

INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

UMI

A Bell & Howell Information Company
300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA
313:761-4700 800:521-0600

Parent and Professional
Perspectives of Communication
in Developmental Treatment Settings

by


Kathleen Clotfelter Watson

A dissertation submitted in partial fulfillment
of the requirements for the degree of

Doctor of Philosophy

University of Washington

1994

Approved by 
(Chairperson of Supervisory Committee)

Program Authorized
to Offer Degree School of Nursing

Date 9/21/94

UMI Number: 9523773

Copyright 1994 by
WATSON, KATHLEEN CLOTFELTER
All rights reserved.

UMI Microform Edition 9523773
Copyright 1995, by UMI Company. All rights reserved.

This microform edition is protected against unauthorized
copying under Title 17, United States Code.

UMI

300 North Zeeb Road
Ann Arbor, MI 48103

©Copyright 1994
Kathleen Clotfelter Watson

In presenting this dissertation in partial fulfillment of the requirements for the Doctoral degree at the University of Washington, I agree that the Library shall make its copies freely available for inspection. I further agree that extensive copying of this dissertation is allowable only for scholarly purposes, consistent with "fair use" as prescribed in the U.S. Copyright Law. Requests for copying or reproduction of this dissertation may be referred to University Microfilms, 1490 Eisenhower Place, P.O. Box 975, Ann Arbor, MI 48106, to whom the author has granted "the right to reproduce and sell (a) copies of the manuscript in micriform and/or (b) printed copies of the manuscript made from microform"

Signature Kathleen Claford Watson

Date 09-29-94

University of Washington

Abstract

Parent and Professional Perspectives of Communication in Developmental Treatment Settings

By Kathleen Clotfelter Watson

Chairperson of the Supervisory Committee: Assistant Professor Gail M. Kieckhefer
Department of Parent and Child Nursing

The focus of this study was the communication process between parents of children with developmental delays and disabilities who are seeking services for their child and the professional providers in developmental treatment centers who provide services to them. The purpose of the study was to begin development of middle range substantive theory of parent-provider communication in the developmental treatment setting. The specific aims of the study were: to explore both parent and provider perceptions of the communication process in developmental treatment settings, to identify concepts relevant to this parent provider communication process, and to further suggest relationships between the identified concepts. The design for this study was exploratory and interpretive. It was based on symbolic interactionism and used modified grounded theory methods to attempt to answer the central question, "What is it like for parents and providers to communicate with one another in developmental treatment settings?" In keeping with the grounded theory approach, multiple data sources were used, including formal unstructured interviews with both parents and professional service providers, participant observation by the investigator in the treatment setting, and professional and lay literature. The sample in this study was a

convenience sample from two developmental treatment centers to which I had access.

Fourteen families and fifteen providers participated in this study.

The core concept identified from this study was Striving for Therapeutic Relationships Within a Context of Uncertainty. Conditions for the core concept were Identification of Child Delay and Referral for Treatment. The context was Provider Uncertainty and Parent Uncertainty. Intervening Conditions were Differing Parent and Provider Perspectives and Change Over Time. Strategies for Action/Interaction were Balancing, Questioning, Reading the Cues, Managing the Sessions and Managing Uncertainty. The strategy of Balancing was further categorized as Balancing Competing Needs, Balancing Competence and the Need for Intervention, Balancing the Here and Now and the Future, and Balancing Parent and Provider Roles. The consequences identified for the core phenomenon were Parent-Provider Relationship Perceived as Therapeutic, Child-Provider Relationship Perceived as Therapeutic, Parent Perception of Competence in Parent Role, Provider Perception of Competence in Provider Role and Changes in Child Competence.

TABLE OF CONTENTS

List of Tables	iv
Chapter I: Introduction	1
Statement of the Problem	1
Significance of Study	10
Summary	10
Chapter II: Conceptual Framework	11
Introduction	11
Conceptual Framework	11
Symbolic Interactionism	12
Uncertainty and Information	14
Review of Relevant Literature	20
Parent and Family Needs	20
Parent Provider Communication	24
Differing Parent-Provider Perspectives	26
Chapter III: Methodology	29
Design	29
Pilot Study	31
Sample	33
Data Collection Procedures	37
Participant Observation	37
Formal Unstructured Interviews	37

Memos and Field Notes	38
Professional and Lay Literature	40
Protection of Human Subjects	41
Data Analysis	42
Constant Comparative Analysis	43
Open Coding	43
Axial Coding	44
Selective Coding	44
Trustworthiness of Data	45
Credibility, Transferability, Dependability, and Confirmability	46
Critique of Approach to Trustworthiness	47
Alternative Approaches to Trustworthiness	49
Rationale for Choice of Method	50
Chapter IV: Results	51
Introduction	51
Situating the Study	51
The Participants-Description of the Sample	52
Description of the Context	53
Striving for Therapeutic Relationships Within a Context of Uncertainty	57
Overview of Striving for Therapeutic Relationships	59
Conditions for Striving for Therapeutic Relationships	63
Context for Striving for Therapeutic Relationships	68
Intervening Conditions for Striving for Therapeutic Relationships	78
Action/Interaction Strategies	81
Consequences of Striving for Therapeutic Relationships	121
Chapter V: Reflexivity In Method	124
Reflexivity	124
Relationship of the Researcher to the Informants	125
The Researcher as Parent	126
The Researcher as Colleague	128
The Researcher as Nurse	130

Relationship of the Researcher to the Data	133
Relationship of the Researcher to the Reader	136
Chapter VI: Discussion	137
Introduction	137
Discussion of the Core Category	139
Story Line	140
Identification and Referral	144
Uncertainty	144
Differing Perspectives and Change Over Time	145
Strategies for Action and Interaction	148
Therapeutic Aspects of Developmental Treatment	155
Establishing Trust	156
Deceptive Communication	160
Stigma and Normalization	162
Limitations of This Study	181
Characteristics of the Setting and Participant Group	181
Limitations of the Methodology and Design	182
Limitations of the Researcher	184
Implications for Nursing Practice	185
Implications for Nursing Science	189
Summary	191
References	193
Appendix A: Parent Letter	201

LIST OF TABLES

Number	Page
1. Axial Coding of the Core Phenomenon	76

ACKNOWLEDGMENTS

This research could not have been accomplished without the assistance and participation of the parents and providers whose words appear in this paper. The providers were willing to allow me into their centers and their treatment sessions to observe them at work. They gave up valuable time to talk with me and provide information I needed. The parents and other family members not only allowed me into their treatment sessions and their homes, but shared with me some of their most personal experiences. To all of these participants I am deeply grateful.

When I undertook the process of furthering my education, I knew I was committing myself to a challenging program which would require a great deal of effort. I was nevertheless dismayed at the swift manner in which school took over all aspects of my life and demanded priority. The acceptance, support and encouragement of my husband, family and close friends was invaluable to me in being able to continue and complete my program. My partner and husband, Jim Watson, spent many hours alone and completed many of our jointly planned projects without my assistance. My family and friends also accepted my extended pre-occupation with school and my resultant neglect of them and my usual roles. I received encouragement and support from them at every opportunity.

Sincere thanks go to my Supervisory Committee members, who were supportive of my desire to finish my program in a timely manner and were willing to be flexible in scheduling and re-scheduling: Special thanks to Dr. Gail Kieckhefer for her

invaluable support as chairperson of my committee throughout this process. She has been reliable, straightforward and open to new ideas, as well as a consistent advocate. She patiently read and painstakingly critiqued many versions of my dissertation.

Thanks go to Dr. Marcia Killien for her ability to provide constructive criticism as well as encouragement and advice. She has been a valued advisor and teacher from my entry into the School of Nursing through the completion of my program. Thanks go to Dr. Ellen Olshansky for her guidance and support in using the Grounded Theory methods and for her invaluable sense of perspective and to Dr. Kathryn Barnard for many years of inspiration in regard to the role of nurses with families and young children and the importance to nursing practice of scholarly inquiry by nurses. Thanks also to Dr. Howard Becker, the graduate faculty representative on my committee, for his ability to put aspects of being a graduate student into perspective, and for introducing me to a different view of science.

In addition, special thanks go to two mentors in this program who were Doctoral Candidates when I entered and who have since graduated. The first is Dr. Barbara Cochrane, for whom I worked as a Teaching Assistant. She loaned me her books and offered invaluable information, support and friendship. The second is Dr. Sarah Shannon, for whom I gladly worked for two years as a Research Assistant. She has been an excellent role model as both a researcher and a project director. In addition, she has been constantly available to offer information, advice and friendship.

Finally, I acknowledge my parents. Although my father, John Clotfelter, died during my time in this program, I feel his pride in whatever I have accomplished. My mother, Norma Clotfelter, has always been my role model of a good nurse. To her I owe the inspiration to become a nurse and to always continue my education. They have my unending love and gratitude.

DEDICATION

This project is dedicated to my daughter, Amanda, to whom I have tried to be a good parent, and who seems to accept me just the way I am. It is also dedicated to other women and men who are struggling to be good parents to children who have developmental delays and disabilities. May the results of this research contribute in some way to the quality of life and peace of mind of other families like us.

CHAPTER I

INTRODUCTION

Statement of the Problem

Parents of young children who are exhibiting developmental delays are thrust into a sequence of diagnostic and treatment interactions which usually begins with a physician and eventually includes multiple professional providers of various disciplines. In the absence of an obvious medical problem or syndrome, it is often impossible to predict the developmental outcome for a young child. Because normal development is a process which unfolds over time, the determination of a diagnosis and prognosis for a child with developmental delays must be evolutionary, and often continues over an extended period of time. If the child's delays prove significant or are deemed to be caused by a condition which is permanent, diagnosis of a developmental disability will eventually be made and contacts with professional service providers will likely continue until the child reaches adulthood. It is the goal of providers who work with families throughout this process, not only to provide direct services to the child, but also to provide information and assistance to the family in caring for the child. The communication process between parents of children with developmental delays and

disabilities who are seeking services for their child and the providers in developmental treatment centers who provide services to them is the focus of this study.

My interest in the parent professional communication process in developmental treatment settings is personal as well as professional. My daughter, who is now 23 years old, has the diagnoses of static encephalopathy and mental retardation. My past and ongoing experiences with my daughter influence the view I have of other families in which there is a child with developmental disabilities as well as my view of the professionals who provide services to these families. As a professional nurse, I have been employed in developmental treatment settings as the provider of services to families. My experiences in that role have also contributed to my view of both families and providers in those settings. It is these personal and professional experiences which have led to my interest in the parent provider communication process and which are an integral and unavoidable part of my interpretation. These perspectives which I bring to this study are addressed in Chapter V.

Developmental disability is a generic term which has been used since the late 1960's to describe clinical conditions that cause disability, begin early in life, and require supportive services (Pope & Tarlov, 1991). Developmental disabilities include a wide variety of conditions, which can be divided into five groups by time of onset: hereditary conditions, early alterations in embryonic development, late pregnancy or perinatal conditions, acquired childhood conditions and conditions of unknown etiology

(Pope & Tarlov, 1991). Included in the 'unknown etiology' category are autism, cerebral palsy, epilepsy, mental retardation of unknown etiology and learning disorders. The two most common developmental disabilities are mental retardation and cerebral palsy. Of all children with developmental disabilities, approximately two thirds have more than one condition. For example, of all children who have mental retardation, about 10% have the additional diagnosis of cerebral palsy, about four percent also have sensory impairment and about 40% also have emotional or behavior problems. Of those children with cerebral palsy, approximately half also have some degree of mental retardation. Overall it has been estimated that between 2 million and 4 million people of all ages have developmental disabilities (Pope & Tarlov, 1991).

Children who have developmental disabilities receive services for traditional health or medical problems in medical settings such as hospitals and medical clinics from health care providers such as physicians and nurses. The additional developmental services provided to these children generally occur in a different setting. Children from birth to three years of age receive these developmental treatment services in a variety of settings, both home based and center based; one-on-one and group. One common intervention setting among these is the developmental treatment center or clinic in which children are typically seen by health and/or educational providers in individual sessions, often on a weekly or biweekly basis. The children are accompanied by their parents or caregivers, who generally sit in on the session and thus

have ongoing interaction with the treating professional. Treatment may also be provided in the family's home on an as-needed basis. Children with developmental disabilities generally receive treatment in such a clinic setting until they are three years of age, at which time those who continue to need services are transitioned to a preschool program in their school district. In some cases, parents choose to continue therapy in these initial developmental treatment settings in addition to that provided by the school program. Thus, interactions between the parents and providers may extend over six or more years. It is the parent-professional communication process in these developmental treatment centers which is the focus of this study.

Developmental services have evolved over recent years and are currently based on a combination of health/medical and educational models. These services are provided by various combinations of educators, occupational and physical therapists, speech therapists, nurses and social workers. Programs which include the services of health oriented providers such as therapists and nurses generally operate under a rehabilitation model rather than the traditional medical model. The focus is on care rather than cure, maximizing of the potential for quality of life rather than eradication of disease. Because of differences in these rehabilitation oriented settings in contrast to typical medical settings, research findings regarding parent and professional communication from studies which have been carried out in acute care settings or in regard to diagnoses of chronic or acute illness rather than developmental disability may

not be fully informative regarding parent and professional communication in developmental treatment centers.

Much of what goes on in developmental treatment settings can be said to revolve around communication. Communication has been defined as "the process of sharing information using a set of common rules." (Northouse & Northouse, 1992, p. 2). Communication is an ongoing process rather than a static event, and it is transactional, involving reciprocal influences as the actors both send and receive messages over time. Communication is also a multidimensional process with two dimensions or levels. The content dimension refers to the actual words or information in the message while the relationship dimension refers to aspects of the relationship between the two participants (Northouse & Northouse, 1992). How the message content is interpreted by the recipient depends a great deal on the relationship aspect. For parents of children with developmental disabilities and the professionals who treat them, the content dimension of communication takes place in the context of their developing and on-going relationships within the treatment situation.

As providers of developmental services, professionals such as nurses, occupational therapists, physical therapists, speech pathologists, educators and others are expected to offer a great deal of information. Although physicians provide the medical diagnosis and at least some information to parents, it falls to the disciplines who provide ongoing treatment in various developmental specialties to gather

information, answer questions and provide information on a week to week basis. In addition to the information gained from developmental assessment, providers need information from parents about the child's history, the parents' concerns, and the child's function at home. Providers also want to impart information to the parents about the child and what the parents might do at home to promote the child's development.

