 50 are still in the dark ages regarding disabled women's health let alone pregnancy." A visually impaired woman noted that a handicapped person should not be pre-judged. Rather, medical persons should "talk with them, ask them questions and find out what their various needs are and how they can better help them in their situation." Another felt that she had to convince her pediatrician that she could take care of her children. (blind) Over time, she felt, the pediatrician's reservations ceased.

Five of seven respondents in the NM group felt that medical professionals needed to provide increased support to the disabled; five also discussed the need to provide information or referral. One respondent asked that doctors "listen to their patients" and be willing to try non-traditional approaches because "handicapped people do need different considerations" (multiple sclerosis). She also advised that the woman be told whether an event in the pregnancy was related to her disability and that there be better preparation for labor. She added

that the staff should be well prepared in advance of the disabled woman's arrival. In this way, her needs and their affect on the staff could be anticipated. Other suggestions included: keeping a list of names of women with disabilities as a resource for woman with the same disability; and having nurses ask if help is needed rather than waiting for the woman to "always have to ask cause [s/c] I don't." A mother with spinal cord injury commented that doctors seemed to be "afraid" to provide certain information to a woman with a disability despite the fact that the same information was commonly shared with able-bodied women. She stated, "None of the doctors I ever had... mentioned breast-feeding or birth control.... I just had to find out on my own, or through some nurses. Till we had like the [last two]." She felt that the physician's attitude was that "she [the disabled mother] probably couldn't do it anyway so why bother." Another commented that doctors should become aware of agencies, self-help groups, and other options available in the area. (spina bifida)

Two respondents mentioned that environments must be modified to improve accessibility to doctor's offices and examining tables. Two discussed the need to use appropriate communication patterns--"address the person with the disability, and not the person with them"(spina bifida). The hearing impaired respondent mentioned the necessity for using appropriate vocabulary and simple words, because of the numbers of low-verbal deaf women. Two women with NS impairments commented on the need for medical professionals to accept the woman's need for control during the pregnancy. One woman was told "You were my favorite patient" when she refused to take any medications during her pregnancy that might have jeopardized her baby's development. (multiple sclerosis)

The interviewees were able to offer a number of suggestions to improve health care received. While most suggestions came from the women in the NM group, the majority of women in both groups felt that health care providers needed to become better informed.

Disabled Women as Resources

The women were asked whether they would have contacted a physically disabled mother who would have been willing to share her experiences with them. All responded affirmatively. This is similar to the findings of Shaul et al. (1981) who noted that most women wanted to speak with a similarly disabled woman. Two women in the NM group had already done so, as had one visually impaired mother. Only one adoptive mother qualified her response saying that she felt it was more important to discuss a child's behaviors and attitudes rather than the affect of her disability on childrearing. (post-polio) She went on to say that she would like to discuss her concerns with a group of disabled women or parents, not because of her disability, but because they would recognize that her concerns were not associated with her disability.

When asked whether they would be willing to act as a resource to a woman with a physical disability who was considering becoming a parent, the responses were all positive. A respondent with a visual impairment and one with a hearing impairment had already done so, as had a mother with spina bifida and one with post-polio paraplegia. One mother described her relationship with a severely disabled single woman who was currently pregnant and had virtually no support from family or friends. At this point, she described her role as one of listening, answering

questions, and giving information. While she had suggested that parenting a child alone would not be easy, she recognized that the woman needed to make her own decision whether to give the child up for adoption or choose to raise the child. Should the woman select the latter action, the respondent indicated that she would do whatever she could "to make sure her support system in the... community is viable."

Two women qualified their affirmative responses to acting as a resource to another physically disabled woman. The first woman, a mother of five children, would do so if that woman initiated the contact and was "genuinely interested" (SCI). The second mother indicated that she would be especially interested in working with breast feeding mothers with special needs. (post-polio)

Persons who are perceived to have successfully adapted to or mastered a difficult personal experience are often sought out by others in similar situations and asked for advice. Some who have been asked to help others in this way, find that they enjoy the opportunity and may develop a local reputation as a resource for guidance and support (Caplan, 1974). Caplan (1974) states:

Almost anyone with an illness or disability, or who is exposed to a personal or family predicament or challenge, has a tendency to seek guidance from somebody else who has travelled a similar experiential route and who can tell what to expect as well as what options have proved to be the best for grappling with the burdens and challenges. (p. 13)

Occasionally, articles have been written by or about disabled mothers (Dunn, 1978; Moore, 1981; Grouse, 1983) for dissemination to the disabled population.

Each respondent was asked what she would say to another physically disabled woman who was considering becoming a parent. Nine of eleven interviewees, 82%, indicated they would offer encouragement and proceeded to offer specific advice (see Table 29). Responses spanned eight categories. All seven respondents in the NM group and two of four women in the NS group indicated they would provide encouragement. Among the comments voiced were: "Go for it!"; "There are a lot of worse problems to have, why not go for what you want if you really want to have a baby"(multiple sclerosis); "It doesn't matter what you think your capabilities are. Capabilities are the minor factor in whether you want a child or not. Any manner of adjustment can be done" (spina bifida); and "I'm very encouraging about it because, I think that disabled people have been so discouraged" (post-polio paraplegia). Four women with NM impairments felt that the woman should seek information to make an informed decision as did two respondents in the NS group. The respondents gave this advice: "Find out everything you can so you're not surprised" (multiple sclerosis); "understand what you're getting into (spina bifida)"; and "check with the doctor first to make sure you have... nothing to say no--genetic-wise or whatever" (multiple sclerosis).

Two women with neuromuscular disabilities and two visually impaired mothers felt that the woman should "be realistic" in assessing her own abilities/limitations. Three respondents in the former group

Table 29

*Advice for Other Physically Disabled Women Who Are Considering
Becoming a Parent*

Coding Category	Number in NS group Mentioning Category (N=4)	Number in NM group Mentioning Category (N=7)	% of Total Responses* (n=24)
Seek information to make an informed decision	3	4	29.2
Make an independent decision/ don't let negative attitudes influence you	2	3	20.8
Realistically assess abilities/limitations	2	2	16.7
Have a support person/ system available	2	1	12.5
Don't make assumptions	0	2	8.3
Communicate needs to others	0	2	8.3
Prepare for physical difficulties of pregnancy	0	1	4.2

Note: *Percentage error due to rounding.

also suggested that a prospective mother make an independent decision that was not influenced by the negative attitudes of others. This theme was reflected in the comment: "The decision to have a child is her's alone. She should not let anyone influence her" (post-polio paraplegia). This was reiterated by two visually impaired mothers. One said, "Since there are people that are going to be against your decision, to make your decision on your own.... and not be influenced by... negative things that other people might be saying to you." Three women--one in the NM group and two in the NS group--mentioned the necessity of a support-person or support system. The women advised others to, "Seek out groups who are supportive" (post-polio paraplegia) and "have emotional, financial, physical supports from hubby or someone" (deaf).

The remaining suggestions included: not making assumptions, communicating needs to others, and being prepared for the physical difficulties of pregnancy.

The largest proportion of women in both the NS and NM groups suggested that a disabled woman contemplating pregnancy seek information to make an informed decision. The advice was similar to that given physicians; seek information so that it can be shared with others. Perhaps the women recognized the actual and potential problems associated with pregnancy and childrearing and felt that this knowledge should be conveyed to others. Perhaps the suggestion arose from the frustration the women encountered trying to locate such information. All the advice offered, however, arose from the personal experiences of women who desired to make the parenting process easier for a disabled woman considering parenthood.

A mother of 2 children under 4 years of age, who did not participate in the interviews, added a comment on the questionnaire that summarizes some of the feelings of a majority of the respondents. She wrote:

From adolescence until my late 20's I thought I should not have children, that physically my body would not be able to take the stress or that it was possible that I would not be able to care properly for a child. All of those thoughts, thusfar, have been unfounded. I have two healthy children, my physical status has been virtually unchanged, and I love being a mother. I feel that many years of my life I was tortured by the thought of not ever having children unnecessarily. My parents... and doctors were the roots of my fears. I know they were trying to protect me from their own uncertainties and, luckily for me, were proved wrong. (spina bifida)

The developmental task of becoming a mother functions as an organizer of personality and requires a significant adjustment in physical and emotional resources. The mother is viewed as primarily responsible for the children's socialization, adjustment, and interpersonal relatedness (Stott et al., 1984). Disabled mothers have needs, concerns, and responsibilities similar to their non-disabled counterparts, as well as some that are unique to a woman with a disability. With support, initiative, and creativity the respondents in the study have successfully adapted, and are continuing to adapt, to parenthood.

Implications

On the basis of the findings of the study, implications for education and nursing practice can be advanced.

Implications Related to Research Question 1

The physically disabled woman was able to perceive differences in support provided by family, friends, and professionals when making the decision to become a parent. The fact that medical persons provided significantly less ideological support for the woman's decision to become a parent than spouse and friends suggests that the medical community may benefit from exploration of attitudes toward the disabled. The finding that medical persons also were perceived as providing significantly less emotional support in the woman's decision to become a parent than the spouse may be a result of their perceived lack of support for her parenting decision. On the measure of information provided, medical persons were not seen as offering significantly more, or less, support than other support persons. This may reflect that, while information is offered, it is not perceived as more adequate than that provided by the spouse or friends.

The finding that spouse and friends were perceived as significantly more supportive than other support persons in all categories of support except instrumental assistance is important. It suggests that these persons are sought for support and may have implications for health professionals, childbirth educators, counselors, and the like. They are in positions to both foster and strengthen these existing systems.

Implications Related to Research Question 2

The findings supported a relationship between the emotional support, information, and instrumental assistance provided and the physically disabled woman's decision to become a parent. Multiple factors may have influenced the outcome. The possible relationship between the presence of a strong social network and the decision to become a parent and the absence of a strong social network and the decision to remain childless must be considered.

Implications Related to Research Question 3

The health care experiences of 11 respondents when making the decision to become a parent, when pregnant, and when raising their children were explored through interviews. Additional areas of interest to the researcher were explored with the participants in order to obtain a more complete picture of the physically disabled woman's perception of parenthood. The interviews revealed many interesting findings and resultant implications for practice, some of which will be discussed below.