Past studies which have attempted to examine parent stresses and concerns have confirmed that the need for information is very significant to parents of children with developmental delays. These studies indicate that the information parents want includes a diagnosis and the implications of the diagnosis for the child's future (Bernheimer, Young & Winton, 1983; Kornblatt & Heinrich, 1985; Meeropol, 1991; Strauss & Munton, 1985). Parents also want to know what action they should take now, and how the family can find appropriate services (Sloper & Turner, 1992; Walker, Epstein, Taylor, Crocker & Tuttle, 1989).

This broad parental need for information parallels the provider desire to share information. While providers try to plan and carry out direct interventions that benefit the child's development, they expect that one or two hours of professional intervention each week are inadequate to accomplish their purposes and that parents must be the primary interventionists for their child. Thus providers must adequately communicate the specifics of the treatment plan to parents (Seitz & Provence, 1990).

These long recognized needs for parent and provider information exchange and parent involvement in child treatment programs have been institutionalized in the United States by legislative mandate. The most recent of these was Public Law 99-457, which was signed into law in 1986, and calls for a team approach to child treatment in which the family is a central member of the team and where the intervention plan includes interventions for the family to help them to best care for the affected child. The family is expected to play an active role and take responsibility for decision making regarding the child. These legislative developments have led to increased focus on parent-professional communication and parent-professional partnerships (Hutchins & McPherson, 1991). But while the need and mandate are evident, multiple factors work to constrain communication.

Although parents need and want information, and providers wish to provide it, the determination of diagnosis and prognosis of developmental delay in young children is often an emerging process fraught with uncertainty. While there are developmental disabilities which have known causes, such as alcohol toxicity, intracranial hemorrhage, or metabolic deficits, in most cases the cause may be speculated, but is never confirmed. Even when there is a clear diagnosis such as Down Syndrome, the mechanism remains unknown and the range of prognosis for an individual child is very broad (Richardson & Koller, 1994). Early predictions of prognosis are tentative due to lack of functional equivalence between the pattern of a child's early development and

the later developmental outcome of that child. This may be attributed, in part, to the fact that developmental disabilities are multidimensional and multidetermined (Wachs & Sheehan, 1988). There are many mediating variables that influence expression of the condition for an individual child, such as other co-occurring disabilities, general health, nutritional status and the degree of support in the immediate environment.

When children do not develop normally, parents experience a great range of negative emotions which may be very intense at times. These emotions may influence the parents' ability to take in and share information. This accounts to some degree for the need of parents to have new information given to them more than once. Although parents want information, the information is often threatening. Parents want to consistently hear positive things about their child and their parenting and to be able to maintain hope in the future (Strauss & Munton, 1985). Little is known about how providers and parents in a developmental treatment center manage their communication in the face of these needs and constraints.

In diagnostic or acute care settings, the extent to which parent professional communication has been viewed as a problem has been documented. That research centers around the diagnostic process and generally focuses on physicians, who are charged with making and communicating the diagnosis. The communication between parents and providers in developmental treatment centers has not as yet been strongly documented as problematic. In fact, clinicians suggest that developmental treatment

centers 'spoil' parents, making it difficult for them when they transition to a public school setting. While it would appear that communication which occurs in the developmental treatment setting has the potential to be a very powerful influence in the life of the child with developmental delays and the lives of his or her family members, there is little empirical data specific to communication in this setting and thus no middle range theory which has been put forth to guide clinical practice or research.

Statement of Purpose

The purpose of this study was to begin development of middle range substantive theory of parent-provider communication in the developmental treatment setting. This theory could then be used both to guide practice and to point directions for further research. The specific aims of this study were:

1. To explore both parent and provider perceptions of the communication process in developmental treatment settings.
2. To identify concepts relevant to this parent provider communication process
3. To further suggest relationships between the identified concepts.

I have utilized modified grounded theory techniques in the symbolic interactionist tradition to attempt to answer the central question, "What is it like for parents and providers to communicate with one another in developmental treatment settings?"

Significance of Study

Information about parent and provider perceptions of communication in developmental therapy could be useful to parents in better fulfilling the needs of themselves and their children; to educators in preparing providers to work with this population; to clinicians in refining their communication content and styles with this population; and to legislators and policy makers in planning for changes in health care delivery.

Summary

In this chapter, I have attempted to identify the population and setting of interest and show why it deserves study. I have briefly described the purpose and methodology for the study and situated myself in relation to the study. In Chapter II, I will discuss concepts which I felt were relevant to the study when I began it, and review related research.

CHAPTER II

CONCEPTUAL FRAMEWORK

Introduction

The purpose of this chapter is to articulate the conceptual framework for this study and review related research. The first section contains the overarching framework which guided the methods used for data collection and analysis. This section also contains a discussion of two concepts which I felt were central to the phenomenon of interest and which were utilized as sensitizing rather than definitive concepts. The second section contains a review of previous research conducted on service needs of families, communication between parents and health care providers and divergent parent provider perspectives.

Conceptual Framework

The research paradigm for this study is symbolic interactionism. Within this, and consistent with its views, is a transactional view of the communication process (Northouse & Northouse, 1992). Concepts which I felt to be integral aspects of the communication between families with a child who has developmental delays and professional service providers are information and uncertainty. These concepts have

repeatedly been found in my scholarly, clinical and personal experiences in this area. Rather than using them as definitive concepts with which to order and integrate data, I attempted to use them to sensitize me in asking questions. Each of them is discussed more fully in following sections.

Symbolic Interactionism

The study is based on symbolic interactionism, a term coined by Herbert Blumer (1969) to describe the approach to research whose basic premises are:

...that human beings act toward things on the basis of the meaning the things have for them...that the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows...that these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters. (Blumer, 1969, p.2)

Using the ideas of George Herbert Mead as a basis, Blumer developed the methodological position which is known as the Chicago school or tradition of symbolic interactionism (Burr, Leigh, Day & Constantine, 1979). Symbolic interactionism is built on the works of many scholars of Pragmatic philosophy, but Blumer credits Mead with laying the foundations for the approach (Blumer, 1969). The Chicago tradition of symbolic interactionism is distinguished from those of the Iowa and Minnesota groups by a stance which advocates indeterminacy, qualitative data, discursive theory and emphasis on unpredictability (Burr, Leigh, Day & Constantine, 1979).

In addition to the three basic premises listed above, there are two aspects of symbolic interactionism which make it a useful framework for this study. First, the approach emphasizes the symbolic nature of language and the view that words have no intrinsic meaning, but rely on meanings which are learned in social interaction and attributed to the words. Thus, the meaning lies in the person and not in the words, making shared meaning necessary for effective communication. Given the assumptions of symbolic interactionism, it is clear that to understand the communication process between parents of young children with developmental delays and the professionals who provide services to them, it is necessary to explore the meaning of the experience from the point of view of the individuals involved. Second, the symbolic interactionist perspective assumes an emergent view of reality which is produced in social interaction. This makes it a useful approach for studying processes. The symbolic interactionist perspective has been found useful in studying both family processes and processes that occur in health care situations. Thus, this approach lends itself to study of the communication process between parents and providers in developmental treatment centers.

In concert with symbolic interactionism, this study was guided by a substantive view of communication which describes it as a transactional process with both content and relationship dimensions (Northouse & Northouse, 1992). According to this view, there are four different relationship patterns which occur in health care settings. These

are professional-professional, professional-client, professional-significant other, and client-significant other (Northouse & Northouse, 1992). The interactions that occur in any of these relationships can affect the others. When these patterns are applied to the case of children with disabilities and their parents, there is the added dimension that the parents are both significant others to the child, and themselves clients of the professional service providers. They must act on behalf of their child as well as themselves, and the providers must interact with both the child and the parents.

The transactions between the family members and providers include both verbal and non-verbal communication, both of which must be considered by each individual as he or she interprets the content and relationship dimensions of the message sent by the other. The context for these transactions includes both the physical setting and the interpersonal setting. In this study, the physical setting is usually the clinic, but sometimes the family home. The interpersonal setting may vary from a one-to-one interaction between the parent and one or more providers within the clinic to a group meeting between the family and service providers from two or more agencies. This leads to increased complexity in the communication process.

Uncertainty and Information

Some degree of uncertainty surrounds the diagnosis and prognosis of each child in a developmental treatment setting. Closely related to uncertainty is information, which is said to reduce uncertainty. The literature on these two concepts was reviewed

as a means of increasing my awareness of their taken-for-granted use in my view of the developmental treatment setting.

A middle range theory of uncertainty in illness was developed by Mishel (1988), and reconceptualized to include the experience of living with continued uncertainty (Mishel, 1990). Mishel defines uncertainty as:

...the inability to determine the meaning of illness-related events. It is the cognitive state created when the person cannot adequately structure or categorize an event because of the lack of sufficient cues. Uncertainty occurs in a situation in which the decision maker is unable to assign definite value to objects or events and/or is unable to predict outcomes accurately. (Mishel, 1990, p.256).

Mishel's theory of uncertainty in illness (Mishel, 1988) takes an interactionist approach, and is built on theories of cognitive appraisal (Mishel, 1988). The theory uses terminology common to cognitive theories and much importance is attributed to the meaning given to an event by an individual. Mishel's theory identifies two appraisal processes, inference and illusion. In inference, the person evaluates the uncertainty based on related situation examples and determines the uncertainty to be either an opportunity or a threat. In illusion, the person constructs beliefs that have a generally positive outlook, which then allows the uncertainty to be assessed as opportunity. This process is said to be used in situations where there is a negative trajectory (Mishel, 1990). The vague and ambiguous situation of uncertainty allows for this creation of illusion. Mishel has developed an Uncertainty in Illness Scale (MUIS) (Mishel, 1981),

and a Parent Perception of Uncertainty in Illness Scale (PPUS) (Mishel, 1983). In the PPUS, ambiguity, lack of clarity, lack of information and unpredictability were proposed as the characteristics of uncertainty for parents of hospitalized children. The PPUS has not been used extensively, but the MUIS has been used to test and develop the Mishel Uncertainty in Illness theory. Mishel's model of Uncertainty in Illness is very broad and inclusive of research in many different related areas. However, it has not been tested on samples of families with a child who has developmental disabilities. It therefore has little specificity for this population of families. It also does not address uncertainty from the provider's point of view, or how that uncertainty is handled between parents and providers.

Another model of uncertainty was developed using a sample of parents whose children were hospitalized in a critical care unit. An interpretive approach and grounded theory methods were used. (Turner, Tomlinson, & Harbaugh, 1990). Findings were that ambiguity, conflicting information, and perceived inefficiency in the hospital setting gave rise to parental uncertainty in the four areas of environmental uncertainty, illness uncertainty, caregiver uncertainty, and family systems uncertainty. This qualitative study identified dimensions of the intensive care hospital experience that had not been previously discussed in the literature and were not covered in Mishel's model. However, the intensive care experience for parents of a critically ill child can not reasonably be assumed to shed light on the developmental therapy

experience of parents of children with developmental delay. Uncertainty has not been studied in parents of children undergoing developmental diagnosis and treatment.

From the point of view of the clinician in a health care setting, there are several important aspects of uncertainty. These can be found in the literature on various diagnoses, with cancer being a good example (Amir, 1987; McIntosh, 1974). First, there may be uncertainty surrounding either the diagnosis, the prognosis, or both. The distinction between the concepts of diagnosis and prognosis is important, because of their differing implications for the patient or client (Amir, 1987). Second, there may be uncertainty on the part of the provider as to how much the patient should be told about the diagnosis or prognosis. Patient factors thought to influence how much the patient should be told include how much he or she truly wants to know, how much he or she is capable of understanding and how he or she will react to the information (Amir, 1987). The physician's beliefs about information sharing, his or her approach to patients and years of experience are believed to be very important in determining how he or she handles giving the diagnosis and prognosis. In Amir's study on physician considerations in informing cancer patients, more information was given to patients who were perceived as intelligent, but only if they asked (Amir, 1987).

These perspectives on informing the patient in the clinical health care setting in general seem to also be relevant to families who have a child with developmental delay. Even when uncertainty concerning diagnosis or prognosis for a particular child is

reduced, providers may choose not to share information with parents for various reasons. In his study of the families of 14 polio victims and the hospital setting that treated the children, Davis (1991) observed four categories of communication between physicians and families: communication, dissimulation, evasion, and admission of uncertainty. When the physician felt certain of the prognosis for the child, he or she could either share the prognosis (communicate) or feign continued uncertainty (evade). Conversely, when the physician was uncertain of the prognosis, he or she could either admit uncertainty or feign certainty (dissimulate). Davis (1960) distinguished between 'real' and 'functional' uncertainty, functional uncertainty being when either real or pretended uncertainty is used by physicians in the management of patients and their families. Davis suggested that in some cases, functional uncertainty was used to avoid the parents' becoming upset and taking up a great deal of the physician's time. It was also stated by the physicians that it was better for families to come to gradual realizations about the child's prognosis rather than have a shock all at once (Davis, 1991).

Complicating the issues of uncertainty and information is the fact that professional views and practices in regard to information sharing have evolved over recent years as the consumer movement and alternative health care movements have developed. In addition, attitudes about these issues vary by institution, by discipline

and by individual. These multiple factors make the concepts of information and uncertainty very complex.

From the point of view of the patient or parent, uncertainty is also a complex issue. While the reduction of uncertainty can have a positive role in coping, it also has the potential to interfere with coping by decreasing hope. This is reflected in the often reported desire of parents that information about their child be presented in a positive manner. For example, Knafl, Breitmayer, Gallo and Zoeller (1992) report that parents of children with chronic illness

“...wanted providers to moderate the amount to information they received on possible complications and unfavorable prognoses. Although they realized the necessity for such information, they preferred that providers ‘not paint too gloomy a picture’ by dwelling on negative possibilities” (p. 93).

The desire of parents to acquire information about the diagnosis and prognosis for their child seems to exist in dialectical tension with the desire not to hear negative information. The relative balance of these often conflicting goals is influenced by the meaning the parent makes of the information and how the providers choose to share information. Thus these two concepts of uncertainty and information provide a contextual frame of reference within a symbolic interactionist perspective which frames my approach to explicating the communication process in developmental treatment centers.

Review of Relevant Literature

Research on parent and provider relationships often contains a mixed sample of children including those with acute and chronic illness as well as developmental disabilities. Terminology used to describe samples, such as chronic illness or disability may have different meanings for different studies. It is typically not possible to separate out the factors that might relate specifically to children with developmental disabilities only. Thus, this review reflects this mixed sample and is inconclusive in determining areas of commonality and difference between the experiences of families who have a child with a developmental disability and those who have a child with a chronic illness.

Parent and Family Needs

A great deal of the recent research about families who have a child with a developmental disability seeks to determine the service needs of the family. The need for information and the importance of the manner in which it is delivered are foremost among priorities identified by parents. A study of the needs and coping of 24 families of children who had been seen at a center for children with handicaps revealed an increased need for information regarding the child's diagnostic implications and lack of knowledge and utilization of existing community resources (Kornblatt and Heinrich, 1985). Similarly, results of a questionnaire mailed to families of children with a wide variety of chronic conditions, including mental retardation, also revealed a desire on the

part of parents for more information on a variety of topics, including available programs and services (56%), financial planning for the future (45%), the child's particular health problem (42%), financial aid (40%), insurance plans (31%), and prescribed treatment (28%) (Walker, Epstein, Taylor, Crocker & Tuttle 1989).

Information was the most commonly identified unmet need in a study of the service needs of parents of children with severe orthopedic handicaps conducted using written questionnaires and parent interviews (Sloper and Turner, 1992). Among the most important characteristics of a helpful professional identified by the participating parents were openness and honesty and giving information. The discipline of the professional provider was not as important to parents as their personality and the relationship they developed with the family.

In a parallel fashion, a study which focused on the parents' view of physicians and nurses collected qualitative data from 51 families of children seven to 14 years of age with chronic illness (Knafl, Breitmayer, Gallo and Zoeller, 1992). Following an interview regarding their most memorable experiences with health care providers, the parents were asked what advice they would offer to providers caring for a family like theirs in the future. The advice the parents offered to providers centered around four themes: information exchange, interactional style, establishing a relationship with the child, and fostering parental competence. Of note is the fact that information exchange has to do with the content aspect of communication, while fostering of parental

competence, interactional style and establishing a relationship with the child all have to do with the relational aspect of communication.

Each of these studies indicates that parents need and desire information, but none of them addresses the issue of what actually happens during the communication process when providers try to provide information or parents try to obtain it. Yet it is in this process that there are inherent difficulties in providing developmental information to parents of young children. There can be contradiction between providing accurate and straightforward information and providing positive, hope-maintaining information.

It has been pointed out (Tuckett & Williams, 1984) that most studies of information giving in clinical settings evaluated the information in terms of length of time, number of sentences or words and so on, without examining the actual content of the information. One exception to this practice was a study by Svarstad (1974) who determined *a priori* what the reasonable universe of information would be in the situation and categorized each encounter accordingly. Prediction for patient compliance using the content of the information as the criteria was much greater than demonstrated in studies which had the amount of information as the criteria.

In a later study (Svarstad & Lipton, 1977), the focus was the relationship between the content of information given to parents in a diagnostic clinic for developmental disabilities and subsequent parental acceptance of the diagnosis. They

studied the diagnostic process using interviews with the parents before and after the informing interview, observation and audiotaping of the informing interview, a brief questionnaire of the informing professional, and review of the child's clinic record. They found that there was significant variability in the degree of frankness of the information actually given to parents. Parental acceptance of the child's condition was related to the degree of frankness of the informing professional. Although the degree of frankness was a significant factor, the authors emphasized that it was not a necessary or sufficient condition for parental acceptance.

Another study which examined the content of the information actually given to parents was one by Matheny and Vernick (1969) in which they sought to prove the thesis that parents needed clear and concrete information about their child's diagnosis rather than psychotherapeutic counseling. They designed a protocol for diagnostic evaluations at their facility which was focused on the goal of informing parents from the beginning that they would be involved in every aspect of the evaluation process and that communication of all the information which was discovered would be provided. A pre-post parent questionnaire indicated that parent perceptions of their child's future prospects had been changed to perspectives more consistent with those of the providers. Of significance was that parents were not incapacitated by their emotional reaction to the child's diagnosis and were able to take in and act on carefully presented information.

Parent Provider Communication

Much of the previous research on the communication process between parents and providers has been carried out in regard to communication between parents and physicians. A study of doctor-patient communication conducted in the late 1960's examined the interaction between mothers and physicians in an emergency room walk-in clinic (Korsch, Gozzi & Francis, 1968; Francis, Korsch & Morris, 1969; Korsch & Negrete, 1972). Findings were that the physicians used medical jargon that the mothers did not understand, physicians showed little concern for the worries expressed by the mothers, and physicians did not provide mothers with a reason for the child's symptoms or a diagnosis. The authors recommended improved training in communication techniques for physicians in order to improve patient satisfaction and compliance with treatment recommendations. In the years since this study, significant attention has been paid to the communication process between patients and physicians in general, and parents of children with developmental disabilities and physicians in particular. Of particular interest has been the improvement of medical school curricula content about handicapping conditions (Richardson & Guralnick, 1978; Widrick, Whaley, DiVenere, Vecchione, Swartz & Stiffler, 1991) and about working with families (Richardson, Guralnick & Tupper, 1978), and information on communication of the diagnosis of a handicapping condition (Quine & Pahl, 1986; Cottrell & Summers, 1990; Svarstad & Lipton, 1977; Krahn, Hallum & Kime, 1993).

Research on the communication between parents of handicapped children and disciplines other than physicians or in regard to the treatment rather than the diagnostic process is not as readily available. One study was located which examined the communication between parents of handicapped children and physicians, nurses, social workers, occupational and physical therapists and others using a tool called Sequential Analysis of Verbal Interaction (SAVI) (MacKinnon, 1984). The purpose was to determine whether the interactions between parents and providers were conducive to problem solving. Grouping the providers as either physicians or non-physician allied health professionals, MacKinnon found that all three groups (parents, physicians, allied health professionals) used cross purpose communication patterns which were non-interpersonal and non-goal oriented. The investigator noted surprise that the allied health professionals, a group which included both nurses and social workers as well as others, did not differ significantly from physicians in their communication patterns. She suggested that structural influences of the hospital outpatient department clinic could be an element in the unanticipated similarity of communication patterns of physicians and other providers.

Important research has been done on the relationships between health care providers and patients in situations of chronic illness by Thome and Robinson (1988; 1989). Qualitative methods were used in a series of studies of persons with chronic illness and their family members to develop a stage model of relationship development

from the patient or parent perspective. In the model developed from these studies, families were seen to go through three stages of relationships with health care providers: naive trust, disenchantment, and guarded alliance. During guarded alliance, the family members formed reconstructed trust which varied along the two dimensions of trust and confidence to form four different types of relationships with providers. While this stage model may prove relevant for the population of parents and providers of interest in the present study, the focus in its development was chronic illness and the perspective was only the patients and family members, not the health care professionals. Thus, Thorne and Robinson's theory was not assumed to be relevant to parent provider relationships in the developmental treatment setting without further corroboration.

Differing Parent-Provider Perspectives

There is evidence that there are often discrepancies between what nurses and other providers of care believe to be client needs and what the clients themselves perceive. Many of these difficulties have been attributed to the different perspectives from which parents and providers view the situation. The following are some examples of this discrepancy.

In a study of 25 children with leukemia, their parents and physicians, Mulhern, Crisco and Camitta (1981) found that parents and children were more hopeful than physicians about the child's prognosis. What was of interest to note in this study was that the parents perceived the physicians to be as hopeful as themselves and the

physicians perceived the parents to be as "realistic" as themselves. Demonstrated differences between parent and professional perceptions were also found by Bradford (1991) using a survey approach to gather data from parents of 54 children with liver disorders. The questionnaire examined parental satisfaction with information and emotional support, the magnitude of emotional problems experienced by the parents, and the parents' opportunity to discuss their concerns. Parent responses were compared with estimates made by the staff in the clinic, including medical, paramedical and nursing staff. In comparison with parent responses, the clinic staff underestimated the psychological impact of the disorder and overestimated the opportunities parents had to discuss their worries.

Two studies have examined the difference between parent distress or adaptation and professional perception of parental distress or adaptation. Wikler, Wasow and Hatfield (1981) found that social workers underestimated the degree of upset parents experienced as the child grew older. Blackard and Barsh (1982) found that the providers in their sample magnified the impact of the handicapped child on the families compared to the information given by families. Both studies were weakened by not using parent-professional pairs who worked together.

In a study of ventilator dependent children and their families, Thomas (1986) used ethnographic style interviews to examine the experiences and views of seven families whose children were or had been ventilator dependent at home. Because of the

medical needs of their children, these families had intensive and long term involvement with health care providers which extended into their homes, sometimes 24 hours each day. There were many instances of differences between the family members and providers, both in the hospital and at home. Of particular interest to my research is the conceptualization Thomas made of the reason for these differences, which she labeled divergent paradigms. The parents and providers had difficulties because of their differing paradigms or life views on critical topics such as quality of life versus quantity (or length) of life. Parents and providers were totally unable to see each other's point of view in some of these areas. As a result, providers labeled parents, used controlling measures, and withheld information. Parents used various means to gather information from other sources and felt alienated from care providers. How these common processes evolved over time was not examined, but the importance of personal relevancy to the communication of parents and providers is evident here.

CHAPTER III

METHODOLOGY

Design

The design for this study was exploratory and interpretive. It was based on symbolic interactionism and used modified grounded theory methods. Grounded theory is a qualitative method which has been developed by sociologists trained in the Chicago school of symbolic interactionism. It was originally described by Glaser and Strauss (1967) and has since been expanded upon by the original authors and others. (Charmaz, 1990; Glaser, 1978; Strauss, 1987; Strauss & Corbin, 1990; Schatzman, 1992). The purpose of grounded theory is to develop substantive theory that is grounded in the empirical data. While there is no single, agreed upon method of grounded theory, this study used components of the method described by Glaser and Strauss (1967), Strauss (1987) and Schatzman (1992). These included (1) constant comparative analysis, (2) open, axial and selective coding, (3) dimensionalizing, and (4) memoing. Distinctive elements of the grounded theory method are that the data are concurrently analyzed as collected, the data are constantly compared to all data previously collected, and the content of the data drive the emerging focus of the study, including the sampling.

This study was also influenced by the constructionist perspective of grounded theory espoused by Charmaz (1990). This view of grounded theory emphasizes the interaction of the researcher with the data and the fact that the researcher constructs the analysis which is further based on the social constructions of the participants which are found in the data. This perspective departs from the idea of the theory being discovered within or emerging from the data. The perspective of the researcher is thus made more explicit within the analysis.

In keeping with the grounded theory approach, multiple data sources were used, including formal unstructured interviews with both parents and professional service providers, participant observation by the investigator in the treatment setting, and professional and lay literature. This practice of using multiple data sources is also called triangulation of data sources (Denzin, 1970; Mitchell, 1986). The purpose of this type of triangulation is to obtain a more complete picture of the phenomenon of interest by collecting data from diverse sources.

Grounded theory was selected as a useful method for this study because questions I wanted to ask dealt with participant interpretations of complex social processes and the influences these interpretations had on their communication with one another. Grounded theory methods enabled me to use many different types of data to answer these questions and it also allowed flexibility in following the lead of the participants as they told me what was important to them in regard to communication in

the treatment setting. In addition, the grounded theory method provided more structure than other interpretive field methods and was thus a useful heuristic for me as a beginning researcher with limited experience in field methods and analysis.

Pilot Study

Prior to the beginning of this study, a pilot study was conducted to explore the feasibility of interviewing both parents and providers and analyzing the interviews as paired with each other. This study was conducted over a six month period during which I wrote up the proposal, acquired Human Subjects Committee exemption, acquired approval of the agency, and conducted the interviews. The agency was a diagnostic clinic which evaluated children and made referrals to community agencies for treatment services as needed. I made contact with providers who gave me the names of three parents they had seen recently and whom they thought might be interested in talking with me. All three expressed interest in participating in my pilot study, but for various reasons, I was able to actually interview only one of them. I also talked with two providers, both of whom I interviewed. Although the pilot study was useful in many ways, I was not able to answer my primary question about the feasibility of paired interviews. Neither of the providers had more than a vague memory of their interactions with the mother I had been able to interview. Although their interactions had taken place within the previous few weeks, each of them had only seen this family once or twice and had seen a number of other families in the interim period. The

mother I was able to interview lived in the immediate vicinity and was more than happy to participate. The other two mothers both lived in outlying areas and had busy schedules transporting their children into the city for therapy services. One of them had been asked to speak as part of a parent panel for graduate students interested in working with children with developmental disabilities. We arranged to talk prior to that meeting, but she was late in arriving (after the other parents had already begun to speak), and I had to leave before the meeting was over. I made field notes on the comments made by the parent panel. The third mother I contacted was very interested in participating, but wanted me to videotape the interview because she had involvement in the deaf community and was therefore accustomed to signing and felt audiotaping was not adequate to capture all the nuances of interpersonal communication. There was delay in our arrangements while I explored this option, but funding and limitations of my Human Subjects approval precluded my using videotaping, and my time ran out before we were able to make contact.

The first provider interview was barely audible on the tape due to my inexperience and an inadequate microphone. The second provider interview went well and was transcribed without incident. The one parent interview went well and was transcribed without incident. Although the pilot study did not provide information to fulfill the intended purpose, it was a useful learning experience in other ways. First, I gained experience in the process of gaining Human Subjects approval, designing

consent forms and obtaining institutional approval. I also obtained better recording equipment and refined my procedures for audio taping. This pilot study confirmed for me that my interests lay in the area of communication during ongoing treatment rather than during the diagnostic process and I made the decision to conduct my study in treatment centers where the relationship between parents and providers was ongoing rather than a one or two time event.

Sample

The sample in this study was a convenience sample from two developmental treatment centers to which I had access. These centers were selected as pools of potentially available participants who fit the general criteria for the population of interest for this study. Data collection was done at the two centers sequentially, for ease of scheduling and to afford uninterrupted time at each center for participant observation.

Sampling in interpretive methodologies is based on obtaining "thick description" of the phenomenon of interest and not on representativeness of a population. Generalizability is addressed in regard to the concepts identified and relationships generated or experiences described rather than to populations. Sample size for grounded theory studies is typically determined by theoretical saturation of the data. That is, when the interviewer begins to hear the same information over and over, the data is considered saturated and sampling may be discontinued. The method of

determining sample size by theoretical saturation makes *a priori* determination of the size of the required sample impossible. The sample size estimated for this study for purposes of the research proposal was twenty-five participants, including both parents and providers. The actual sample size was 15 mothers and five fathers (representing a total of 15 children), and 14 providers for a total of 34 participants.