A physically disabled woman needs to be (a) informed if the disability may be inherited by offspring, and (b) given all available information about pregnancy and her specific disability. She may then make an educated decision about the risk of pregnancy to herself and any children. An uninformed woman may be faced with difficulties which she would have chosen to avoid and could have prevented. Thus, it is the responsibility of medical persons to offer this information or refer her to an adequate source of information without waiting for her to request it. She may then choose to accept the information or not. It must be

recognized that women with neurosensory deficits are less likely as women with neuromuscular disabilities to be receiving ongoing medical care. Thus, a special effort must be made to reach and educate these women.

Adoption was an alternative to the risks of pregnancy for two of the three mothers. Their experience with agency caseworkers' suggestions that they consider a child with special needs caused some added distress. Therefore, adoption workers may wish to avoid the assumption that a disabled woman would prefer to adopt a disabled child. They first need to question the couples' desire.

The women's reflections on childhood experiences suggest that schoolage peers both recognized and reacted to the presence of a disability in the respondents. Whether the experiences of a disabled child today have been more positively affected due to mainstreaming the handicapped in the school system remains a matter of debate. Regardless, it would be helpful to assess the attitudes of classmates toward disabled peers and, if necessary, institute programs to educate for attitude change. It would also appear important to encourage socialization of disabled children with both able-bodied and other handicapped children. Activities, both school and leisure, could be structured to permit the disabled child to be valued for what he can contribute. Overprotective parents could be encouraged to foster independence in their children while continuing to recognize their limitations and required adaptations. Parents of disabled children could be encouraged to join a support group.

When the women discussed problems encountered in the parenting decision, the need for information sharing and teaching was evident. It would seem that the public could benefit from information about, and increased association with the disabled, to help eliminate some misconceptions. Classes, or other means of conveying information on normal growth and development could be helpful, as would the opportunity to discuss their concerns about parenting with other disabled and non-disabled parents. This information would be helpful in recognizing and dealing with many usual aspects of childrearing. It could also be useful when the child begins to ask questions about the parent's disability or if the child reports being teased by peers because his mother is "different". Disabled women considering parenthood should be helped to recognize that many of their concerns, including whether they will be a "good" parent, are concerns of the non-disabled as well. Some problems are unique to them.

More research on pregnancy and disability must be done and disseminated to health professionals. This should have the effect of improving the information offered to women considering parenthood as well as those attending childbirth education classes. Anticipatory guidance regarding the hospitalization for labor and delivery could be improved. Classes could be offered for disabled parents-to-be, should they choose that option. If the numbers of disabled, prospective parents are small, one class on pregnancy and disability might be satisfactory.

When the respondents discussed the childbirth experience, the value of a private room was evident. While most insurance companies pay

only for a semi-private room, there is a reasonable alternative to this policy. The woman could be asked whether or not she would prefer a roommate. Should she request the privacy and the space, she could be assigned to an empty semi-private room. If the post-partum unit is not crowded, an attempt could be made to meet her request without an additional charge. The nursing staff must be aware that non-traditional approaches are often necessary if the disabled woman is to accomplish her goals. The woman's knowledge of her body and its limitations should be acknowledged. If possible, the staff and new mother should negotiate until a satisfactory conclusion is reached.

Nurses must be educated about various disabilities so they can both offer suggestions as well as learn from the mother. Nurses must also be educated in appropriate ways of offering assistance to the disabled. Incorporating care of the disabled into the curriculum content would be appropriate.

The interviewees in the NM group were more likely to report inadequacy of feeding, bathing, and family planning information. Whether the infant is discharged from the newborn nursery or intensive care unit, the mothers are entitled to this information. They may also need more than one opportunity to practice newly learned childcare skills.

The mothers reported several adaptation made in the daily care of children due to their disabilities. Most commonly mentioned were modifying the environment and using a special position or location to facilitate these activities. The mothers were creative in the adaptations they used. However, it may be helpful to compile a list of

resources for childcare equipment and make it available to prospective parents. Devices such as the "talking thermometer" to assist the blind parent could be included. Disabled parents could contribute adaptations they found successful. Articles written by, or about disabled parents could be included. These resources could be kept in obstetricians' offices, distributed to obstetrical units, and to parent/child organizations.

The respondents offered some important advice to medical professionals interested in assisting a disabled person. Health care professionals should examine their own attitudes toward pregnancy and disability. Individuals recognizing their own negative attitudes might consider referring a disabled person to someone more sensitive and supportive and with rehabilitation experience. with rehabilitation experience. A resource file of physicians experienced with pregnancy and specific disabilities could be maintained, and medical referrals made to interested doctors. Medical professionals need to ensure that the disabled woman receives the same information, modified for her needs, as a non-disabled woman.

The women valued contact with other physically disabled mothers, both when considering pregnancy and when raising their children. To provide an opportunity for such contact, a nation-wide list of disabled mothers could be maintained by organizations dealing with persons with specific disabilities. Currently, a woman may have difficulty obtaining such assistance from an agency in her community. These same agencies could maintain a resource file of articles about the disability and the implications of pregnancy, written for the disabled population. These

measures would increase the support network available to the woman, should she wish it.

Suggestions for Further Research

Due to the exploratory nature of the research and the use of a non-random sample, generalizations to the larger population of physically disabled women cannot be made. However, a major purpose of this type of research is to generate ideas for further research, and this purpose has been achieved.

Another study comparing a geographically representative, larger sample of women with specific disability types should be done to confirm the relationships among variables found in this study. A similar study using a larger number of subjects for each of the subgroups, neurosensory and neuromuscular, could be done to facilitate further comparisons between subgroups. This type of sample may best be obtained through cooperation with one of the national organizations for persons with disabilities or through state departments of rehabilitative services. The study may further seek to compare the responses of women with disabled spouses to those with non-disabled spouses. A comparative study of perceptions of social support and childbearing and childrearing experiences could be performed using women with chronic illnesses and a matched sample of physically disabled women. Another interesting study could examine the available social support and experiences of disabled women choosing to have children and those choosing to remain childless. Social support could be examined using one or more of the measures of social support available in the research literature. Studies may be

done to examine the perceptions of social support at times other than the decision-making phase. It would be interesting to explore why some mothers chose to participate in the research and others did not.

Additional studies may be done to examine the effects of maternal disability on children. Little research has been done in this area. Most references to effects of parental disability are the result of speculation. (Buck and Hohmann, 1983) Effects on children with maternal disability could be compared with effects of paternal disability. A longitudinal or cross-sectional study of the child's perceptions of the affects of parental disability as the child matures could be compared with parental perceptions of effects. The mother's perceptions of the effect of maternal disability on her children could be compared with the child's perception of the effects.

It would be interesting to examine attitudes of health care providers towards the disabled. One could compare the attitudes of professionals working with the disabled in a rehabilitation setting with those who have only infrequent contact. The attitudes of medical professionals could be assessed prior to and following contact with disabled persons to determine whether there has been any change, and if that change is positive or negative.

In the present study, the amount of perceived social support accounted for by the person variables ranged from .6013 to .8067. Further research may be done to increase the internal validity of the scales. Additional valid and reliable instruments could be administered to subjects to increase internal validity by decreasing error variance.

Further measures may be taken to control sources of extraneous variance. Criteria specifying age of onset of the disability could be established. A determination could be made as to whether any other family members, especially the spouse or partner, was disabled. Examination of availability and utilization of support services or involvement in community organizations could be done to increase the validity of interpretations made.

The researcher acknowledges that sources of extraneous variance may have been introduced into the study due to the varied methods of data collection. Thus, future research limiting the methods of data collection is warranted.

Additional analysis of data could be performed and further research done to determine whether a relationship exists between variables such as age and educational background, and the perception of social support. The assumptions generated from the analysis of the interview data could be explored. Finally, experimental or quasi-experimental research, where variables related to social support are manipulated could be performed; interventions to increase the perceptions of available support could be attempted. An understanding of ways to increase social support could be helpful to those involved in providing social support and quality care to mothers and their children.

Summary

The purpose of this final chapter is to summarize the exploratory investigation of the perceptions of social support, needs, and experiences of physically disabled women during childbearing and childrearing.

The findings relating to each of the three research questions were discussed. Examination of Question 1 led the researcher to conclude that the physically disabled woman does perceive differences in support provided by family, friends, and professionals when making the decision to become a parent. It is acknowledged that the small sample size and use of volunteers may have biased the results.

Exploration of the relationship between the emotional support, information, and instrumental assistance received from the social network of family, friends, and professionals and the disabled woman's decision to become a parent. Analysis of Question 2 revealed significant correlations for the total group of social support participants. When these analyses were done for participants from the NM group, significant correlations were found for all types of support and for all support persons, with the exception of sisters, in-laws, and nurses in the social support category. These analyses, when performed for respondents in the NS group revealed few significant correlations. Only support received from the spouse, in the information category of support was correlated with an influence on the decision to become a parent. In the emotional support category, spouse, sisters, doctors, and nurses were significantly correlated. Only brothers were significant in the instrumental assistance category. Many factors were felt to have influenced the outcome of these analyses, and must be considered when drawing conclusions based on the findings.

Question 3 led the researcher to examine the health care experiences of physically disabled women when considering a family, when pregnant, and when raising her child/children. Eleven interviewees

contributed their perceptions on many subjects. As a result of their responses, the investigator advanced a variety of hypotheses.

A variety of ways that researchers may use the results as a basis for further investigation are identified. Implications for practice and suggestions for future research are discussed.

Chapter VI contains a summary of the research.

CHAPTER VI

SUMMARY

The exploratory study addresses the problem of limited data relating to the physically disabled woman's perceptions of social support and health care experiences when contemplating pregnancy, anticipating birth, and raising her child/children. The intent of the research was to generate a database and hypotheses to guide future research.

The following research questions were examined:

1. Does the physically disabled woman perceive differences in the support provided by family, friends, and professionals when she is making the decision to become a parent?
2. Is there a relationship between the emotional support, information, and instrumental assistance received from the social network of family, friends, and professionals and the disabled woman's decision to become a parent? and
3. What are some of the health care experiences of disabled women contemplating, anticipating, and raising a child/children?