In the first center (Center A), which was the smaller of the two, letters explaining the study and a copy of the consent form for audiotaping were mailed or given to all parents except those who were excluded for some particular reason. The primary reason for exclusion was that the family was non-English speaking. Other criteria for exclusion were parents under 18 years of age, or child's disorders attributed to illegal drug use of the mother. At center A, children whose only disability was hearing impairment were excluded because there was no suspicion of cognitive deficit. Children who were seen only on a home visit basis were not included because of the travel time which would overlap with sessions of other families at the center. Parents were approached for participant observation by me based on direction by the therapist about which parents were available and might be good informants at the time I was able to be present at the center, or parents who had expressed an interest in my study after receiving the introductory letter. The participant observations were selected very casually, with the goal of becoming familiar with the center and how therapy sessions worked so as to better understand the context in which the parent and provider

communication process took place. In fact, all the parents whom I observed in therapy indicated that they were willing to participate in a taped interview, so this convenience sample became the basis for my sample at Center A. Of 13 families who were observed for at least one session, all indicated they would be willing to participate in an interview. Of these thirteen, eleven were asked to do an interview and agreed, and nine were actually interviewed. Of the eleven who agreed to an interview, one mother changed her mind when she was called for an appointment, and another rescheduled twice and was not home at the time of the scheduled home visit. Of the nine families who were interviewed, all nine mothers and three fathers participated. The children ranged in age from 15 months to 14 years and their diagnoses included mild and severe forms of cerebral palsy, mild and severe degrees of mental retardation, and spina bifida.

At the second center (Center B), which was larger and had more professional disciplines and a higher number of staff, letters were not given to all parents. This decision was made based on the high proportion of parents at Center A who were willing to participate after reading the introductory letter and the fact that time, scheduling and data saturation would not allow me to include all parents who might express an interest. I felt that parents might feel disappointed to have their expectations raised and then not be approached to participate in the study. At Center B, I met with the staff and shared with them my parameters for theoretical sampling and the constraints of my time schedule. In general, I wanted to meet more families

whose developmentally delayed child was younger (three years or less) and more involved (number and significance of delays) than those I had met at the previous center. The staff made a list of parents whose children generally fit these guidelines and whom they thought would be articulate and willing informants. During the first week I was at the center, one of the treating providers gave each of the designated parents my introductory letter, described my study briefly and asked if I might come in to observe. None of the approached parents declined to have me in their sessions. As at Center A, all parents who were observed at Center B indicated that they would be willing to participate in a taped interview. Ten families were observed for at least one session. The tenth mother was not approached because of the subsequent serious illness of her child. Of the remaining nine families, seven were approached for scheduling and were interviewed. From these seven families, two fathers participated in addition to the seven mothers.

Professional participants were those providing evaluative and treatment services to parents and children who participated in my study at the two centers. No providers at either center declined to participate or indicated any hesitation. Only one treating professional was not available for interview due to vacation and scheduling conflicts. Following the interviews, several providers indicated that they had enjoyed the interview, and found it "easier" than they had anticipated.

Data Collection Procedures

Participant Observation

As stated, participant observation was conducted at both centers prior to beginning individual interviews. This consisted primarily of observations of individual treatment sessions, but also included observations which occurred during my unscheduled time and between sessions in the hallways, lobby and offices. I was unable to participate in family conferences because none were scheduled for any of my informants during the time I was observing at either center. I did participate in a staff meeting at each center for the purpose of explaining my study and answering questions, and I also observed a formal interdisciplinary screening meeting at Center B.

Formal Unstructured Interviews

Formal, unstructured interviews were conducted with individuals regarding their communication experiences as a parent or a professional in this treatment center. The interviews with parents were done by home visit with two exceptions, while most of the providers preferred to be interviewed in a private room at the treatment center during unscheduled work time. All formal interviews were audiotaped and transcribed by a professional transcriptionist for subsequent analysis.

The interviews took from one-half hour to two hours each. I began by giving the participant some information about myself, including the fact that I have a daughter

who has mental retardation and that I have worked with many of the treating providers in the past. I assured parents that in spite of my past history with the center and its staff, I would not be sharing information between staff and families and that if they had any feedback, whether positive or negative, to give the providers, it would be their responsibility to do that in whatever way they chose. Several parents informally asked for confirmation of this confidentiality immediately prior to sharing concerns or criticisms of the providers with whom they were working or had worked. For example, one mother said, "...and this is confidential, right?" before she shared her dissatisfaction with a provider. Similarly, I emphasized to the providers that I was not able to discuss with them any information I received in interviews with parents. These issues are further discussed in Chapter V.

Initial questions were broad, as illustrated by examples below. As the study progressed, the initial questions continued to be broad in order to elicit each individual's experience, but subsequent questions during the interview were more explicit as data collection progressed. Re-interview was used in one case when requested by the mother, and in another case when requested by a provider. Both parents were interviewed in five of the 15 families.

Memos and Field Notes

Memoing is a practice of note-taking which goes on throughout the study and whose purpose is to document ideas about the analysis as they arise (Strauss & Corbin,

1990). Types of memos used in this study were theoretical memos, code notes, operational memos and field notes. These memos and notes were made in a small notebook as soon as possible following any data related activity and at any other time related thoughts came to mind. Memos were re-read and utilized throughout the data collection and analysis process and provide a record of the analysis. In addition, as analysis progressed, diagrams were also made as visual representations of thought processes. These diagrams were representations of relationships between concepts and of interactions between participants.

Theoretical memos reflected my thinking as I proceeded through data collection and analysis. Prior to the beginning of the data collection, I began the process of writing theoretical memos. The first set dealt with situating myself in relation to the study. These memos included my experiences as the parent of a handicapped child and as a professional providing services to young handicapped children and their parents. They also included a discussion of my beliefs about the communication process I was beginning to study. Situating myself in this way was helpful to me as I analyzed the data, allowing me to become more aware of my biases and reminding me to go back to my data for confirmation of my assumptions.

Code notes, written on the transcripts, represented the actual coding process. When I first began reading transcripts, I made many notes which essentially repeated what I thought to be interesting or significant selections from the data. As I went

further in the data collection and analysis, I began to develop provisional code labels for concepts in the data. As analysis continued, many of these labels changed or were subsumed under others. The transcripts were read over and over and further comments, questions and codes written on them. Clean copies of transcripts were also used as needed for recoding or gaining a fresh perspective.

Operational memos were written in regard to practical decisions and questions that needed further follow up or attention. They were generally recorded along with field notes or theoretical memos. They served as a reminder to me of the circumstance and rationale for decisions made along the way.

Field notes were made on observations and activities which occurred in the field. For example, I made notes regarding each of the therapy sessions I observed at each center. Observations made at the centers outside of therapy sessions and during interviews and home visits were also recorded in field notes for analysis concurrently with the transcribed data.

Professional and Lay Literature

As data collection and analysis proceeded at each site, review of the pertinent literature also continued. As the investigator, I attempted to become immersed in all available data having to do with the communication that goes on between providers and parents of young developmentally delayed children in the developmental treatment setting. When concepts, patterns or categories in the data brought to mind similar

concepts in the literature, I went back to the literature for comparison. One example is the concept of trust. Many of the stories told to me by the participants brought to mind the work of Thome and Robinson (1989) on reconstructed trust in persons with chronic illness. This example is discussed further in Chapter VI.

In addition to the professional literature, I also re-read some of the writings of parents of children with developmental disabilities. Again, these data were compared to those I collected during interviews and participant observation and are discussed in Chapter VI.

Protection of Human Subjects

Rights of human subjects were protected by the procedures outlined in the Human Subjects Application for the University of Washington. Participation in the study was voluntary and confidentiality was protected. A consent form was used for all participants who were audiotaped. (See Appendix A) The consent form explained the study and outlined the rights of the participant to withdraw from the study at any time. There were no expected benefits to participants in this study other than the opportunity to talk to someone who was interested in hearing about the parent's or providers' experiences. The only risk, stress or discomfort anticipated from participation in this study was the possibility of stress or discomfort associated with being observed, being recorded, or talking about any communication experience which may have been unpleasant or difficult. All participants were reminded of their right to withdraw from

the study at any time for any reason without penalty of any kind. In addition, for the parent participants, the service providers were asked for their input regarding any parents for whom they felt participation in this study might prove too stressful.

All providers at each center were made aware of my study and my intent to interview providers as well as parents. I emphasized that participation was voluntary and I did not assume any professional would participate until I asked her specifically. Because there were only one nurse and two social workers, all three of whom were employed by the same center, extra care has been taken to assure confidentiality in reporting data regarding interactions in which they were involved.

Data Analysis

Grounded theory procedures and techniques for analysis of data have been described in detail for researchers who are interested in learning the method (Strauss & Corbin, 1990). However, the actual process of data analysis is not a linear one. For that reason, the procedures which will be described briefly here did not occur in such an orderly fashion. Instead, the analysis was a back and forth process between inductive analysis using various procedures described here and a deductive return to the data to check out developing theoretical ideas.

Constant Comparative Analysis

The method of data analysis was constant comparative analysis. With this method, data is analyzed as it is collected and constantly compared to all data collected up to that point. Due to various time constraints, this method was modified somewhat. At Center A, the bulk of my time was spent in participant observation and the interviews were done in a compressed time period at the end. This resulted in more than one interview being done in one day on many occasions. Due to difficulties with transcription, the turn around time did not allow for analysis of each transcribed interview prior to continuing with the next. I attempted to modify these constraints by listening to the tapes prior to sending them to transcription, and by waiting for transcription of Center A interviews to be completed prior to beginning interviews at Center B. Time constraints did not allow for the same period of participant observation at Center B that I had at Center A, and again, the interviews were compressed into a short period of time to maximize the time available for participant observation.

Open Coding

Analysis of interview data begins with line by line reading of the first few transcripts for identification of any and all categories. These are written on the margins of the transcripts. This beginning process is called open coding or substantive coding. These initial categories then begin to guide further data collection. As data collection

proceeds, the many categories are compiled into groups and given conceptual names. The categories are then developed by identifying their properties and dimensions of the properties. That is, the characteristics or attributes of a category are identified and each characteristic or property is located along a continuum.

Axial Coding

The next step, axial coding, begins to draw relationships between the groups of categories. The concepts or categories are analyzed in terms of a paradigm which includes conditions, context, action and consequences. The paradigm then describes the phenomenon in terms of under what conditions and in what context it occurs; what action and interaction strategies are used to handle it; and what the consequences of it are. The concepts and categories can be arranged in different ways to form such paradigms and it is the task of the researcher to try different ones to best represent the patterns and complex relationships in the data.

Selective Coding

In selective coding, the next step in a linear depiction of the process of analysis, a core category is selected. A story line is developed that tells the story of the phenomenon of interest and is the core category. The core category is then related to the other identified categories, identifying linkages and verifying the linkages in the

data. During this time theoretical sampling is used to ask more focused questions and verify the categories that have been developed.

Trustworthiness of Data

Trustworthiness of the data is an issue which has long been addressed in positivistic methodologies by techniques intended to assure and document reliability and validity. Attempts to assure trustworthiness in interpretive methodologies have been modeled after positivistic techniques using analogous language (Atwood & Hinds, 1986; Guba, 1981; Kahn, 1993). Criticism has been increasingly leveled at the practice of using techniques appropriate for a positivistic paradigm to evaluate research conducted in an interpretive paradigm (Sandelowski, 1986; 1993). There is growing consensus that the techniques for evaluating research should be driven by the underlying assumptions and purposes of the methodology (Kahn, 1993). Various approaches to this problem are discussed in the current nursing literature (Kahn, 1993; Lamb & Huttlinger, 1989; Lipson, 1991). The following sections will discuss common current methods for establishing trustworthiness of qualitative data, provide a criticism of these techniques from the literature, describe an alternative approach, and indicate the reasons for my choice of the alternative approach for this study.

Credibility, Transferability, Dependability, and Confirmability

A way of looking at trustworthiness of data which is used frequently is that espoused by Guba (1981). Guba identified four categories of trustworthiness for research. These were truth value, applicability, consistence, and neutrality. Different strategies are suggested for evaluation of these categories for qualitative research than those typically used for quantitative research. These strategies for qualitative research are credibility, transferability, dependability, and confirmability.

Credibility represents the truth value of research. In qualitative research, there is the assumption of multiple realities, and thus the search is not for the single tangible reality, but for adequately representing the multiple realities of the informants. One way of testing this representation is by presenting the findings to persons who are familiar with the phenomenon being studied to see if the findings are recognizable to them. Ways of accomplishing this include having participants or others who have experienced the same phenomenon review the findings, or having a panel of experts in the field review the findings.

Transferability represents the applicability of the findings. This means that the findings fit into contexts outside the study situation. This is determined by the similarity or goodness of fit of the two contexts and is determined by the reader based on information supplied by the researcher. This is also an example of the idea that a

qualitative study may be generalizable in terms of its concepts rather than in terms of the population studied.

Dependability refers to the consistency criterion. Repeatability is not expected in qualitative research as it is in quantitative research. Instead, there is the expectation of variability and an attempt to represent the range of variability. The strategy of dependability relies on the trackability of this variability. The variability is described and attempt is made to account for the source of the variability.

Confirmability is the strategy in qualitative research which attempts to account for neutrality. In quantitative research, this neutrality refers to the researcher. In qualitative research, it refers instead to the data. It is said to be met when the first two criteria of creditability and transferability are met.

Critique of Trustworthiness Approach

The criteria for evaluating the trustworthiness of data outlined for qualitative research by Guba (1981) and Lincoln and Guba (1985) are modeled on techniques used for quantitative data. While they address some of the issues and attributes of qualitative research, such as the assumption of multiple realities, using a format designed for another paradigm seems awkward and unnecessary. For example, Guba identifies four categories, or criteria for trustworthiness. The third one essentially says that it is met if the first two are met. This seems contrived and tautological.

Two common methods of documenting reliability within this framework (credibility or truth value category) in interpretive research are member checking or submission of portions of the analysis to participants for their confirmation, and submission of selected portions of the data to a panel of experts for comparison of their coding with that of the researcher. Sandelowski (1993) criticizes these practices as possible threats to validity on the basis of inherent aspects of the interpretive paradigm.

Of primary importance in her argument is the fact that interpretive research assumes the existence of multiple constructed realities rather than one reality waiting to be discovered. There is an art to qualitative research which addresses the essence of the phenomenon and defies attempts at scientific replicability (Sandelowski, 1993). The revisionist nature of narrative means that the stories told by research participants may change from one telling to the next as the act of telling produces different interpretations. The discursive act of narrative has many purposes, some of which may be to find order and meaning in the events described. This may account for the therapeutic nature of participation in research described by some participants. For example, Thomas (1986) found that the parents who participated in her in depth interviews regarding their experiences in their homes with children who had been or were ventilator dependent found the interview to be therapeutic to them.

Sandelowski (1993) illustrates these points with the example of the practice of member checking in qualitative research. Participants asked to do member checking

may not remember some things they said in the original interview, or they may feel differently about them and wish to change what they said. The theoretical conceptualizations made by the researcher from her or his scholarly point of view and scholarly purposes may not make sense to the participant or may include realities not part of that person's experience. If the participant disagrees with the interpretations or conclusions of the researcher, or feels they were misquoted or misunderstood, he or she might wish to have his or her data withdrawn from the study or changed. Thus, the use of this technique for increasing trustworthiness may place the researcher in the position of making difficult decisions, thus having unintended ethical and moral consequences for the researcher as she decides whether to alter or eliminate data disputed by the participant, possibly compromising or changing the conclusions of the study

Alternative Approaches to Trustworthiness

Current discussions of validity or trustworthiness that attempt to be more reflective of the assumptions of the interpretive paradigm frequently include the term reflexivity (Lamb & Huttlinger, 1989; Lipson, 1991). Reflexivity is a method of critical thinking which examines and reflects upon the ways that the researcher and that which is being researched influence each other. The sharing of this type of critical thinking with the reader of research reports is intended to provide a means for the reader to evaluate the trustworthiness of the data.

This practice of accounting for trustworthiness by discussing reflexivity is, however, criticized by Kahn (1993) who argues that a better way of discussing validity is in terms of relationships. The relationships he identifies as important are the relationships between the researcher and the participants, the researcher and the data, and the researcher and the reader. By providing this information, the researcher accounts for the relationships which are 'at the heart of the qualitative process' (Kahn, 1993, p.124).

Rationale for Choice of Method

I chose to utilize the concept of reflexivity to address the issue of trustworthiness and to discuss reflexivity in terms of the relationships suggested by Kahn (1993) because I believe this to be the most contemporary and comprehensive approach consistent with my view of the symbolic interactionist framework. These relevant relationships will be discussed at length in Chapter V, which will, in addition to the detailed descriptions of methodology in Chapter III and the extensive illustrations from the data in Chapter IV, provide for the reader the basis for judging this study for its trustworthiness and applicability in clinical practice.

CHAPTER IV

RESULTS

Introduction

This chapter will present the framework for a middle range substantive theory of Striving for Therapeutic Relationships Within a Context of Uncertainty by parents and providers in developmental treatment settings. The results of the study were informed by the parents and providers themselves as well as the researcher's observations and interpretations and reference to professional and lay literature. The first sections of this chapter will situate the study in terms of settings, time frame and participants, and present the framework that was developed from the data. The framework is illustrated with the words of the informants. Throughout this chapter, descriptors may be slightly altered as necessary to conceal the identities of the participants.

Situating the Study

The data from this study were obtained by the investigator from parents and providers in two different developmental centers and in the homes of parent and provider participants. This section will provide demographic descriptions of the

children in treatment, their families and the providers, as well as descriptions of the settings for data collection.

The Participants-Description of the Sample

The Families

There were 15 families who participated in this study by allowing me to come into their treatment sessions and their homes, and by talking to me about their experiences as parents bringing their child to therapy and communicating with the service providers. With one exception, the families were all couples, and with two exceptions they were the child's birth parents. One mother was not living with her child's father and functioned as a single parent. A second family had received their son shortly after birth for adoption. After his illness with severe neurological insult which occurred during the first six months of life, they chose to maintain foster parent status rather than proceed with adoption. A third couple were raising their grandchild who had lived in their home since birth and for whom they had had total responsibility since the accident that caused his neurological damage. The number of siblings living in each household ranged from none (two families) to three (two families).

The Children

The children in this study ranged in age from 18 months to 13 years with nine of them being less than three years old and five being between three and 13 years. The

most frequent diagnosis was cerebral palsy (ten children) from a variety of causes and with varying degrees of severity and associated problems. The other diagnoses included spina bifida, global developmental delay, and speech delay. Children had been in treatment at their respective centers for time periods ranging from several weeks to three years.

The Providers

The 14 providers participated by allowing me to come into their treatment sessions and watch them as they did their work and by taking time from their busy schedules to talk to me about their experiences. The disciplines represented by the provider participants at the two centers included one nurse, two social workers, four occupational therapists, three physical therapists, and four speech pathologists. Their years of experience ranged from two to 20 years with ten of the 14 providers having at least ten years of experience in pediatrics and all having at least two years experience in pediatrics. In addition, ten of the 14 providers had children of their own.

Description of the Context

Settings

The first site for data collection, Center A, was a private, for-profit therapy center which offers occupational, physical and speech therapies. The therapists are partners in the business and occasionally hire other therapists on an as needed basis.

There is a secretary/receptionist who also does billing and sometimes helps with funding issues. There is also a baby-sitter who provides child care for the therapists on an as needed basis at the center. The center provides a wide range of funding options, including private insurance, private pay, DSHS, and Children With Special Health Care Needs, and is a preferred provider for some insurance plans. The therapists schedule their own evaluations and manage their own funding arrangements for each of the families they see.

Center A is fairly new and was designed and decorated for its current use. Parents are asked to leave their shoes in the lobby as a means of keeping the carpet cleaner for the children in the treatment rooms. There is one large therapy room which has hooks on the ceiling for various swings and hammocks used in therapy. There are large floor to ceiling mirrors on two different walls, large balls and pillows, and a plastic one room playhouse. The room is large enough to be used for two sessions at once. Four other rooms open off this larger room. Three of them are small treatment rooms. Two have mirrors on one wall and are used primarily for motor therapies and the third has a small table and chairs and is used primarily for speech therapy. The fourth room is the baby-sitting room and is staffed by a sitter who cares for the children of the therapists. There is no child care provided for siblings of children being treated. It is necessary to go through the large treatment room to get to any of these four smaller rooms. In addition to the lobby and treatment rooms, Center A has a small

staff office, a bathroom with a diaper change area, and a small kitchen/toy storage room.

The second site for data collection, Center B, is an outpatient clinic of a non-profit community hospital which is also a Level II Neuromuscular Center for Children with Special Health Care Needs. Center B offers nursing and social work services as well as occupational, physical and speech therapies. In addition, Center B is affiliated with a pediatrician in the community who acts as medical director, as well as other community physicians who consult for diagnostic clinics. Center B has a service coordinator who receives the initial referrals to the center and makes all funding arrangements for the families. There is also a staff person who provides childcare and activities for siblings on an as needed basis when she is available.

Center B is a much larger facility. It was designed for another purpose and has been adapted for its present use. While it is not as new or conveniently arranged, effort has been made to make it pleasant and functional. Center B is on two levels. On the main level, there are the lobby, main office and reception area, staff and public bathrooms, conference rooms, staff office, two treatment rooms with toys, swings and mirrors, one treatment room with a table and chairs, and an evaluation and testing room. Downstairs there are more staff offices and a large treatment room with large ball, pillows, swings, ramps and riding toys. In spite of the larger size of Center B,

there is often a feeling of limited space due to the amount of equipment stored in the rooms and hallways.

Center A is basically smaller and has fewer disciplines and services than Center B. Both centers are set up in a similar manner, with a lobby, staff offices, treatment rooms with various equipment and toys, and a public bathroom. Both have storage for toys and games, feeding equipment and snacks for the children, and linens such as sheets and towels and cover gowns for staff. The lobby at Center B is larger and has a small kitchen area with coffee and tea, as well as a well equipped and fenced play area for children. There is a cabinet where parents can leave used children's clothing and select items for their children free of charge. Center A does not provide coffee for parents. Both lobbies have magazines for parents to read, children's books, and bulletin boards with information and articles of interest to parents.

Time Frame of Study

I was a participant observer at Center A for eight weeks from mid October to mid December 1993. Taped interviews were conducted with participants from Center A during the last part of January, 1994. I was a participant observer at Center B for the first three weeks of February of 1994 and conducted interviews with Center B participants during the following two weeks.

Striving for Therapeutic Relationships Within a Context of Uncertainty

The core process identified as a result of this study was Striving for Therapeutic Relationships Within a Context of Uncertainty. Parents and providers in developmental treatment centers are brought together in a unique situation for the ultimate purpose of improving the life of the child who has developmental delays or disabilities. The stated goals of the intervention are to provide direct services to the child in the form of therapy and to the parents in the form of education and support. The general philosophy is that the intervention is family centered and that some degree of follow-through by the family at home is necessary for the best outcome for the child. Stated and assumed goals of parents are to find what the child's problem or problems are and to get help in ameliorating them. These collective goals are pursued in a pervasive atmosphere of uncertainty for both the parents and the providers. The relationships that develop between parents and providers during the frequent and extended contacts of developmental therapy are formed at a time of increased need and vulnerability of the family members and are significant in their lives. These relationships develop through parent and provider communication in the situation of the treatment sessions. The findings of this study reveal the complexity of the communication process and how the participants make meaning of the interactions which then guide their further communication and interaction.

Table 1: Axial Coding of the Core Phenomenon

Core Phenomenon

Striving for Therapeutic Relationships Within a Context of Uncertainty

Conditions

Identification of Child Delays

Referral for Treatment

Context

Uncertainty

Intervening Conditions

Differing Parent and Provider Perspectives

Change Over Time

Action/Interaction Strategies

Balancing Competing Needs

Balancing Competence and the Need for Intervention

Balancing the Here and Now and the Future

Balancing Parent and Provider Roles

Questioning

Reading the Cues

Managing the Sessions

Managing Uncertainty

Consequences

Parent-Provider Relationship Perceived as Therapeutic

Child-Provider Relationship Perceived as Therapeutic

Parent Perception of Competence in Parent Role

Provider Perception of Competence in Provider Role

Changes in Child Competence

Overview of Striving for Therapeutic Relationships

Within a Context of Uncertainty

This section will briefly outline the paradigm for the core category of Striving for Therapeutic Relationships in a Context of Uncertainty (See Table 1, page 58). The paradigm consists of conditions, context, intervening conditions, action/interaction strategies and consequences for the core category.

The conditions for Striving for Therapeutic Relationships were the Identification of Child Delays and Referral for Treatment. The particular developmental problems of the children and the experiences parents had with the health care system during Identification and Referral prior to coming to the centers varied widely. Most parents came to the treatment setting with little idea of what to expect. What they found usually differed sharply from health care situations they had experienced in the past. The weekly sessions in which at least one provider focused exclusively on them and their child and on offering services to meet their particular needs were generally seen as a very positive situation. Many parents identified the relationships developed with the providers as therapeutic to themselves as well as their children.

Regardless of the nature of the child's delays and the mechanism of referral, however, there was a pervasive context of Uncertainty. For the parents, there was Uncertainty surrounding the diagnosis and prognosis for their child as well as Uncertainty about the nature of therapy and the competence of the providers. Parents

also expressed Uncertainty in terms of their new roles as parents of a child with special needs and their abilities to deal effectively with the health care system. The uncertainties about the diagnosis and prognosis for the child tended to decrease with the passage of time, but were not completely resolved for any parent in the study. For providers there was also Uncertainty regarding the diagnosis and/or prognosis for each child, but their professional experience and expertise gave them a better idea of the range of possibilities for a particular child. In most cases, the Uncertainty expressed by the providers was more pressing in regard to the parents and their level of knowledge of, and concerns about, their child's condition, their desire for technical information about the child's condition and where they might be in the grief process.

The intervening conditions in Striving for Therapeutic Relationships were identified as Differing Parent and Provider Perspectives and Change Over Time. In most cases, parents and providers were able to view the situation from only one perspective. Providers didn't have experience parenting a child with disabilities and in some cases, were not even parents themselves. Parents generally had no experience in working with disabled children, although several of the mothers had nursing backgrounds. Both parents and providers tried to see the situation from the point of view of the other with varying success. Change Over Time occurred for parents, providers and children. Regardless of the child's developmental changes, however, the passage of time revealed more of what could be expected in the future. For parents,

needs and concerns changed as the child changed and as they gained information. For parents and providers, the relationships grew and developed. Providers also reported changes in their own attitudes and approaches over the years of their careers.

Five main strategies for action/interaction in Striving for Therapeutic Relationships were identified which were utilized by both parents and providers in their communication in a variety of situations. These were Balancing, Reading the Cues, Questioning, Managing the Sessions, and Managing Uncertainty. Balancing involved balancing various options for interaction between parents and providers. This balance depended on meshing of the personal philosophies and styles of the parents and providers. Balancing strategies included Balancing Competing Needs; Balancing the Here and Now and the Future; Balancing Competence and the Need for Intervention; and Balancing Parent and Provider Roles.

Questioning and Reading the Cues took place throughout the balancing process. Questioning was utilized by both parents and providers and involved not only the asking of questions, but also evaluating the questions asked, evaluating the answers to questions, evaluating the response to question-asking, and questioning of self. Reading the cues was also utilized by both parents and providers. They included not only concrete observations about facial expression, tone of voice and questions, but also getting "a feel" for how the other was responding. Providers were vigilant for cues from parents about their needs and preferences in regard to the child's treatment

program and abilities. Parents were vigilant for cues about how the provider interacted with their child, whether the provider seemed knowledgeable and competent, and whether their roles as parents were respected and their needs and concerns heard. All these strategies of parents and providers were carried out in the treatment sessions for the child and were part of the development of the relationship between the parents and the providers. Management of the sessions by the providers (Managing the Sessions), and management of uncertainty by both parents and providers were the other categories of Action/Interaction identified.

Consequences of Striving for Therapeutic Relationships had to do with parent and provider feelings of success and competence in their roles (Parent Perception of Competence in Parent Role and Provider Perception of Competence in Provider Role), and parent and provider feelings that the relationship was therapeutic for child and family (Parent-Provider Relationship Perceived as Therapeutic and Provider-Child Relationship Perceived as Therapeutic). Obviously, changes in the competence and abilities of the child (Changes in Child Competence) were important aspects of the therapeutic value of the relationship, but this was variable, depending on the child and his or her potential for change and parent and provider perception of this potential. Some parents identified the relationship with at least one provider as therapeutic for themselves, but not all of them identified this as an important aspect of their relationship with the providers. The family focus of both centers was identified as

positive and helpful. The nurse at Center B was particularly mentioned by several families as helping them to keep a family focus.