Fifty women over 18 years of age with neurosensory (NS) or neuromuscular (NM) disabilities participated in the research. Each completed a self-administered questionnaire rating, on a Likert scale, (a) support provided by various family, friends, and professionals when making the decision to become a parent, and (b) the perceived influence

of that support on the parenting decision. The women could obtain assistance, as needed, in completing the questionnaire. Demographic information was also requested.

Thirty-four respondents who perceived that they had made a decision to become a parent were included in the analysis of social support. Social support participants rated 13 support persons across four categories of social support. The spouse received the highest mean rating in all categories except ideological support, where sisters received a higher rating.

The responses of social support participants were used in the analysis of subgroup differences. When t-tests were performed, the only significant difference between women in the NM and NS group was for the *influence* of emotional support provided by the spouse. The presence of similar impairments in the spouses of interviewees in the NS group and the absence of physical impairments in the spouses of interviewees in the NM group suggests a reason for the difference. However, one must note that the interviewees were not randomly selected from the sample and, thus, may not be representative of the larger group. In addition, interpretation of the findings must be made cautiously because of the use of volunteers and the small sample size.

Analysis of variance (repeated measures) and *a posteriori* comparisons using Tukey's HSD were used to examine Question 1. These analyses revealed that the physically disabled woman does perceive significant differences in the social support provided by family, friends, and professionals when making the decision to become a parent. On the measure of ideological support, the spouse was perceived to be

significantly more supportive than medical persons and mothers. Friends were perceived as significantly more supportive than medical persons, mothers, in-laws, and fathers. Statistical analysis of the measure of information provided revealed that friends were perceived as providing significantly more information than in-laws. The spouse was seen as providing significantly more information than in-laws, father, and siblings. On the measure of emotional support, friends were perceived as significantly more supportive than in-laws. The spouse was perceived as providing significantly more support than in-laws, medical persons, siblings, father, and mother. On the measure of instrumental assistance, the spouse was perceived as providing significantly more support than all remaining person variables. Possible reasons for the significant differences were discussed.

Pearson correlation analyses were used to examine research Question 2. These analyses provided statistical support for the conclusion that a relationship existed between the emotional support, information, and instrumental assistance received and the influence of that support on the decision to become a parent. However, the multiple factors that may have influenced the results of the analyses casts doubt on the validity of the findings.

Eleven respondents were selected for participation in nonschedule, standardized interviews. Most interviews were conducted by the researcher over the telephone because of the wide geographic distribution of the sample. Participants were asked to respond to questions designed, (a) to validate certain responses to the questionnaire, and (b) to reveal perceptions about experiences during their transition through parenthood.

The women were asked about genetic counseling. None of the women in the NS group sought genetic counseling or medical information on the potential effects of pregnancy on their disabilities. Six of seven women in the NM group sought genetic counseling or information about the effects of pregnancy on their health. This led to the hypothesis that the reason women in the NM group were more likely to receive genetic counseling or information about the effects of pregnancy on their health than women in the NS group lay in the ongoing contact of the former group with medical professionals.

The experience of adoption for three respondents was emotionally difficult. All desired to adopt a healthy infant and reported that they met resistance from agency-workers during the process. However, all eventually became adoptive parents of healthy children.

The mothers reflected on their childhood experiences. Six of eight respondents identified social isolation as a perceived difference in childhood experiences from children who were not disabled.

When asked to identify the two biggest problems a woman with a disability faced when making the decision to become a parent, 7 of 11 respondents identified the concern for their ability to physically care for their children. Four of eleven cited insufficient information and resources. Respondents identified concerns common to many women considering a family as well as concerns arising because of the disabilities.

Interviewees with NS impairments seemed to have had more positive experiences with childbirth education classes than women with NM disabilities. All five women the the NM group indicated a desire to

attend one or more classes addressing the needs of a pregnant woman with a disability. The speculation was made that childbirth educators may be more aware of techniques that are useful in overcoming the limitations of visual or hearing impaired clients than the more varied limitations of women with neuromuscular impairments.

Three of four mothers in the NS group reported health problems during pregnancy. All five women in the NM group experienced health problems. Some of the problems were extensions of existing disabilities. Some problems arose as a result of conditions frequently associated with their disabilities. In spite of medical complications, all the pregnancies resulted in live births.

Interviewees recalled both positive and negative experiences surrounding the births of their infants. While a private room on the post-partum unit was valued by some mothers in both groups, they varied on many other issues.

The responses of interviewees suggested that the women in the NM group were more likely to experience a minimum of education about infant feeding and bathing, as well as family planning. The possible reasons for the perceived information deficit were not explored during the interviews.

The mothers were asked whether they had done anything because of their disability to make some aspect of physical care of their children easier. Ten of eleven reported some type of environmental modification. Seven used a special position or location to perform certain childcare activities. All, however, reported success in childcare tasks.

Six of seven mothers in the NM group and all four mothers in the NS group reported some concern for their child's safety as a result of limitations due to their disabilities. Restricting the child's mobility outside the home was the most commonly mentioned precaution.

The interviewees perceived that their disabilities had, or would have, some affect on their children. Five of eleven felt that their children were more sensitive to others than children of able-bodied parents. Five of eleven were concerned that their children might be embarrassed or have a sense of being different.

Responses to the question about their greatest satisfactions in parenting and to the question about their greatest satisfactions in parenting as a result of their disability fell into two major categories: parent-centered and child-centered. The most frequently reported satisfactions in parenting were a sense of fulfillment and appreciation for the child's normal growth and development. The most frequently identified satisfactions in parenting that were a direct result of the disability were a sense of normalcy, increased self-confidence, increased sensitivity, and an appreciation for the special abilities of their children.

Nine of eleven interviewees reported that medical professionals could more effectively assist a person with a disability by becoming better informed. A variety of suggestions were offered to accomplish this goal. Five of seven respondents in the NM group felt that medical professionals needed to provide more information and referral. Five also felt the need for increased support.

When asked whether they would have contacted a physically disabled mother who was willing to share her experiences with them, all responded affirmatively. All were willing to act as a resource to another woman with a disability who was considering becoming a parent. When asked what advice they would give to other physically disabled women considering parenthood, 9 of 11 stated that they would provide encouragement. Seven of eleven stressed that the woman should seek information to make an informed decision. Five suggested that she make an independent decision without letting the negative attitudes of others influence her.

The women interviewed had needs, concerns, and experiences similar to their non-disabled counterparts, as well as some concerns unique to a woman with a disability. However, with support, creativity, and initiative the mothers in the study had successfully adapted, and are continuing to adapt, to parenthood.

Implications of the research fell into several major categories: strengthening the support system, increasing the amount of information and disseminating the information to this population, educating medical professionals in regard to the needs of the disabled, examining the attitudes of medical professionals to pregnancy and disability, and increasing the number of available resources.

Suggestions for future research included: investigation of the population using a more representative sample, a larger number of subjects, and reliable measures of social support to determine whether the findings of this research are duplicated; investigating the attitudes of medical professionals toward pregnancy and disability;

exploring why some disabled women choose to become parents and some not;
and comparing the effects of maternal disability on the children with
that of paternal disability.

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APPENDIX A

Dear Survey Participant:

This survey is for women only. Your opinions and attitudes toward parenthood are important. Your responses will be kept confidential.

After you have completed the survey, please mail it back to me in the enclosed envelope. It is important that this survey be completed and returned within one week.

I will also be doing a follow-up interview of some of the women returning the survey. As with the survey, confidentiality in the interview is assured. I hope that you will consider participating.

A report of the results of the research will be available to interested participants.

PLEASE CHECK: I am interested in receiving a brief summary of the research findings. YES NO
I am interested in participating in a follow-up interview, please contact me. YES NO

If you have checked "YES" to one or both of the above statements, please complete the following:

NAME _____

ADDRESS _____

TELEPHONE _____

Thank-you for agreeing to participate. Please read and sign the consent form on the back of this page.

Sincerely,

Beverly Kopala
Beverly Kopala, MS, RN

Participant Information:

Little is known about the needs, perceptions and experiences of physically disabled women who are considering, anticipating or raising a child/children. I am interested in obtaining your responses to questions contained in the attached survey in order to gain this information.

Therefore, you are being asked to think about and answer these questions, and then return the completed survey to me by mail. If you sign the consent form, confidentiality is assured. If you choose not to sign the consent form but still return the completed survey, your anonymity is assured.

If you decide to participate in the study there is no known physical risk or discomfort. Although you may not benefit directly from this study, the information I obtain may benefit others.

CONSENT:

I, _____, state that I am over 18 years of
(Participant)
age and that I wish to participate in a program of research being conducted by Beverly Kopala.

I may choose to complete and return the survey with or without signing the consent form. If I return the completed survey without a signed consent, it is still with the intent of having my responses included in the data analysis.

I understand that no physical risk is involved and that I may choose not to participate by not completing or returning the survey.

I consent to publication of any data which may result from these investigations for the purpose of advancing knowledge, providing my name, or other identifying information such as initials, is not used in connection with such publications. I understand that precautions to maintain confidentiality will be taken.

(Signature of Participant)

Date

GENERAL DIRECTIONS

When answering the following questions, please CIRCLE the number of the statement that applies. A few questions will ask you to fill in certain information. After answering some of the questions, you will see a black line which leads from the number you circled to the next question or set of directions. Please follow it.

1. At what age did you make the decision to become a parent?

1. ____ years of age
2. I do not remember
3. The first pregnancy was unplanned
4. Other (please explain) _____

2. Did you decide to seek genetic counseling before or after making your decision, or did you not seek genetic counseling?

1. I sought genetic counseling before making the decision
2. I sought genetic counseling after making the decision
3. I did not seek genetic counseling

If you circled #3, SKIP TO QUESTION #4 ON THE NEXT PAGE

If you circled #1 or #2, CONTINUE ON TO QUESTION 3

3. Who suggested that you seek genetic counseling? Circle all that apply.

1. Self
2. Physician
3. Family Member(specify relationship) _____
4. Friend
5. Other(specify relationship) _____
6. Does not apply

4. How would you describe the response, if any, of the following persons when learning of your decision to become a parent?

	STRONGLY POSITIVE	POSITIVE	MILDLY POSITIVE	INDIFFERENT/ UNCERTAIN	MILDLY NEGATIVE	NEGATIVE	STRONGLY NEGATIVE	DOES NOT APPLY
A. Spouse	7	6	5	4	3	2	1	X
B. Mother	7	6	5	4	3	2	1	X
C. Father	7	6	5	4	3	2	1	X
D. Brother/s	7	6	5	4	3	2	1	X
E. Sister/s	7	6	5	4	3	2	1	X
F. In-laws	7	6	5	4	3	2	1	X
G. Other family members	7	6	5	4	3	2	1	X
H. Friends	7	6	5	4	3	2	1	X
I. Doctors	7	6	5	4	3	2	1	X
J. Nurses	7	6	5	4	3	2	1	X
K. Social Workers	7	6	5	4	3	2	1	X
L. Teachers	7	6	5	4	3	2	1	X
M. Clergy	7	6	5	4	3	2	1	X
N. Others (specify)	7	6	5	4	3	2	1	X

THE DIRECTIONS FOR THE NEXT THREE SETS OF QUESTIONS ARE ON THIS PAGE. EACH QUESTION HAS 2 PARTS, PART(A) AND PART(B).

5(A). This question asks you to think about how much certain persons PROVIDED INFORMATION to you in your decision about parenthood. The persons are identified in the center column. Using the scale from "TOTALLY" to "DOES NOT APPLY", answer the question for each person listed by circling the one number in the Left column that most closely matches your feelings.

5(B). For the next question, think about how much the INFORMATION YOU RECEIVED from each of the persons listed INFLUENCED YOUR DECISION about parenthood. Using the scale in the Right column, circle the number that most closely matches your feelings.

5(A). To what extent, if any, do you feel that each of the following persons PROVIDED INFORMATION to you IN REGARD TO YOUR DECISION TO BECOME A PARENT for the first time?

5(B). To what extent, if any, do you feel that the INFORMATION you RECEIVED from each of the following persons INFLUENCED YOUR DECISION TO BECOME A PARENT for the first time?

TOTALLY	VERY MUCH	SOMEWHAT	CAN'T DECIDE	VERY LITTLE	ALMOST NONE	NOT AT ALL	DOES NOT APPLY	<u>PERSONS</u>	TOTALLY	VERY MUCH	SOMEWHAT	CAN'T DECIDE	VERY LITTLE	ALMOST NONE	NOT AT ALL	DOES NOT APPLY
7	6	5	4	3	2	1	X	H. Friends	7	6	5	4	3	2	1	X

EXAMPLE: If you feel that friends provided you with "VERY MUCH" information, circle "6" in the Left column. If you feel that the information you received from your friends influenced your decision "NOT AT ALL", circle "1" in the Right column.

5(A). To what extent, if any, do you feel that each of the following persons PROVIDED INFORMATION to you IN REGARD TO YOUR DECISION TO BECOME A PARENT for the first time?

5(B). To what extent, if any, do you feel that the INFORMATION you RECEIVED from each of the following persons INFLUENCED YOUR DECISION TO BECOME A PARENT for the first time?

TOTALLY	VERY MUCH	SOMEWHAT	CAN'T DECIDE	VERY LITTLE	ALMOST NONE	NOT AT ALL	DOES NOT APPLY	<u>PERSONS</u>	TOTALLY	VERY MUCH	SOMEWHAT	CAN'T DECIDE	VERY LITTLE	ALMOST NONE	NOT AT ALL	DOES NOT APPLY
7	6	5	4	3	2	1	X	A. Spouse	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	M. Mother	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	C. Father	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	D. Brother/s	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	E. Sister/s	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	F. In-laws	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	G. Other family member (please specify relationship)	7	6	5	4	3	2	1	X

CONTINUE ON TO NEXT PAGE

TOTALLY	VERY MUCH	SOMEWHAT	CAN'T DECIDE	VERY LITTLE	ALMOST NONE	NOT AT ALL	DOES NOT APPLY		TOTALLY	VERY MUCH	SOMEWHAT	CAN'T DECIDE	VERY LITTLE	ALMOST NONE	NOT AT ALL	DOES NOT APPLY
7	6	5	4	3	2	1	X	<u>PERSONS</u>	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	H. Friends	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	I. Doctors	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	J. Nurses	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	K. Social Workers	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	L. Teachers	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	M. Clergy	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	N. Other (please specify relationship)	7	6	5	4	3	2	1	X

6(A). To what extent, if any, do you feel that each of the following persons PROVIDED EMOTIONAL SUPPORT to you IN YOUR DECISION TO BECOME A PARENT for the first time?

6(B). To what extent, if any, do you feel that the EMOTIONAL SUPPORT you RECEIVED from each of the following persons INFLUENCED YOUR DECISION TO BECOME A PARENT for the first time?

TOTALLY	VERY MUCH	SOMEWHAT	CAN'T DECIDE	VERY LITTLE	ALMOST NONE	NOT AT ALL	DOES NOT APPLY	PERSONS	TOTALLY	VERY MUCH	SOMEWHAT	CAN'T DECIDE	VERY LITTLE	ALMOST NONE	NOT AT ALL	DOES NOT APPLY
7	6	5	4	3	2	1	X	A. Spouse	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	B. Mother	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	C. Father	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	D. Brother/s	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	E. Sister/s	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	F. In-laws	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	G. Other family member (please specify relationship)	7	6	5	4	3	2	1	X

CONTINUE ON TO NEXT PAGE

TOTALLY	VERY MUCH	SOMEWHAT	CAN'T DECIDE	VERY LITTLE	ALMOST NONE	NOT AT ALL	DOES NOT APPLY		TOTALLY	VERY MUCH	SOMEWHAT	CAN'T DECIDE	VERY LITTLE	ALMOST NONE	NOT AT ALL	DOES NOT APPLY
7	6	5	4	3	2	1	X	H. Friends	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	I. Doctors	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	J. Nurses	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	K. Social Workers	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	L. Teachers	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	M. Clergy	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	N. Other (please specify relationship)	7	6	5	4	3	2	1	X

7(A). To what extent, if any, do you feel that each of the following persons PROVIDED MATERIAL GOODS AND/OR SERVICES to you WHICH RELATED TO YOUR DECISION TO BECOME A PARENT for the first time?

7(B). To what extent, if any, do you feel that the MATERIAL GOODS AND/OR SERVICES you RECEIVED from each of the following persons INFLUENCED YOUR DECISION TO BECOME A PARENT for the first time?

TOTALLY	VERY MUCH	SOMEWHAT	CAN'T DECIDE	VERY LITTLE	ALMOST NONE	NOT AT ALL	DOES NOT APPLY	PERSONS	TOTALLY	VERY MUCH	SOMEWHAT	CAN'T DECIDE	VERY LITTLE	ALMOST NONE	NOT AT ALL	DOES NOT APPLY
7	6	5	4	3	2	1	X	A. Spouse	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	B. Mother	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	C. Father	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	D. Brother/s	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	E. Sister/s	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	F. In-laws	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	G. Other family member (please specify relationship)	7	6	5	4	3	2	1	X

CONTINUE ON TO NEXT PAGE

TOTALLY	VERY MUCH	SOMEWHAT	CAN'T DECIDE	VERY LITTLE	ALMOST NONE	NOT AT ALL	DOES NOT APPLY		TOTALLY	VERY MUCH	SOMEWHAT	CAN'T DECIDE	VERY LITTLE	ALMOST NONE	NOT AT ALL	DOES NOT APPLY
								<u>PERSONS</u>								
7	6	5	4	3	2	1	X	H. Friends	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	I. Doctors	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	J. Nurses	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	K. Social Workers	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	L. Teachers	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	M. Clergy	7	6	5	4	3	2	1	X
7	6	5	4	3	2	1	X	N. Other (please specify relationship)	7	6	5	4	3	2	1	X

8. Has your obstetrician(s)/birth attendant(s) had any previous experience providing care for women with physical disabilities?

1. No
2. Yes
3. I do not know
4. Does not apply

9. Did you happen to participate in childbirth education classes as a disabled woman?

1. No
2. Yes

↓
If you circled #2, SKIP TO QUESTION 11

↓
If you circled #1, CONTINUE ON TO QUESTION 10

10. What influenced your decision to NOT participate in childbirth education classes? Circle as many as apply.

1. No class conveniently located
2. No desire to attend
3. No need to attend(specify reason) _____

4. No class was designed to meet my needs
5. Disinterested spouse
6. Too early in pregnancy to attend
7. Too late in pregnancy to attend
8. Unaware of a class
9. Other(specify reason) _____

IF YOU ANSWERED QUESTION 10, SKIP TO QUESTION 13.

11. Were any adaptations made in the CONTENT of the childbirth education classes to meet your needs/concerns as a disabled women?

1. No
2. Yes
3. I do not know
4. Does not apply

12. Do you wish that some information would have been included in the content of the childbirth education classes, but was not?

1. No
2. Yes
3. I do not know
4. Does not apply

13. Were any/ Will any special arrangements be made for you in the hospital at the time of delivery because of your disability?

1. No
2. Yes
3. I do not know
4. Does not apply

14. Do you wish that some special arrangements would have been made for you in the hospital at the time of delivery?

1. No
2. Yes
3. I do not know
4. Does not apply

The following items are questions which will help in analyzing the results of this survey.

15. Please list your age. _____ years

16. What is your marital status?

1. Married
2. Widowed
3. Divorced
4. Separated
5. Single/Never Married

17. Circle the highest grade of school you have completed.

<u>Grade School</u>								<u>High School</u>				<u>College</u>				<u>Graduate School</u>			
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17 or more			
																↓	↓		
																List any degrees obtained		_____	

18. Circle the number that matches your race.

1. Asian American/Oriental
2. Black/Afro-American
3. White/Caucasian
4. Hispanic
5. American Indian/Native American

19. Are you currently employed?

1. No
2. Yes

What is your occupation? _____

20. How many children do you have?

- _____ 1. None, but I have made the decision to become a parent
- _____ 2. One
- _____ 3. Two
- _____ 4. Three
- _____ 5. Other(Specify number) _____

Are you currently pregnant?