In the following section, each part of the paradigm will be discussed in detail, utilizing direct quotes from study participants as illustrations and examples. Quotations will be labeled “KW” for the researcher, “Pr” for any provider, “Mo” for mothers, and “Fa” for fathers. Foster parents and grandparents who are parenting the child will be referred to as if they were the mother or father to conceal their identities.

Conditions for Striving for Therapeutic Relationships

Identification of Developmental Delay and Referral for Treatment were conditions for Striving for Therapeutic Relationships in the developmental treatment setting. For many parents, the two conditions of Identification and Referral occurred in close sequence. For others, there was some period of time between identification of a problem and referral for treatment. A period of delay between the time concerns were raised and the time diagnosis and treatment were initiated was usually an uncomfortable situation for parents because of the delay in getting definitive information and beginning intervention.

Mo: We started [children’s hospital], the neurologist evaluated him thoroughly, said, "He's got hemiparesis, a form of cerebral palsy. He probably will not run. He may have trouble walking. He may not speak." She just listed off a whole bunch of things and it was a devastating moment in our lives, but we felt like this sounds right. This makes sense. It's what we've seen and it felt, we felt like we finally gotten some answers. And she put us through, you know, speech eval, hearing eval, everything. So we had a ground basis, some place to start.

Whereas the occupational therapist that we were seeing once a month at [other hospital] said, ... we had raised questions, "Oh, he's too young. We can't tell you." You know, "That's just spending a lot of money to evaluate him." She just didn't listen and didn't take even the slightest concern. We would have had a really huge concern and we would state it as you know kind of put a flare out or test her on how she would respond. And it's hard to put your foot down as a parent and say this is what I want done if the therapist is in any slight way questioning or not drawing you out. (11101)

Children whose parents participated in this study had a range of delays, but were more representative of significant delays than mild ones. The source of the initial concern about the child's development and the age at which the concern was raised varied in these families. Three children clearly had problems at the time of birth and were referred for treatment early. Three other children had catastrophic events or illnesses after the time of birth and were also referred right away for treatment. Three children had difficulties at the time of birth which raised suspicions, but did not demonstrate delays or disabilities until they were nine months or older. Concerns were identified for these children by health care providers at follow up visits, and referrals made. Two children had an illness or event in the first year of life, but no immediate concern was raised. One of them was identified at a routine follow-up visit and the other was identified only after great persistence of the child's parents. The remaining four children had developmental difficulties which became apparent gradually and for no apparent reason. All four of these children had initial concerns raised about their development by their parents. Thus, nine of these 15 children began treatment during

the first year of life, five by the second birthday and one at age three. Some parents Sought services for their child, some Accepted the referrals made by health care providers, and one actually Resisted referral.

Parents of a child with spina bifida were told therapy was not needed until the child was one year old, but the parents did not want to wait and Sought services at three months. One child with significant cerebral palsy was not diagnosed and referred until nine months of age when his mother Sought a diagnosis from her pediatrician. The pediatrician referred to a specialist, who immediately diagnosed cerebral palsy and referred the child for therapy. In spite of suspecting that something was wrong and insisting on further evaluation, this mother had difficulty hearing the diagnosis.

Mo: Yes, before, when, before he was nine months old and I stood in the doctor's office and said, "Hey, I'm not leaving because I know there's something wrong and you're not telling me." I didn't even have a doctor's appointment the day that I went in and [child] was, the day that Dr. [Pediatrician] saw him and said that, "Okay, there may be something wrong." I didn't even have an appointment. I just came in off the street, and I said, "You know what, I'm not leaving here until you guys look at him. There's something wrong." And then I was still, you know, shy. I was scared. I always felt that, hey, doctors know it all. They go to medical school for twelve years or however many years. They've got to know more than I do, and so that's how I felt the first nine months was he knows what he's talking about. He's the doctor, he's the one with the degree, and then even when I got to [the children's hospital] the first time around, I kept thinking, well, you know, he's the Chief of Staff here at [the children's hospital]. He must know what he's talking about. Because when he first told me that [my child] had athetoid cerebral palsy, I pretty much just called him a liar. (12106)

KW: Dr. [Specialist]?

Mo: Yes. Like, "Well, how do you know? You don't even know my son. How do you know that?" (12106)

Fa: Actually, we walked out of Dr. [Specialist's] office, and she looked at me and she goes, "Well, he said [Child] doesn't have cerebral palsy, right?" And I just looked at her and said, "Who were you talking to? He was really clear, both him and the nurse that was in there were very clear that [Child] had cerebral palsy." (12206)

One mother whose child has speech delays and mild cognitive delays was not able to get her child evaluated and referred for services until he was three years old, in spite of having communicated her concern to a health care provider before the child was two years old. [sought services]

Mo: Well, when [my son] was about 2 years old I asked my general practitioner about his speech and I was concerned at the time. And the general practitioner said just to wait, "Let's see what's going on. There's nothing wrong with him." Well when he came to three and he still wasn't talking, we ended up having him tested. We actually took him to, I ended up taking him to a pediatrician because I didn't like the answer from this general practitioner because I thought there was something wrong when he's not even saying one or two words at three years old. So we took him to a general practitioner -- a to a pediatrician and he recommended us to go have his hearing tested. And then we ended up having him tested through the [school district] in their special preschool classes. And the test came out that he was pretty much below of where he should be. He was about a year and a half behind where he should be in speaking. And because he was so shy that was another disadvantage because we weren't really sure whether he was just not talking because he didn't want to talk to someone strange or he didn't have the ability. His hearing was O.K. The test came back on that. So he was in the preschool when he was 3, 4 and 5, and then when he was 6, we dual placed him. He was in the kindergarten program with [school district] that has special needs kids and he also went to a regular kindergarten class....But I do feel, and I have been angry about is that the general practitioner didn't think anything was wrong at two years old, because I felt that if we had started him then instead of waiting another year that things would have been better. You know, you start it

earlier and start working; the earlier you start the better it is for the child. So. But since that was the first time I had ever confronted a problem with a child, that I just assumed that the doctor knew best. (11106)

On the other hand, another mother, whose child has global developmental delays and sensory integration problems, resisted taking her child for the recommended evaluations and therapy for several months.[resisted services]

Mo: The first time he smiled at me I screamed. He was old, I mean, he was like six months old when he smiled at me, and I scared him so that he didn't smile for days, but anyway. And when they first told me to come, the doctor told, recommended therapy, [Pediatrician] did. I didn't want to come. So then she kept saying I should go, so finally I called and I talked to [the therapist] and [she] recommended that I come in and I still didn't want to go. And I was interviewed and he was evaluated and I still didn't want to come. But then a couple of weeks later, I thought, well, okay, we'll try this. And then we started out two days a week, and [the therapist] was really good because she would deal with him even when he was crying. She would just keep going, you know what I mean? (11107)

After this child was established in motor therapy, speech therapy was also recommended, and his mother also resisted that.

Pr: Umhm, and it was real hard for her to accept a speech therapist coming into the session. It took an evaluation and then about, I think, when they did the eval, I think, I can't remember, us talking back and forth just kind of going through and just because she's chitty chatty, but it took probably about eight months. (21304)

Consequences of the identification and referral process were three-fold. First, the process affected how early the child was referred for treatment. Second, it affected the expectations and feelings the parents brought with them to the treatment situation.

Finally, knowledge of how the referral process had gone affected how the providers at the center viewed and interacted with the parents. For example, knowledge that parents had changed physicians sensitized providers to be more “careful” of doing anything to upset them.

KW: ...So there's one that you feel like they don't want to hear it and they need to cling to the positive stuff. And one that you can be really comfortable saying things, and I'm trying to figure out how you know that.

Pr: I think that it's just really different personality styles, and I think that it's from what the family asks for and what they say. And I think facial expression and avoidance of answering questions directly.
(21304)

KW: Umhm.

Pr: I think the [Browns] give us very, well, very clearly I think to [primary therapist] at first when they started firing a couple of doctors that gave them a diagnosis that was not okay with them, I believe?
(21304)

Thus, the provider felt that the family “firing” doctors was a message not to tell them anything they didn’t want to hear. In talking with the family, the reasons seemed to have more to do with how the information was given than the diagnosis, per se.

Context for Striving for Therapeutic Relationships

Uncertainty was identified as the Context for Striving for Therapeutic Relationships. The concept of Uncertainty was dimensionalized as Parent Uncertainty and Provider Uncertainty. Parent Uncertainty was comprised of lack of information

about the here and now and the future and lack of trust or confidence in the providers as competent and in oneself as the parent of a special needs child. Provider Uncertainty was comprised of uncertainty about the parents and their concerns and needs and uncertainty about the child and his or her diagnosis, prognosis and treatment needs.

Parent Uncertainty

Lack of information about the here and now . All families wanted help for themselves and their child but few of them had any idea of the nature of therapy for a young child. Most families came to the center with very limited ideas of what to expect from therapy. One mother said,

Mo: And in the hospital I didn't know we were going to be doing all this stuff. I had no idea what we were doing when we came home. I never knew therapy existed like this. (12102)

Another expressed her fear about therapy.

Mo: And so then at that point they said that she would be going to therapy and I was really nervous about it at first because I didn't know what they did. I'd never been around a special needs child. (12107)

One problem many parents had was difficulty in identifying what, if anything . the therapist was doing that was therapeutic. Many parents described this as a problem they had in the beginning that was alleviated as they learned more from asking questions and watching what the therapist did. Therapists were aware of the confusion produced by the fact that therapy looked like play and attempted to explain what they were doing and why. One therapist described the rationale for the playful approach:

Pr: ...because we're pediatric physical therapists, you know, the child needs to be engaged in a playful situation. You know, we're not the kind of physical therapists who have to do a treatment on a non-compliant patient where if you were working, say, in wound care or burn care or, there are times when a physical therapist might have to impose their treatment on a screaming, fussy child, you know. And, you know, with developmental therapy, that's totally against what we're trying to accomplish...I just feel that that goes contradictory to anything I know about motor learning and how children develop, so that's not my style of practice. (22205)

Another mother was concerned early on, but asked questions and began to be able to identify for herself what the goal of the therapist was in a particular activity.

Mo: There was a lot of times when I thought [therapist] wasn't doing anything, and then she would talk and say, you know, "Look at how she's doing this or that" and I'm going, "Oh well, she's observing [child] and watching things to work on" you know. You know, I didn't know that at first and I was thinking "How come she's not doing anything?" you know. But she was. And I, even if I wouldn't have asked [her] about that, I think there probably are people that probably think that the therapists aren't doing anything but they really are, you know. (12107)

Lack of information about the future. Parents varied in the degree to which they discussed the future for their child. Some preferred to take one day at a time, while others asked the tough questions and wanted to know. Those who took one day at a time did not discuss the future or discussed it as if it were going to be perfectly normal. They did not ask questions about what the child would be doing later.

Lack of trust in providers as competent. Once parents decided the therapists were knowledgeable, they tended to trust that the therapists were doing something useful even if they couldn't identify what the ultimate purpose was.

KW: So has it been pretty easy for you to see what [speech therapist] is doing?

Mo. Umhm. She talks like when she's working with utensils and things like that, she tells me what she's doing. Like "I'm looking for her tongue to do this and this" and I really don't know why her tongue needs to do what she's trying to get her to do, but that's okay. I know there's a reason there. [Speech therapist] is doing this for a reason. Eventually it's all going to come together, you know. (12107)

Another mother still has difficulty understanding what goes on in therapy. Her son started therapy at age nine months and is now almost two. This parent's trust in the therapist seems tentative, in spite of the good things she had to say about the therapist.

Mo: I've been very happy with [therapist]. My personal experience is, at first, because I didn't know what therapy was all about, I thought, "So what is she doing with him? So they play games and they throw balls, and so what? How is this going to make my son any better?" That was my first impression. And then for, he was eighteen months old before he started doing anything. I mean, he used to just lay on the floor and cry twenty-four hours a day. (12106)

KW: So did you come to a point where you could see that what [therapist] was doing, or did you ask about that?

Mo: I ask, and she, you know, answers me. Sometimes I'm not pleased with the answers that she gives me, but I just wait it out, and then the end result is, hey, [child] can write. [Child] is able to hold still and put a puzzle piece in a puzzle. So even though I'm not happy with what she's doing at the time, I don't ever say, "Well, I don't think you're doing this right", because I don't know. But the end result is now he can put puzzle pieces in a puzzle." (12106)

This parent, who expressed her early skepticism about therapy (discussed above), now expresses trust in her therapist which sounds unreserved.

KW: Did you like have a, see a need for speech before she [the speech therapist] came? Or how did that, were you concerned about speech or oral motor things or was it [the motor therapist]? How did they sort of decide that?

Mo: Well, that's a hard question because I knew that she wasn't talking at where she should be, you know. She's only two but she should be saying more words than what she says. But I really wasn't all that concerned about it until [the speech therapist] came and started teaching her things, and then I kind of opened my eyes to think she really does need to start communicating even though she can't talk, there's other ways of communication. And I really wasn't, my eyes weren't really open to that aspect of her life then until [the speech therapist] came and said, you know, we need to be doing these kinds of things. (12107)

KW: So you agreed to have her come without really sort of knowing or having that much of a concern about what she was going to do.

Mo: Yes, yes, because I think [the motor therapist] knows, I think [she] knows better than I do what [my child] needs because she's the professional in this field, you know. I could tell her if her [car needs to be tuned] or something, but, you know, this is where her expertise comes in. I don't have any in this field. (12107)

Lack of trust in self as parent. Parents expressed varying degrees of trust or confidence in themselves as parents of a child with special needs. This lack of confidence in their own competence in this area made it very desirable to be able to trust the provider to know what was best for their child. In many instances parent descriptions of trust or lack of trust in the provider was paired with comments about their own competence in the matter, as in the above example.

Provider Uncertainty

Provider uncertainty about parents. Providers had uncertainty about the parents in regard to where they were in their understanding of the child and in their readiness to be involved with treatment. This uncertainty was at a maximum when a new family began treatment. One provider said:

Pr: I've just started with this new family and I don't know her at all and I'm still trying to feel out kind of where she is and what she's been told and what she believes, how much she's ready to talk about, you know. (21102)

Providers talked about trying to "get a sense" of where parents were or "get a feel".

Early in the relationship, they did more formal asking in regard to concrete areas, such as the form in which parents would like to receive information, and whether they found written materials, pictures, verbal descriptions helpful. This provider describes how she explores learning preferences with new parents.

Pr: For different families I do pretty different stuff. For those families who, I think, and I don't really know how I get this feeling, but I have the feeling that they want info or they don't all want info, or they have access or they don't have access. It usually just in the very beginning is when I talk more about what resources I can give them or lend them books or articles and stuff like that. (21205)

KW: So you actually talk to them about that.

Pr: Yes, I usually ask if they like reading stuff, if that's helpful, or if they don't do so well, or if they don't enjoy reading or they don't find written information helpful, or whatever. And if they say that they like written information, then I will say, "Well, I have a number of books or a number of articles, and I'd be glad to lend you any of them," you know. "Would you be interested in that?" And some do and some aren't, and some say, "Well, not now but maybe later." I'm not very

good at following up on that, though. I don't think I do that very frequently unless it comes from them. But in terms of talking about what I'm doing, I try pretty hard to make sure that a parent knows basically what I'm working on and why, and to talk fairly technically about what I think the child needs and what we need to focus on. But that may not continue throughout the time they're in therapy. I mean, I have some families who I certainly talk about that a lot with in the first few sessions, and then don't talk a lot about what I'm doing. More often with families like that, I will talk about what I see the child doing. "Oh look, he's standing, she's standing on that leg now for a lot of time without me having to shift her weight over there. She's doing that herself. Can you see that?" Or "Can you see, oh look what she's doing here," you know. "She's stepping up with the right foot instead of the left foot. That means that she has better balance on the left foot now", and making those kinds of observations about what the child's doing. And there's some parents who I explain everything of what I'm doing. I think of like [parent], I'm quite technical, or I have been at least in exactly what I'm focusing in on and why and talking about what the techniques are and what the techniques are supposed to do. And partially I think that comes from, you know, a parent who's responsive when I talk about anything or who asks questions, and if I have that experience a few times, then that just encourages me to being more communicative about it ongoing without them having to ask very much. There's certainly parents who say, to me "It doesn't matter what you're doing, just do what you're doing," you know. And those are generally, I think, more of the parents who would just rather talk and not talk about, they don't find it interesting to talk about what's happening actually with the child, but are more chatty about other things. And then there are parents that you can't read, or I feel like I can't read at all, and I have no idea if in fact they want more information or less information, and I don't have a good sense of what's helpful and what's not. And with those people, I just tend to ramble on and on, probably much more than I should, about what's happening with the child and I have no idea if it's of interest to them or not. (21205)

This therapist uses questions and offers information, but she also looks for cues such as the responsiveness of the parent and the questions they ask in determining how much information they want.

Provider uncertainty about child. Provider Uncertainty about the child was in regard to the child's abilities and temperament as well as his or her diagnosis and prognosis. Whether the child was irritable and how much he or she would tolerate being handled was critical to how the sessions were managed and how the providers related to the parents. If the child did not give clear cues in response to interactions and handling, the providers enlisted the help of the parents in reading the child's cues or states. There was a back and forth interaction between the providers getting help from the parent in reading the child and the parents getting support from the providers in living with a difficult child.

KW: I mean, I've just been in a few sessions but I hear you sharing that. "This is what I had in mind" and I heard you doing that. "This is what I'm doing, this is why I'm doing this."

Pr: Umhm.

KW: "What do you think about how he's reacting to this?"

Pr: Umhm. With [child] in particular, I ask [his mother] quite a bit. Or I'll tell, I'll tell [child's mother] what my observations are and how I'm interpreting them about his behavior. He's a really different little guy in terms of being able to read his cues. One of the most challenging I've worked with in terms of really being able to read his cues. Because so often, you know, for a very long time he would look irritable and upset, and our style is sort of like to try to help him regroup. And [child's mother] would kind of bring in that "Why did you stop doing that. He enjoyed it, he was liking it." You see, and we were like totally, well, I

thought he was having a miserable time and mom thinks he's doing fine with it, you know. So my strategy to help with that communication was to bring her in, "Do you think [child] is enjoying this?" or do you think, you know, what do you think, you know. And I learned to ask her because at least we all need to be in agreement that it's working or it's not working. He's gotten much better in terms of being able to, you know, I feel like I can read his fussy cues a little bit better, and I think they're just more clear. You know, the past six months I think there's been a pretty significant change with that, which has been helpful. But I still ask her, you know. (22205)

In general, the degree of uncertainty about a child decreased over time. As the child developed and matured, the degree and rate of developmental change began to suggest the significance of his or her delays. Although providers better understood the significance of the rate and degree of change over time, they didn't generally point this out to the family unless the implications of the changes were positive. In some cases, however, there remained a greater degree of uncertainty even for the providers. For one child who was quite severely physically disabled, there were some indicators that made the providers think the child might have untapped cognitive function. At the time of the interview, the child has been followed by this therapist for two years.

Pr: I go back and forth with [Child]. Some days I think he's not very cognitively impaired, if at all. (22205)

KW: Really.

Pr: And other days I think I really wonder how much he's processing, and.. (22205)

KW: So it's still really uncertain even for you.

Pr: Very uncertain. He has, he's so impaired with his motor skills and then also his sensory overload. But, I mean, if he is able to select

between two Barney videos by vision and absolutely throw a hissy fit if you put the wrong one in, I mean, that's fairly high level. (22205)

In this next situation, the child has been in treatment for a while, but the provider is new to the treatment team. She has been discussing how busy treatment sessions can become when there is co-treatment with several providers present at the same time. It has been difficult for this provider to decrease her own uncertainty about the child's status and prognosis.

Pr: Umhm, umhm. Yes, my experience, I think probably the busiest therapy sessions are with [Child] and that has been probably the most frustrating to me because there is a lot that's going on and it's been a little personally difficult for me just because [provider] has treated her for so long and seems to be really close to that family and close to [Child] and I'm kind of the new kid on the block. And [this child] in some ways is still a little bit of a mystery to me. She has lots of kinds of things that impact my area as far as oral motor and cognitive and language and communication. There's just lots of things and now some behavioral concerns, lots of things going on together. It's taken me quite some time to kind of parcel out each of it.... And [she] is just a difficult child to, at least I think it is, difficult child to kind of get in tune with that situation. You know, just to get to know and to get to feel for...So about speech. It's hard to know at this point how far [she] is going to go speech-wise. (22309)

And later in the interview, she discusses her feelings about the child's development and her unwillingness to share her feeling with the child's mother. She is expecting the parents to pick up on some cues about the child's development, primarily the slow progress or lack of change over time.

Pr: I, you know, deep down in my gut I don't think she's going to be a verbal communicator just by what's going on with her motorically. But I really wouldn't want to say that to [her mother]. But she, time is going to sort of tell here because what has happened, which is hard for

[her mother] to deal with too, is that, yes, she has been in OT and PT longer than speech, but she is showing some motor gains, and she really is not, at least speech-wise and verbally, she's not picking up any more concepts. Things really aren't changing. And I think they're astute enough to pick that up. And she, you know, time's going on. She had her two year birthday and, you know, it's going to become more apparent as maybe other motor gains come and speech doesn't. So we have some other things, you know, kind of in the works. We're doing some signs and we're doing some, her gestures to communicate, and I want to start working on some pictures. I don't know that she's quite at the picture recognition level yet, I'm not quite sure, but we have to kind of get some pointing and some requesting going first. And, you know, who knows. I feel like she'll be saying some words, but I just don't know how realistic like sentences are going to be just from what her motor skills are like at this point. (22309)

Intervening Conditions for Striving For Therapeutic Relationships

Intervening Conditions were identified as Differing Parent Provider

Perspectives and Change Over Time. Parents and Providers interpreted situations from very different points of view and their interpretations changed over time as various aspects of the situation changed.

Differing Parent and Provider Perspectives

Parent Perspectives varied according to the parents' past experience with the health care system, their parenting experience, and their personal views and expectations. Parents were experiencing a very personal crisis with little related experience upon which to draw or by which to judge the quality of the services they were receiving. Parents who had experienced trust reducing interactions with health care providers in the past were more wary in new relationships.

Mo: ...But it has set us up to really question any medical people and distrust anybody that doesn't feel right to us. Just even if there's no substantial data or anything you can put your hands on, if they respond in any slight way, it's like -- and maybe that's unfair to the medical people or to therapists. But that's what brought us to that. (11101)

Parents who had older children sometimes felt their knowledge of normal development was helpful in evaluating the development of the child with developmental delays. The parents' view of the child and how the child fit in the family and their expectations for him or her influenced how they responded to the child's developmental difficulties. Their past experiences with handicapping conditions and their attitudes toward handicaps in general were also important. One mother mentioned her previous attitude toward persons with handicaps, which she described as fear. Several parents had concerns about their child's self esteem in regard to attending therapy.

Providers had a broader perspective from which to view the situation. They had more of an idea of the possible outcomes for the child and opinions about how intervention now might affect the child in the long term. These opinions about efficacy of intervention varied from one provider to another, and were affected by the discipline in which they were trained, their past work experiences and their own personal experiences. These ranged from providers who believed that the interventions they had to offer were critical to the child's development to providers who felt that their interventions must be considered within the context of the family and that the family life

was most important. Some providers identified changes in their beliefs which had occurred with years of experience or having their own children.

Change Over Time

Throughout the parent and provider relationship in the developmental treatment setting, there was Change Over Time. Change occurred in the child, the parents and the providers. Uncertainty tended to change over time, decreasing for both parents and providers as the child's development unfolded and as parent provider relationships developed. Issues about the child's development became more clear and both parents and providers knew more of what to expect from one another. Uncertainty was never totally absent, however, and continued to have an influence on the communication between the parents and providers and on their relationships. The following excerpt came from a provider who treats children who have sensory integration problems and attention problems, both of which are difficult to diagnose.

Pr: Yes. And you know I've had parents speak to me of a lot of frustration where somebody will evaluate their child and they'll make conclusions, and the conclusions are very negative and very limited. And they really don't reflect the true potential of the child, and so, you know, in that way it's real, it's hard sometimes to deal with the whole idea of diagnosis. And, you know, when that happens, I guess it's really a matter of, you know, just keeping, keep gathering new information and just, you know, really watching the child's progress and adding all of the progress and things that are going on to that, I guess, base of information about the child and, you know, it depends on the age. It depends on so many other things, and so. (22108)

Another example of the relationship of Change Over Time to Uncertainty and the parent provider relationship was a mother mentioned earlier who could identify her own changes in attitude about having a wheelchair for her child. She related her own change in attitude to changes in how the child was responded to by the public, prodding from the providers at her center, and the child himself. The child enjoyed his wheelchair and it proved to be convenient for his mother to use. As it became more clear the child would not walk in the near future (decreased uncertainty) the mother became more accepting of a wheelchair.

This mother maintained uncertainty about whether her child would walk by changing her goal each time the old one was not met.

Mo: And I was first told by this brace man that makes braces there and he had been making them for thirty years because I have an ex-brother-in-law that's severely CP, and he used to be at Kenney's. He told me that they don't put labels on them until they're three. And, because then I used to go in and talk to him when he was making the braces, and I'd say, "Well, how long do you think she'll have to use these?" because I had goals as to when she ought to walk independently, and then when that didn't work, I'd raise my goal to another five years, whatever, but he told me for a long, long time this was the way it was going to be, so, so I didn't know. And I didn't know the system, but I got used to being in that system when she was a baby, whether I knew what she had or not, too, and that whole team of doctors that saw the kids. (11108)

Action/Interaction Strategies for Striving For Therapeutic Relationships

One broad category of Action/Interaction Strategies was identified as Balancing and was comprised of strategies for balancing and making compatible the differing

perspectives of parents and providers, and differing potential goals of interaction and treatment. The four main categories of Balancing were Balancing Competing Needs, Balancing Competence and the Need for Intervention, Balancing Parent and Provider Roles, and Balancing the Here and Now and the Future. Crossing over all these strategies in the Balancing categories were strategies of Questioning, Reading the Cues, Managing the Sessions, and Managing Uncertainty.

Balancing

Balancing Competing Needs. As is often the case with families, the needs of one member may be in competition with the needs and priorities of another, or of the family as a whole. In addition, in the therapy setting, the needs of the provider sometimes entered into the picture. Competing needs was an issue with which both parents and providers struggled. For parents, the needs of siblings for attention during the therapy sessions sometimes competed with the needs of the child in treatment. One family dealt with these competing needs by having the father bring the child for one of the therapy times each week so the mother could stay home and have one-on-one time with the sibling. Another family felt the presence of the sibling in the therapy sessions was helpful to him as well as the child being treated. The providers, however, felt the presence of the sibling was distracting to both child and therapist and asked the parent to bring something for him to do so that he could sit in the lobby during the sessions. This was very upsetting to the child's mother, who said,

Mo: But he responds better in therapy when his brother is there. Did you notice that last week even? Were you watching? He wouldn't do anything because his brother was in another room with the door shut. (11107)

The conflict between the child and family needs was also mentioned by the providers in regard to family members whom they saw as “needy” and who took up a lot of their time and attention during treatment sessions. Situations where parents were seen as particularly needy were ones in which the therapist providers relied on the skills of nursing and social work if they were available. These were cases where nursing and social work support were greatly appreciated by the therapists. When these services were not available to the therapists, there was a range in their feelings of willingness and competence to deal with situations, depending on the circumstances. In the following segment, the situation was particularly stressful to the provider.

Pr: ...Like I with [child's mother], you know, all of her craziness in her life and her men and her alcohol and her this and her that, it's like I don't want to have to deal with it. I want to be able to treat her kid the way I know how, the way he needs, and I'm not able to do it when she's, you know, ranting at me in a therapy session. She needs work. There's no doubt about it, and it no doubt impacts her ability to parent her child, but I'm not the one to do it. I don't want to not have sympathy but I try to refocus her back to working with him when she starts to talk about the other areas of her life. And she has stopped talking about it and I'm much more able to do what I'm being paid to do.(21102)

In another situation, the therapist felt more able to deal with difficult family member needs.

Pr: ...Yes, and so [the mother] must have been sixteen or seventeen years old and a mom, and [She] was living with her mother at the time. And she has always been more brassy kind of individual, but upon first

meeting she came across as having a really, really hard shell and was very, I think, wary of anyone that might come across as an authority figure. So she was a real extra challenge to begin working with them as mother and infant to still try to affirm her and not come across as someone who was telling her what to do. (21103)

Another way in which the needs of the family had to be balanced against the needs of the child was in terms of how much the providers expected the parents to do at home with the child and how the treatment sessions were scheduled. Some therapists felt the child needs came first and expected the parents to comply with recommendations. Others took into consideration their assessment of the family's needs and capabilities in making their recommendations. These examples represent two extremes:

Pr: Well, I think if a child comes here once a week for an hour, you're not going to get anywhere unless there's carryover, I mean, that's pretty obvious. But, I mean, if they're not going to do it at home, it's like why even bring them in, you know. They're not going to change. I mean, they might learn the routine of what we do here, but they're not going to carry it over once they leave the building. So I like the parents to carry over. Well, I could do better in telling them more or giving them examples of what they can do at home or have them show me, instead of me telling them because you kind of fall into that habit of you telling them what to do at home rather than having them demonstrate, so you know they're doing it right. (22302)

In the above example, the provider focus is on the child, while in the next example, there is a balancing process going on from the provider's point of view, between the needs of the child, the needs of the family and the context of uncertainty.