- 1. No
- 2. Yes

21. Were any of your children adopted?

- 1. No
- 2. Yes

↓
How many children were adopted? _____

22. Are any of the children foster children?

- 1. No
- 2. Yes

↓
How many children are foster children? _____

23. Please list the age and sex of each of your children.

<u>Age</u>	<u>Sex</u>	
_____ months	M	F
_____ years	M	F
_____ years	M	F
_____ years	M	F

Use the space below to list the age and sex of any other children.

24. Were any of your children born prematurely?

- 1. No
- 2. Yes
- 3. I do not know

If yes, how many of your children were premature? _____

25. Were any of your children born with a physical disability?

- 1. No
- 2. Yes
- 3. Uncertain

If yes, how many of your children were born with a physical disability? _____

26. Were any of your children stillborn?

- 1. No
- 2. Yes
- 3. Uncertain

If yes, how many of your children were stillborn? _____

27. Have you had any miscarriages?

- 1. No
- 2. Yes
- 3. Uncertain

If yes, how many miscarriages did you have? _____

28. Please describe the type of physical disability you have, including medical diagnosis.

Medical Diagnosis _____

Describe the extent of your physical disability (use of assistive devices, limitations).

29. How old were you when you became disabled? _____

30. If there is any experience you would like to relate, or comment that you would like to make, please use the space that follows.

APPENDIX B

INTERVIEW QUESTIONS

Survey Validation

1. How did your parents react to your decision to become a parent?
If neg...Did their response change after you became a parent?
2. Who would you say was the one person who provided you with the greatest amount of emotional support in your decision to become a parent?
3. Was there any one person who most influenced your decision to become a parent?
If yes... Who was it?
4. Were there any specific events in your life, which you feel , influenced your decision to become a parent?
If yes... What were they?
5. You indicated on the questionnaire that you decided to get genetic counseling. What were you told?
6. Did the information, in any way, affect your decision to become a parent?

General Questions

1. Do you feel that your experiences as a child were different from children who did not have your disability?
If yes... In what way?
2. Did you ever doubt that one day you would become a parent?
If yes... Could you explain?
3. What do you feel are the two biggest problems a woman with a disability faces when making the decision to become a parent?
4. Did you know any parents with a disability?
If yes, ... Did this affect your decision to become a parent?
5. Before you became a parent, were you given or did you seek any medical information on how the pregnancy might affect your health?
If yes... What information were you given?
6. Did anyone try to discourage you from having children?
If yes... In what way(s)?

Childbirth Education Classes

You indicated on the questionnaire that you attended childbirth education classes. I would like to find out something about the classes.

1. Did you attend all the classes?
2. Were you given any information about whether your delivery might be affected by your disability?
If yes... What were you told?
3. Did you receive any suggestions during the class regarding what you could do ahead of time to make your hospitalization easier for you?
If yes... What were you told?

If no ... Knowing what you now know, is there anything you would have liked to have been told before the delivery?

Pregnancy

1. Did your pregnancy/pregnancies affect your health in any way?
If yes... In what way?
2. Did your pregnancy cause you any special problems with:
comfort?
If yes... In what way?
bladder control?
If yes... In what way?
breathing?
If yes... In what way?
movement?
If yes... In what way?
ability to feel (sensation)?
If yes... In what way?

Labor and Delivery

1. Were there any special plans made for you or your partner in the hospital at the time of delivery?
If yes... What were they?

If no ... Would advance planning have been helpful?
2. During your labor and delivery, did you have any special needs? (or problems?)
If yes... Would you describe the problems you had?

If yes... What did your physician do ?

What did the nurses do for you?

What did your partner do for you?

3. Did you tell the hospital staff, in advance, about any needs or concerns you had because of your disability?

If yes... What did you tell them?

How did you get this information to the staff?

4. Was your child/were any of your children born by Cesarean section?

If no... Could you tell me about the labor and delivery?

5. Did the staff allow you to make some decisions about your care when you were in labor?

Postpartum

You indicated on the survey that one of your children was/may have been born with a physical disability.

1. Could you describe the problem?

How were you told about your child's condition?

How did you feel about having a disabled child?

2. Did the nurses on the postpartum unit encourage you to spend time with your baby?

3. Do you feel that your disability in any way affected the nurse's response to you as a new mother?

If yes... In what way?

4. Did you breast feed or bottle feed your infant?

5. Did anyone teach you about:
breast or bottle feeding your infant?

If yes... Who taught you?

What were you told?

bathing your infant?

If yes... Who taught you?

What were you told?

family planning?

If yes... Who taught you?

What were you told?

6. Since your disability may change the way you do some things, was the information you received practical for your needs?

7. Do you feel that your right to privacy was respected during your

hospitalization?

If no... What happened?

Adoption

You indicated on the questionnaire that you decided to adopt children. I am interested in finding out what the experience of adopting a child was like.

1. Did you have any difficulty finding an adoption agency that would handle your request to adopt?
2. Did the adoption agency encourage you to consider adopting a child with a physical disability?
If yes... What was your response to that suggestion?

Parenting

We all make adaptations based upon what does and doesn't work for us. I am interested in learning if your physical condition affected your experience with parenting, and what adaptations you might have made in the daily care of your children.

1. For example, did you do anything to make it easier for you to feed your child?
If yes... What did you do?

What about carrying your baby?

What about diapering your baby?

What about the physical care of your baby, like bathing and dressing?
2. Did anyone help you with the care of your child/ children?
If yes... In what way?
3. Did you and your (family/spouse/partner) make any changes in the way you handled responsibilities around the home after the (baby was/children were) born?
4. Did you have any special concerns about your child's safety as he/she was growing up?
5. What about caring for your child when he/she was sick?
How did you take his temperature? (blind, paralyzed)

How did you know when he was crying? (deaf)
6. How did you handle disciplining your child?
7. Who, or what, was your greatest source of childcare information?

8. Was your child ever hospitalized?
If yes... Could you tell me about the experience?

What was wrong with your child?

Did you receive all the information you needed?

Do you feel that your disability affected, in any way, the way the staff responded to you?

If yes... In what way?

Do you feel that your disability affected, in any way, the way the staff responded to your child?

If yes... In what way?

9. Overall, what were your greatest satisfactions in parenting?
What did you enjoy most?
10. Did you have any special joys or satisfactions in raising your children which, you feel, were a direct result of having a disability?

Children

1. Do you think that your disability has had any affect on your children?
If yes... In what way?
2. Have your children taken on any extra responsibilities as a result of your disability?
3. Have your children asked any questions about your disability?
If yes... What did you say?

Summary Questions

1. If you had known another woman with a physical disability who was raising a child and would have been willing to share her experiences with you, would you have contacted her?
2. Would you be willing to be a resource person to another woman who has a physical disability and was considering becoming a parent?
3. If you had the chance to speak to medical professionals and tell them how they could more effectively assist a person with a disability, what would you say?
4. If you had a chance to talk with another woman with a physical disability who was considering becoming a parent, what would you say?
5. Are there any comments you would like to make?

APPENDIX C

CONSENTS

*Form A**Project Title:*

Physically Disabled Women: A Study of Perceptions of Needs and Experiences Affecting the Transition Through Parenthood.

Participant Information:

Little is known about the needs, perceptions and experiences of physically disabled women who are considering, anticipating or raising a child/children. I am interested in obtaining your responses to questions contained in the attached survey in order to gain this information.

Therefore, you are being asked to think about and answer these questions, and then return the completed survey to me by mail. If you sign the consent form, confidentiality is assured. If you choose not to sign the consent form but still return the completed survey, your anonymity is assured.

If you decide to participate in the study there is no known physical risk or discomfort. Although you may not benefit directly from this study, the information I obtain may benefit others.

CONSENT:

I, _____, state that I am over 18 years of age and that I wish to participate in a program of research being conducted by Beverly Kopala.

I may choose to complete and return the survey with or without signing the consent form. If I return the completed survey without a signed consent, it is still with the intent of having my responses included in the analysis.

I understand that no physical risk is involved and that I may choose not to participate by not completing or returning the survey.

I consent to publication of any data which may result from these investigations for the purpose of advancing knowledge, providing my name, or other identifying information such as initials, is not used in connection with such publications. I understand that precautions to maintain confidentiality will be taken.

(Signature of Participant)

Form B

Project Title:

Physically Disabled Women: A Study of Perceptions of Needs and Experiences Affecting the Transition Through Parenthood.

Participant Information:

Little is known about the needs, perceptions, and experiences of physically disabled women who are considering, anticipating, or raising a child/children. I am interested in interviewing you to obtain this information. In order to do this you will be asked to think about and answer certain questions. During the interview I would like to tape record your responses to aid in data analysis.

If you decide to participate in the study there is no known physical risk or discomfort. Although you may not benefit directly from this study, the information I obtain may benefit others.

CONSENT:

I, _____, state that I am over 18 years of age and that I wish to participate in a program of research being conducted by Beverly Kopala.

I understand that no physical risk is involved and that I may withdraw from participation in the interview at any time without prejudice.

I consent to publication of any data which may result from these investigations for the purpose of advancing knowledge, providing my name, or other identifying information such as initials, is not used in connection with such publications. I understand that precautions to maintain confidentiality will be taken.

(Signature of Participant)

Date

APPENDIX D

QUESTIONNAIRE CODEBOOK CATEGORIES

DA Age of decision to become a parent

01-50 years

51 don't remember

52 unplanned

53 other

GC Genetic Counseling

01 no

02 yes, before pregnancy

03 yes, after pregnancy

SC1 Self suggested counseling

01 yes

02 no

SC2 MD suggested counseling

01 yes

02 no

SC3 Family member suggested counseling

01 yes

02 no

SC4 Friend suggested counseling

01 yes

02 no

SC5 Other suggested counseling

01 yes

02 no

Response of

A401 Spouse

A402 Mother

A403 Father

A404 Brothers

A405 Sisters

A406 In-laws

A407 Other family members

A408 Friends

A409 Physician

A410 Nurses

A411 Social worker

A412 Teachers

A413 Clergy

A414 Other

Provided information

A501 Spouse

A502 Mother
A503 Father
A504 Brothers
A505 Sisters
A506 In-laws
A507 Other family members
A508 Friends
A509 Physician
A510 Nurses
A511 Social worker
A512 Teachers
A513 Clergy
A514 Other

Influence of information

B501 Spouse
B502 Mother
B503 Father
B504 Brothers
B505 Sisters
B506 In-laws
B507 Other family members
B508 Friends
B509 Physician
B510 Nurses
B511 Social worker
B512 Teachers
B513 Clergy
B514 Other

Provided emotional support

A601 Spouse
A602 Mother
A603 Father
A604 Brothers
A605 Sisters
A606 In-laws
A607 Other family members
A608 Friends
A609 Physician
A610 Nurses
A611 Social worker
A612 Teachers
A613 Clergy
A614 Other

Influence of emotional support

B601 Spouse
B602 Mother
B603 Father
B604 Brothers
B605 Sisters
B606 In-laws

B607 Other family members
 B608 Friends
 B609 Physician
 B610 Nurses
 B611 Social worker
 B612 Teachers
 B613 Clergy
 B614 Other

Provided instrumental assistance

A701 Spouse
 A702 Mother
 A703 Father
 A704 Brothers
 A705 Sisters
 A706 In-laws
 A707 Other family members
 A708 Friends
 A709 Physician
 A710 Nurses
 A711 Social worker
 A712 Teachers
 A713 Clergy
 A714 Other

Influence of instrumental assistance

B701 Spouse
 B702 Mother
 B703 Father
 B704 Brothers
 B705 Sisters
 B706 In-laws
 B707 Other family members
 B708 Friends
 B709 Physician
 B710 Nurses
 B711 Social worker
 B712 Teachers
 B713 Clergy
 B714 Other

Obstetrician experience

01 yes
 02 no
 03 don't know

Childbirth education classes

01 yes
 02 no

If no - reason for non-attendance at childbirth education class

NCBC1

01 inconvenient location

02 no

NCBC2

01 no desire

02 no

NCBC3

01 no need

02 no

NCBC4

01 did not meet needs

02 no

NCBC5

01 disinterested spouse

02 no

NCBC6

01 too early in pregnancy

02 no

NCBC7

01 too late in pregnancy

02 no

NCBC8

01 unaware of class

02 no

NCBC9

01 other

02 no

CA Content Adaptations

01 no

02 yes

03 don't know

WI Wished information included

01 no

02 yes

03 don't know

SA Special arrangements

01 no

02 yes

03 don't know

WSA Wished special arrangements

01 no

02 yes

03 don't know

Age

01-97

MS Marital status

01 married
02 widow
03 divorced
04 separated
05 single

ED Education years

01-17

DG Degree

01 none
02 AD
03 BA
04 BS
05 MS
06 MA
07 BSN
08 ADN
09 MSW
10 EdD
11 PhD
12 other

Race

01 Asian
02 Black
03 Caucasian
04 Spanish
05 Indian

EMP Employed

01 no
02 yes

OCC Occupation

01 student
02 rehabilitation counselor
03 data processor
04 caseworker
05 keypuncher
06 inscriber
07 systems analyst
08 credit manager
09 administrative specialist
10 assistant director, association
11 nurse
12 counselor
13 psychologist
14 occupational therapist

15 consultant
16 pharmacy employee
17 food service management
18 self employed
19 childcare provider
20 social worker
21 secretary
22 transcriptionist
23 volunteer

NK Number of children

01 one
02 two
03 three
04 four
05 five
06 six
07 seven
08 none

PG Pregnant

01 no
02 yes

NAD Number adopted children

01-95
97 none

NF Number foster children

01-95
97 none

NP Number premature children

01-95
96 don't know
97 none

NPD Number disabled children

01-95
96 don't know
97 none

NSB Number stillborn children

01-95
96 don't know
97 none

NM Number miscarriages

01-95
96 don't know
97 none

DX Medical Diagnosis

01 visually impaired
03 hearing impaired
04 post-polio
05 spina bifida
06 spinal cord injury
07 cerebral palsy
08 dystonia
10 multiple sclerosis
11 Charcot Marie Nerve disease
12 Rheumatoid arthritis

PDA Age when disabled

01-95 years
96 birth
97 before one year of age

LOC Location

01-09 IL
30 MO
31 NC
32 CA
33 OH
34 MN
35 CO
36 NY
37 NJ
38 IN
39 SD
40 WI
41 WA

INT Willing to participate in interview

01 no
02 yes
03 uncertain

AFP Age first pregnant

01-97 years

APPENDIX E

INTERVIEW CODING CATEGORIES

1. How did your parents react to your decision to become a parent?

1. positive response
2. negative response
3. unsure

If negative... Did their response change after you became a parent?

1. yes
2. no
3. unsure
4. no response

2. Who would you say was the one person who provided you with the greatest amount of emotional support in your decision to become a parent?

1. spouse/partner
2. sisters
3. friends

3. Was there any one person who most influenced your decision to become a parent? Who most influenced your decision?

1. yes
2. no
3. unsure
4. no response

If yes... Who was it?

1. husband
2. self
3. doctor
4. sister
5. friends
6. parents
7. authors
8. other
9. no response

4. Were there any specific events in your life which, you feel, influenced your decision to become a parent?

1. yes
2. no
3. unsure
4. no response

If yes... What were they?

1. observation of the parenting process
 2. personal experience with childcare
 3. childhood expectations/ dreams (this isn't an event)
 4. age
 5. readiness (setting/priorities complete)
 6. lack of information on medical effects
 7. physical differences - didn't walk
 8. other
 9. no response
5. You indicated on the questionnaire that you decided to get genetic counseling. What were you told?
1. told condition was not hereditary
 2. increased risk of child being born with disability
 3. limited info on effect of pregnancy on disability
 4. negative feedback/attitude from doctors toward a pregnancy
 5. positive feedback/attitude from doctors toward a pregnancy
 6. no understandable opinion given
 7. other
 8. no response
6. Did the information, in any way, affect your decision to become a parent?
1. no
 2. yes
 3. unsure
 4. other
 5. no response

If yes, in what way

1. would not have had children if disability could be inherited
2. affected timing-became a parent before disability worsened
3. adopted
4. had a tubal ligation
5. other
6. no response

General Questions

1. Do you feel that your experiences as a child were different from children who did not have your disability?
 1. yes
 2. no

- 3. unsure
- 4. no response

If yes... In what way?

- 1. social isolation/lack of acceptance
- 2. attendance at special schools/programs
- 3. harrassment/name calling/pointing
- 4. overprotective parents
- 5. unsure
- 6. no response

2. Did you ever doubt that one day you would become a parent?

- 1. yes
- 2. no/ never thought about it
- 3. unsure
- 4. other
- 5. no response

3. What do you feel are the two biggest problems a woman with a disability faces when making the decision to become a parent?

- 1. ability to perform physical care/ care for the child
- 2. dealing with
misconceptions/misunderstandings due to disability
- 3. insufficient information/ resources
- 4. child's safety
- 5. effects of pregnancy
- 6. concern for child's health
- 7. restricted mobility
- 8. lacked confidence to stimulate and physically
challenge the child
- 9. lack of a role model
- 10. other
- 11. no response

4. Did you know any parents with a disability?

Before pregnancy

- 1. yes
- 2. no
- 3. unsure
- 4. no response

After pregnancy

- 1. yes
- 2. no
- 3. unsure
- 4. no response

If yes-before pregnancy

Did this affect your decision to become a parent?

1. yes
2. no
3. unsure
4. other
5. no response

5. Before you became a parent, were you given or did you seek any medical information on how the pregnancy might affect your health?

Other than genetic counseling

1. yes, she did
2. no
3. no, but husband did
4. unsure
5. other
6. no response

If yes... What information were you given?

1. told condition was not hereditary
2. limited info available
3. MD with limited experience with pregnancy and disability
4. negative feedback/attitude from doctors toward a pregnancy
5. positive feedback/attitude from doctors toward a pregnancy
6. no understandable opinion given
7. info from books, journals
8. info from letters of other disabled moms
9. other
10. no response

6. Did anyone try to discourage you from having children?

1. no
2. yes
3. unsure
4. other
5. no response

Who

1. mother
2. spouse's family member
3. friends
4. doctors/service providers
5. coworkers
6. employer
7. persons not knowing her capabilities
8. others

9. no response

In what ways?

1. concern for ability to care for child parenthood
2. concern for woman's physical health/ lifespan
3. financial burden of adoption
4. adopted child would not be part of family
5. unspecified negative reactions
6. other
7. no response

Childbirth education classes

You indicated on the questionnaire that you attended childbirth education classes. I would like to find out something about the classes.

1. Did you attend all the classes?

1. all/yes
2. most/partial attendance
3. attended two sets of classes - hospital and clinic
4. no with one pregnancy, but with another
5. other
6. no response

2. Were you given any information about whether your delivery might be affected by your disability?

1. yes
2. no
3. few knew she had MS
4. other
5. no response

What were you told?

1. educator tried to relate facts woman could directly relate to (unspecified info)
2. do whatever you can do
3. other

3. Did you receive any suggestions during the class regarding what you could do ahead of time to make your hospitalization easier for you?

1. yes
2. no/ treated as others were in class
3. unsure
4. other
5. no response

What were you told?

1. plan to have alternative communication methods available
(interpreter/TTY/writing)
2. basic childbirth educ. info
3. other
4. no response

Knowing what you now know, is there anything you would have like to have been told before the delivery?

1. yes
2. no
3. unsure
4. other
5. no response

What?

1. how to select a health care provider/setting
2. better info on recognition of onset of labor
3. other
4. no response

Would any advance planning have been helpful?/Was advance planning helpful?

1. yes, it was
2. yes, it would have been
3. no
4. unsure
5. no response

What advance planning?

1. to have a private room would have helped - special room accommodations
2. to have a special team available
3. methods to overcome communication deficit
4. treat as high risk pregnancy
5. communication to others re: the disability
6. presence of
husband/partner - as knowledgeable support person

Pregnancy

1. Did your pregnancy/pregnancies affect your health in any way?

1. yes
2. no
3. unsure
4. other
5. no response

If yes...In what way?

1. loss of vision
2. mobility decreased
3. elevated BP
4. bleeding/hemorrhage
5. epistaxis
6. eclampsia
7. DIC
8. ulcer
9. hiatal hernia
10. urinary incontinence
11. hyperventilation/fainting
12. loss of sensation (to bladder fullness/pain/pressure)
13. joint problems
14. UTI's
15. common effects
 - a. morning sickness
 - b. tiredness
 - c. discomfort as size of fetus grew
 - d. chronic heartburn
 - e. harder to sleep on stomach
 - f. gas
 - g. constipation
 - h. urinary frequency
 - i. backaches
 - j. couldn't sleep on back
 - k. difficulty breathing
 - l. eating difficulties
 - m. other

Labor and Delivery

1. Were there any special plans made for you or your partner in the hospital at the time of delivery?
 1. yes
 2. no
 3. unsure
 4. other
 5. no response

What were they?

1. to have a private room would have helped - special room accommodations (only is she's talking about L and D)
2. to have a special team available
3. methods to overcome communication deficit
4. treat as high risk pregnancy
5. communication to others re: the disability
6. presence of husband/partner - as knowledgeable support person
7. other
8. no response

If no ... Would advance planning have been helpful?

1. yes
2. no
3. unsure
4. other
5. no response

2. During your labor and delivery, did you have any special needs?
(or problems?)

1. yes
2. no
3. unsure
4. other
5. no response

Would you describe the problems you had? DURING L & D

1. needed oxygen
2. increased BP
3. decreased BP
4. toxemia
5. autonomic dysreflexia
6. DIC
7. use of forceps-couldn't push
8. positioning
9. long labor/fetal distress
10. spasticity
11. needed anesthesia
12. premature births
13. other
14. no response

If yes... What did your physician do ?

1. administered anesthetic
2. other
3. no response

What did the nurses do for you?

1. positioning
2. provided information
3. provided emotional support
4. were not emotionally supportive
5. sought information from mother
6. other
7. no response

What did your partner do for you?

1. provided physical and emotional support

2. other
 3. no response
3. Did you tell the hospital staff, in advance, about any needs or concerns you had because of your disability?

1. yes
2. no
3. unsure
4. other
5. no response

What did you tell them?

1. need for communication system
2. need for adaptive equipment
3. communicating the existence of the disability
or the associated medical problems
4. other

How did you get this information to the staff?

1. interpreter
2. doctor/chart
3. self
4. other

4. Was your child/were any of your children born by Cesarean section?

1. yes
2. no

Could you tell me about the labor and delivery?

1. no unusual problems
2. home birth cancelled due to long labor and fetal distress
3. mother had some complication develop during labor or
delivery.
4. other
5. no response

5. Did the staff allow you to make some decisions about your care when you were in labor?

1. yes, without qualification
2. yes, with qualification
3. no
4. unsure
5. other
6. no response

Explanations

1. choice of location for delivery or no choice
2. willing to adapt routines to meet special needs
3. other
4. no response

Postpartum

You indicated on the survey that one of your children was/may have been born with a physical disability.

1. Could you describe the problem?

1. oxygen deprivation and concern for brain damage
2. vision impairment
3. other
4. no response

How did you feel about having a disabled child?

1. scared
2. could she take care of the child
3. might not have had a second child
4. would make the best of the situation
5. guilt/responsibility
6. qualified acceptance
7. feel more abnormal
8. stimulate recall of own experiences
9. other
10. no response

Have you thought about how you might feel if you had a baby born with a disability?

1. scared
2. could she take care of the child
3. might not have had a second child
4. would make the best of the situation
5. guilt/responsibility
6. qualified acceptance
7. feel more abnormal
8. stimulate recall of own experiences
9. other
10. no response

2. Did the nurses on the postpartum unit encourage you to spend time with your baby?

1. yes
2. no
3. unsure
4. no response

3. Do you feel that your disability in any way affected the nurses'

response to you as a new mother?

1. yes
2. no
3. unsure/can't remember
4. other
5. no response

In what way?

1. not truthful
2. concern for ability to care for self/infant
3. staff wanted to learn from her
4. provided increased information
5. helpful
6. other

4. Did you breast feed or bottle feed your infant?

1. bottle fed
2. breast fed

5. Did anyone teach you about:
breast or bottle feeding your infant?

1. yes
2. no
3. unsure
4. no response

Who taught you?

1. childbirth educator
2. read books
3. nurse in hospital
4. lactation consultant in hospital
5. other
6. no response

What were you told?

1. general info
2. selection and use of appropriate equipment
3. can adapt usual routines

bathing your infant?

1. yes
2. no
3. unsure
4. no response

Who taught you?

1. childbirth educator
2. nurse in the hospital
3. self taught using common sense and previous experience
4. no response

How were you told?/shown?

1. demonstration/verbal instruction
2. using notes and gestures
3. return demonstration
4. film
5. other

family planning?

1. yes
2. no
3. unsure
4. other
5. no response

Who taught you?

1. midwife
2. MD
3. nurses
4. no response

What were you told?

1. variety of methods
2. diaphragm would not work with disability
3. continued with previous methods
4. other
5. no response

6. Since your disability may change the way you do some things, was the information you received practical for your needs?

1. yes, with qualification
2. yes, without qualification
3. no
4. unsure
5. no response -(nurses in hosp were unaware of disability)

7. Do you feel that your right to privacy was respected during your hospitalization?

1. yes
2. no
3. unsure
4. no response

Reported Adaptations in Daily Care

1. Modifies environment
2. Uses special position/location
3. Avoids performing certain activities
4. Seeks/Trains child to assist
5. Feeds by breast/bottle

Adoption

You indicated on the questionnaire that you decided to adopt children. I am interested in finding out what the experience of adopting a child was like.

1. Did you have any difficulty finding an adoption agency that would handle your request to adopt?
 1. yes
 2. no
 3. unsure
 4. other
 5. no response

Experiences

1. intrusive/ asked many questions
 2. encouraged adoption of child with special needs
 3. initially refused by agency
 4. increased communication with husband
 5. inaccessible office
 6. much paperwork/yearly reviews
2. Did the adoption agency encourage you to consider adopting a child with a physical disability? INCLUDED IN PRIOR QUESTION
 1. yes
 2. no
 3. no response

If yes... What was your response to that suggestion?

1. threatened legal action/charges of discrimination
2. feared having unrealistic goals for disabled child
3. felt unable to provide for disabled child's needs
4. too much disability couple's life

Parenting

We all make adaptations based upon what does and doesn't work for us. I am interested in learning if your physical condition affected your experience with parenting, and what adaptations you might have made in the daily care of your children.

1. For example, did you do anything to make it easier for you to feed your child?

1. yes
2. no
3. unsure
4. no response

What did you do?

1. no problems
2. use adaptive equipment when needed
3. breast fed
4. bottle fed
5. positioning for comfort
6. altered location for feeding
7. no response

What about carrying your baby?

1. do not carry infant/child outside of house
2. no problems
3. use adaptive equipment when needed
(held infant for 7 months in sling/in w/c etc.)
4. carried older child on shoulders/altered position
5. other

What about diapering your baby?

1. no problems
2. use adaptive equipment when needed
3. special position/ location for changing
4. had diaper service so noone would say kids diapers were dirty
5. other

What about the physical care of your baby, like lifting bathing and dressing?

1. no problems
2. use adaptive equipment when needed
3. child assists
4. keeps matching outfits together (blind)
5. never puts child in position where she can't lift her
6. difficulty lifting in w/c
7. other

2. Did anyone help you with the care of your child/ children?

1. yes
2. no
3. unsure
4. no response

If yes, who?

1. mother
2. parents
3. husband/partner
4. other family members
5. friends
6. other
7. no response

In what way?

1. substitute caregiver
2. other

4. Did you have any special concerns about your child's safety as he/she was growing up?

1. yes
2. no
3. unsure
4. other
5. no response

What they've done/plan to do

1. restricted child's outside mobility
2. increased monitoring /watchfulness of the child
3. childproof home
4. other
5. no response

5. What about caring for your child when he/she was sick?

1. knew intuitively if child was sick
2. took child to MD if unsure
3. child's decreased activity
4. felt the child's body

How did you take his temperature? (blind, paralyzed)

1. Braille thermometer
2. assistance of another to take temp

How did you know when he was crying? (deaf)

1. used adaptive device/flashing light
2. children come to her
3. other
4. no response

6. How do you handle/ plan to handle disciplining your child?

Types of Discipline

1. physical punishment
2. verbal messages
3. limit/ restrict something the child likes
4. restrict activities after misbehavior/
remove child from situation/ time out
5. not necessary yet

Persons disciplining

1. husband only
2. mother and father
3. assistant in home
4. mother only
5. no response

Special problems with childrearing as a result of the disability

1. safety
2. need for modified equipment
3. disciplining children/ getting kids to listen to her
4. limit testing
5. need for increased control
6. other's lack of recognitions of limitations of disability
7. frustration - can I cope in an emergency
8. other

7. Who, or what, was your greatest source of childcare information?

People

1. mother
2. parents
3. other family members
4. friends
5. mother's group
6. doctor
7. other

Audiovisual material

8. printed materials
9. television programs on child development
10. other
11. no response

8. Did your child remain in the hospital for an extended period of time following birth?

1. yes
2. no
3. unsure

4. no response

If yes, what was the cause of the hospitalization?

1. neonatal jaundice/hyperbilirubinemia
2. meconium aspiration/fetal distress
3. respiratory distress in full term infant
4. prematurity with resp. problems
5. prematurity without resp. problems
6. neonatal sepsis
7. apnea
8. bradycardia

9. Was your child/ children ever hospitalized?

1. no.
2. yes
3. no response

What was wrong with your child?

1. tearduct surgery
2. tachycardia
3. croup
4. herniorraphy
5. parainfluenza
6. detached retina
7. fractured arm
8. pneumonia
9. diagnostic testing
10. fever of unspecified origin
11. other
12. no response

Did you receive all the information you needed? (let's not deal with whether the infor was given on time)

1. yes, without qualification
2. yes, with qualification
3. no
4. unsure
5. other
6. no response

Do you feel that your disability affected, in any way, the way the staff responded to you?

1. yes, without qualification
2. yes, with qualification
3. no
4. unsure/don't know
5. other
6. no response

If yes... In what way?

1. limited communication
2. enhanced communication
3. more considerate
4. lack of respect/ second class citizen
5. offered limited assistance
6. no response
7. other
8. no response

Do you feel that your disability affected, in any way, the way the staff responded to your child?

1. yes, without qualification
2. yes, with qualification
3. no
4. unsure
5. other
6. no response

In what way?

1. provided increased attention
2. other
3. no response

9. Overall, what were your greatest satisfactions in parenting?
What did you enjoy most?

Parent-Centered

1. sense of control
2. sense of fulfillment/self esteem
3. other

Child-Centered

4. normal growth and development - physical/ emotional/etc
5. success/ achievement in school or tasks
6. desire for mother's presence
7. helpfulness

10. Did you have any special joys or satisfactions in raising your children which, you feel, were a direct result of having a disability?

Parent-Centered

1. eligibility for social security benefits
2. increased awareness/ increased sensitivity
3. sense of normalcy
4. increased self esteem/ increased self confidence

5. sense of accomplishment
6. increased number of children
7. other

Child-Centered

8. special abilities
9. increased sensitivity
10. child's normal growth and development
11. absence of discrimination
12. special opportunities

Children

1. Do you think that your disability has had/ will have any effect on your children?
 1. yes/not much/a little
 2. no
 3. hope not/possibly later when child is older/maybe later
 4. other
 5. no response

If yes... In what way?

1. increased sensitivity to others
 2. increased sensitivity to environment
 3. provides assistance to mother
 4. restricted mobility
 5. may feel embarrassed later/ sense of being different
 6. increased limit testing
 7. special fears for parent
2. Have your children taken on any extra responsibilities as a result of your disability?
 1. yes
 2. no
 3. don't know, too young to know if he will
 4. other
 5. no response
3. Have your children asked any questions about your disability?
 1. yes
 2. no
 3. no, child is infant
 4. no, but sure he knows
 5. other
 6. no response

If yes... What did you say?

1. explained cause of disability/how disability occurred
2. described disability itself/name of the disability
3. explained effect of disability/adaptations required
4. explained difference between normal and disabled function
5. explained difference between types of disabilities
6. provided honest explanation
7. explained before they asked
8. answered questions when they ask
9. developmentally appropriate

Summary Questions

1. If you had known another woman with a physical disability who was raising a child and would have been willing to share her experiences with you, would you have contacted her?
 1. no
 2. yes, without qualification
 3. yes, with qualification
 4. yes, and has done so
 5. other
 6. no response

2. Would you be willing to be a resource person to another woman who has a physical disability and was considering becoming a parent?
 1. no
 2. yes, without qualification
 3. yes, with qualification
 4. yes, and has done so
 5. other
 6. no response

3. If you had the chance to speak to medical professionals and tell them how they could more effectively assist a person with a disability, what would you say?
 1. accept woman's need for control during pregnancy
 2. provide support
 3. seek information
 4. provide information/referral
 5. improve accessibility/modify environment
 6. don't stereotype/don't make undocumented assumptions
 7. use appropriate communication
 8. use appropriate communication patterns (eg speak directly to the woman, not her companion)
 9. other

4. If you had a chance to talk with another woman with a physical disability who was considering becoming a parent, what would you say?
 1. realistically assess abilities/limitations

2. seek information to make an informed decision
3. make an independent decision/ don't let negative attitudes of others influence you
4. don't make assumptions
5. have a support system/person available
7. prepare for physical difficulties of pregnancy
8. communicate needs to others
9. other
10. no response

APPENDIX F

T-TEST RESULTS

A Comparison of t-Tests Between Means of Perceived Ideological Support Broken Down by Selected Person Variables

Variable	n	Mean	Standard Deviation	t	Level of Significance
Ideological support provided by spouse/partner					
Group 1 (NS)	12	5.5833	1.676	-1.31	.208(ns)
Group 2 (NM)	21	6.2857	1.056		
Ideological support provided by spouse/partner, mother and father					
Group 1 (NS)	12	5.222	1.158	-1.34	.198(ns)
Group 2 (NM)	22	5.7273	0.822		
Ideological support provided by spouse/partner, mother and father, brother(s), sister(s), and in-laws					
Group 1 (NS)	12	4.6905	1.046	-0.85	.406(ns)
Group 2 (NM)	22	4.9942	0.899		

Note: (ns) denotes no significance

*A Comparison of t-Tests Between Means of Perceived Information
Provided Broken Down by Selected Person Variables*

Variable	n	Mean	Standard Deviation	t	Level of Significance
Information provided by spouse/partner					
Group 1 (NS)	9	4.1111	2.147		
Group 2 (NM)	19	5.1579	1.951	1.24	.235(ns)
Information provided by spouse/partner, mother and father					
Group 1 (NS)	10	3.5667	1.792		
Group 2 (NM)	21	4.0079	1.695	-0.65	.523(ns)
Information provided by spouse/partner, mother and father, bother(s), sister(s) and in-laws.					
Group 1 (NS)	10	3.4433	1.722		
Group 2 (NM)	21	3.5190	1.702	-0.11	.910(ns)

Note: (ns) denotes no significance

*A Comparison of t-Tests Between Means of Perceived Emotional Support
Broken Down by Selected Person Variables*

Variable	n	Mean	Standard Deviation	t	Level of Significance
Emotional support provided by spouse/partner					
Group 1 (NS)	11	4.8182	2.316	-2.06	.061(ns)
Group 2 (NM)	22	6.3333	1.065		
Emotional support provided by spouse/partner, mother and father					
Group 1 (NS)	11	4.4091	1.566	-1.60	.127(ns)
Group 2 (NM)	22	5.3030	1.405		
Emotional support provided by spouse/partner, mother and father, bother(s), sister(s), and in-laws					
Group 1 (NS)	11	3.9652	1.370	-1.28	.215(ns)
Group 2 (NM)	22	4.6121	1.363		

Note: (ns) denotes no significance

A Comparison of t-Tests Between Means of Perceived Instrumental Assistance Broken Down by Selected Person Variables

Variable	n	Mean	Standard Deviation	t	Level of Significance
Instrumental assistance provided by spouse/partner					
Group 1 (NS)	9	4.111	2.369	-1.07	.304(ns)
Group 2 (NM)	21	5.0952	2.189		
Instrumental assistance provided by spouse/partner, mother and father					
Group 1 (NS)	9	3.9630	1.703	-0.01	.992(ns)
Group 2 (NM)	22	3.9697	1.966		
Instrumental assistance provided by spouse/partner, mother and father, bother(s), sister(s), and in-laws					
Group 1 (NS)	9	3.7148	1.553	0.59	.566(ns)
Group 2 (NM)	22	3.3409	1.755		

Note: (ns) denotes no significance

A Comparison of t-Tests Between Means of Influence of Perceived Information Broken Down by Selected Person Variables

Variable	n	Mean	Standard Deviation	t	Level of Significance
Perceived Influence of Information provided by spouse/partner					
Group 1 (NS)	7	4.2857	1.799	-0.67	.517(ns)
Group 2 (NM)	19	4.8421	2.115		
Perceived Influence of Information provided by spouse/partner, mother and father					
Group 1 (NS)	7	3.6667	1.515	-0.26	.799(ns)
Group 2 (NM)	21	3.8492	1.858		
Perceived Influence of Information provided by spouse/partner, mother and father, bother(s), sister(s), and in-laws					
Group 1 (NS)	7	3.7690	1.464	0.75	.465(ns)
Group 2 (NM)	21	3.2690	1.658		

Note: (ns) denotes no significance

A Comparison of t-Tests Between Means of Influence of Perceived Emotional Support Broken Down by Selected Person Variables

Variable	n	Mean	Standard Deviation	t	Level of Significance
Perceived Influence of Emotional support provided by spouse/partner					
Group 1 (NS)	11	3.5455	2.296	-3.17	.007*
Group 2 (NM)	21	5.9048	1.261		
Perceived Influence of Emotional support provided by spouse/partner, mother and father					
Group 1 (NS)	11	3.2727	1.200	-2.29	.031*
Group 2 (NM)	22	4.3939	1.549		
Perceived Influence of Emotional support provided by spouse/partner, mother and father, bother(s), sister(s), and in-laws					
Group 1 (NS)	11	2.8182	.825	-1.95	.059(ns)
Group 2 (NM)	22	3.6136	1.506		

Note: * denotes significance

A Comparison of t-Tests Between Means of Influence of Instrumental Assistance Broken Down by Selected Person Variables

Variable	n	Mean	Standard Deviation	t	Level of Significance
Perceived Influence of Instrumental assistance provided by spouse/partner					
Group 1 (NS)	9	3.7778	2.108	-1.31	.210(ns)
Group 2 (NM)	21	4.9048	2.300		
Perceived Influence of Instrumental assistance provided by spouse/partner, mother and father					
Group 1 (NS)	9	3.3333	1.886	-0.12	.902(ns)
Group 2 (NM)	22	3.4242	1.719		
Perceived Influence of Instrumental assistance provided by spouse/partner, mother and father, bother(s), sister(s), and in-laws					
Group 1 (NS)	9	2.8352	1.460	-0.03	.976(ns)
Group 2 (NM)	22	2.8530	1.537		

Note: (ns) denotes no significance

*A Comparison of t-Tests Between Means of Influence of Perceived
Emotional Support Broken Down by Mother and Father Variables*

Variable	n	Mean	Standard Deviation	t	Level of Significance
Perceived Influence of Emotional support provided by mother and father					
Group 1 (NS)	10	2.9500	1.707	-0.40	.695(ns)
Group 2 (NM)	20	3.2250	1.936		

Note: (ns) denotes no significance

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The dissertation is therefore accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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