Pr: ... Now I wouldn't, I really would not ever schedule a child for a therapy session right after the child's picked up from day care by the parent. To me that is ludicrous and I go around the building here saying

“Don't schedule that child at 5:00. He hasn't seen mom all day long, and you're expecting mom to pick him up at day care, bring him right over here, and the child..”, and you know, we're talking little kids, two year olds. “You're expecting that child,” or even younger, you know, fifteen months old, “you're expecting him to sit, but mom sit over there and you're going to work with him as a PT”. That's just, that does not compute, you know. But that kind of a thing. I never would have, never would have thought about until I became a parent, and I realized that what the dynamics are when the child is picked up by, I say mom because that's been my experience mostly, but I'm sure mom or dad. They need to be together as a family and you're doing more harm than good, I think, to schedule them. You're doing more good for the child to see him in day care if truly the child has to be in day care five days a week, you're doing more good to see him in day care. This is something I do struggle with in terms of professionally. If you have a family that's really relying on the parents both to work full time, and you have a child who really needs therapy, and you believe strongly that the parents should be the therapists, how do you solve that dilemma? And like me, you believe you shouldn't bring the child in at 5:00. How do you solve that dilemma? I mean, at what point do you lay it out on the line to the parent that they really need to change their work? That is so stressful for the family, you know, and so often with the young baby we don't know quite where they're headed (22205)

Several other providers also talked of how their consideration of family needs had changed over their years of experience or since they had had children of their own.

KW: Do you find they vary a lot as to how much they want to know or do at home?

Pr: Oh yes, because some I know, also me having a kid has helped a lot to understand because your time is just eaten up and to have a certain time to do therapy with your child at home, ha ha ha. When they have, you know, multiple kids or work and then come home and try to feed the child and they're not going to have the patience to sit and do a little therapy with the Nuk brush, so I'm also realistic now much more. (22302)

Balancing Competence and the Need for Intervention. A goal of treatment for providers is to identify problem areas and offer interventions or information which can be used to ameliorate the problem. Identification of problems is also necessary to justify the need for intervention. However, the constant focus on problems or something that is wrong with a child or with the way the parent handles the child can be very disconfirming, so providers often try to also communicate positive information about the child and the parenting. If this is done too much, it can be misleading and give parents the idea all is well and there is no need for concern. Thus, Balancing Competence and the Need for Intervention is a delicate maneuver. There are methods often used by providers in this balancing. These are Normalizing, Affirming, and Taking One Step At a Time.

Normalizing refers to focusing on the normal aspects of the child and family and having normal interactions with them, as well as talking about the abnormal aspects as a part of everyday life for the family. This example illustrates focusing on the normal aspects of the child.

Pr: So with the younger ones I think that, I think a lot of times my role is to be a reality check for parents which can be sometimes very difficult, but I think that most people, I certainly stress the positive things that I see a child doing. Not even the positive things but the most normal things that I see a child doing, and I think for even a parent who is very attached to a child, that just reinforces their own feelings, their own good feelings about the child. And the better a parent feels about the child, the more they're able to hear what people suggest to do to make things better, and the more that they're able to keep up that level of involvement with the child without feeling burnt out. (21205)

And later in the same interview is an example of the provider normalizing by focusing on the parents' interactions with the child:

Pr: I think that some, for the vast majority of families that we see, there is no place that the parent gets positive feedback about, not only about their child but about their interaction with their child, and so I think that having someone else seeing positive things in their children, first of all, bolsters the parents' own feelings about the children, but more importantly, for most parents, I think who have pretty clear, are pretty clear in their feelings about their child, it changes what their expectations of their children are and how they want that child to be in the world, basically, I think. I think this I guess mostly about young, the younger children. I think when you're talking about a thirteen or fourteen year old child it's a different situation. (21205)

This mother sums up her desire to have their family recognized for their normal aspects:

Mo: ...Having people see that he's disabled but we're not. We are functioning people who are trying to make the most of the situation. At times it is difficult but we still want to be the family, we still want to be considered sort of normal in a really abnormal situation. (11104)

The following is an example from the provider's view of the parent being able to talk about the abnormal aspects of their everyday life which were normal for them, such as doing catheterizations and bowel programs, having surgeries and dealing with complications.

Pr: And I think that part of the reason why they had very good attendance and were always at therapy, was not because they felt like what I was doing or what was happening in therapy was so important that they needed to make sure they were there every week, but it was one of their few places where they could say anything they wanted about their child, and where people didn't just gloss over it or ignore it or not say anything about it, and they could kind of let down their guard, especially [the mother]. (21205)

The mother who was discussed by the therapist above had this to say about her view of the therapy:

Mo: Well, what it has been like for me at [the Center] is -- [therapist] and that whole group has really been invaluable. You know, they have been my connection to, you know, how to be with [my child] as a mother, and how to be with him as a caregiver and how to deal with all the medical -- she is really my advocate on how I deal with the doctors, you know, the big, bad doctors who don't seem to know what I need. I can't seem to always get what I want from them. Well she's the one, she comes with me -- she has even come with me on visits to support me and actually talk for me because I just get upset, you know. So, you know, it's almost a therapy for me. You know, I hate to miss my weekly therapy -- I mean not only for [my child], but for me. (11103)

KW: Yeah.

Mo: You know, because I go in and talk about everything about him. She just supports me and [my child] in whatever we want to do and she's like a case worker almost in that she'll help me find whatever I need to find and so even now that I don't go to her, if I have a question and I need something, I call her first. I don't call the nurses or anything. I always call [the therapist]. (11103)

KW: Like your nurses at [the hospital specialty clinic]?

Mo: At [the specialty clinic] or at [the medical clinic], you know, his regular Ped, or the DDD office or whatever. You know, I just don't even deal with them. (11103)

Affirming was the providing of positive feedback about child and parent by direct or indirect means. The following is a specific positive comment about the way this mom was handling her child, but other comments about how the child was dressed, if he looked healthier, or felt less tight . Even comments of awareness about the difficulty or complexity of caring for the child were affirming for parents.

Mo: (Therapist) was really good about that, and she would also tell me. Like if I did something that I just did as a mom or whatever, she'd go, 'That is so perfect from a therapist's point of view, you were doing the exact right thing. You should keep that up.' And I really liked that input. (12105)

Affirming was also provided by parents for providers. One parent made plans to remember to give her child's therapist positive feedback to show that she still appreciated the therapist even though she was not following a particular recommendation. One mother said to me many times both in private and in front of the providers that they were what kept her going and they were like her family. Providers also found it affirming when a child made progress or a parent was able to cope better with the child.

Taking One Step At A Time. In spite of efforts to be affirming or normalizing, it was still necessary to acknowledge the child's need for intervention and whatever role the parent was to take in that. This was often handled by taking one step at a time. In this way, parents could work on what the child was doing at the time without the necessity of making global comments about the child's diagnosis or disability.

Pr: If they're wanting..., [I] need to be responsive to their questions, as well as to try to provide them with enough information to generate the questions, to raise the questions. And when I say provide them with enough information, it's not necessarily to provide them with information about a diagnosis unless that's their specific question. But I think to provide them with information that's relative to their daily living with their child as it relates to basic daily living skills of feeding and moving around in their home and in their community, and that I think provides a better sounding board that if they're wanting to know about a diagnosis, we can get to that more clearly. Or if they're a family who

chooses to really not want to deal with the diagnosis, that's okay, too, because the child isn't the diagnosis. Or the diagnosis isn't the child. It's a label, and I don't feel compelled to drill the label into my interactions with the family. I just want to try to keep them as informed as possible about muscle tone or the influences different situations have on their child because I think that's relevant, and that's the information that's speaking to, that I think, are the primary issues of parents with young children, newly diagnosed children.(21103)

Another therapist described it succinctly:

Pr: And my style with a young, young infant like that, because you really can't predict it very well is to let us take it a step at a time. I think that's what a lot of therapists do... (22205)

Balancing the Here and Now and the Future The uncertainty inherent in the nature of developmental delays and disabilities makes anticipating what is to come in the future difficult. In addition, the implications of developmental delays for the future can be quite upsetting to parents. For many parents, a way of dealing with this situation is to focus on the Here and Now by Living in the Present and holding thoughts of the Future suspended as much as possible. Others prefer to know the range of possibilities, even if they are unpleasant, in order to be prepared to deal with them. They do this by Asking the Tough Questions. If the parent doesn't directly say what their preference is providers attempt to figure it out. For providers, it is difficult to directly pose a question about such preferences to a parent without implying that there is undisclosed information available. Thus, providers attempt to evaluate the parent preference indirectly by reading parent cues.

Providers also vary in their approach to this issue according to their own personal philosophy, with some leaning toward fuller disclosure in response to the tough questions and others continuing to fall back on the uncertainty of the situation even though they have opinions about the range of possibilities. For providers there is often advantage in taking the Living in the Present approach because it avoids the difficult and unpleasant task of discussing an uncertain future.

When the providers did decide that they needed to bring up an issue, there were several approaches they used to Push the Boundaries. One of these was asking questions about how the parent was handling or expected to handle some upcoming activity or transition. One mother was talking about an issue the therapist had brought up to her about bathing her child.

Mo: ...And a lot of times they'll bring these issues up to me before I've even really thought them through. (12105)

KW: Is that helpful?

Mo: Yes, it's very helpful. Yes, because they're helping me to see, I think, for a long time I was not willing to accept the fact that this was the way my life was going to be. He was going to get better, the (disability) was going to go away, ...for sure it is, you know. He'll walk, he'll talk, what's all this, you know. He's not going to get a wheelchair, and I was in denial. And they helped me see that, you know, you need to look at the future. You need to see what's down the road instead of just living in the moment, and they've opened my eyes to a lot of things that I might have had blinders on. (12105)

KW: So how did they do that, by just bringing up things or asking questions?

Mo: Bring it up to my attention, yes, that too. They would say, "Well, what, how are you bathing him? What are you doing for bath time?" "Well, I pick him up, I hold him in the shower on my hip, and try not to drop him". "Well, you might think about getting this bath chair".And then, so they brought that to my attention. The wheelchair, of course, I was in complete denial on that. Now looking back, I didn't think I was at the time but I was. And, you know, they're helping kind of, you know, with a little push, you know, that I think is needed. "No, it's time to get it." (12105)

KW: Yes, the wheelchair, you got rid of that other one, you said you're not ready for that and time went by. Did they then just start mentioning it again?

Mo: Umhm. It was time that he was, well, with him starting school, he needed a safe mode of transportation to and from school. "Was I going to cart him to school in his stroller?" And that's when my husband and I started talking about they perceive him as a baby in this stroller. He needs something age appropriate. And yes, they were very instrumental in helping me get the little oomph push I needed to get me, "Okay, (Child) is not walking at this point. Who says he's not going to walk in a year from now, but right now he needs this." And you know, it's been a blessing, I mean, the wheelchair is very convenient, and he loves it. He doesn't have a problem with it, and so therefore, you know, it makes it easier for me to have him in it. (12105)

Balancing Parent and Provider Roles There were many roles for the providers that were identified by both them and the parents. In addition to the obvious roles of provider of direct treatment services to both the child and parents, provider roles identified by the parents included advocate, therapist, friend, family, mother. Additional provider roles identified by the providers were role model, and normalizer. Roles of parents included not only their parent and family roles, but also those of advocate, therapist, nurse, teacher and pharmacist for the child with developmental

delays. Of these identified parent and provider roles, two categories seemed critical.

These were the role of Parent as Therapist and role of Provider as Friend

The degree to which parents were therapists was negotiated between them and the providers. Providers varied in the degree to which they believed the parent could or should be a therapist for the child. There was generally consensus among providers that one or two hours of therapy intervention each week were not enough to make any significant change in the child's life and that some carry over by the parent at home was necessary. However, how much is enough was a very murky issue. Therapists with a more family oriented view were more flexible in their ideas and practices.

Pr: ...So, so it's O.K. I mean I think, maybe I'm getting old and worn out or something, I think, you know, eight or ten years ago I would have just been fighting for every therapy for everybody that needed it, and now I think people have a lot to do in life and it is O.K. to let people make some choices. Everybody doesn't need everything all the time. I think a summer break or a winter break or a whatever break is good for kids, it is good for therapists. (21301)

KW: I like to call that wisdom or something, not just getting older.

Pr: (Laughs) But you know, I mean if I never have another maternity leave, I'm still going to tell all these guys they need to take some time off or I need some time off or something because more is not necessarily better. (21301)

KW: Do you think you have different ideas about that since you've had children or -- how is that, I'm curious about that because that's something I've heard from other people is that having their own children has some effect -- maybe not a major turnaround but some effect -- on how they work with parents or how they view parents?

Pr: I think so. Yeah. I mean if nothing else having kids has made me realize that my schedule is just so harried, you know. I'm running all

over the place. ...and I think that what parents teach their kids is as important or more important than what therapists do. And so I don't want to see a child if it is going to completely take away that time, you know. If the hour a week that I spend with a child is the only hour that they would have to play, I don't want to see them. You know, that's an extreme example, but, so having kids has taught me that. (21301)

However, even those who felt more strongly that parents should meet a certain minimum standard were inhibited from acting too much on this by the current family oriented philosophy of early intervention in general and the particular family oriented stance of both the centers in this study in particular.

Pr: Let's see, at [previous job] it was up to us, but frankly the child did so much better without the parent. (22302)

KW: Yes.

Pr: And then what I would do is ten minutes until the end of the session and I'd go get the parent, bring the parent in, and then explain exactly what we did and have them demonstrate or whatever. Because the child would just turn to the parent, because typically a lot of the parents worked and so the kids didn't have the attention from the parents, and they'd want it for that hour that they were in [therapy], and I didn't get anything done. So that was really hard. But then (22302)

KW: What age group was that?

Pr: We saw a lot of two and three year olds, the infants, of course the parents are there, but the two and three year olds. (22302)

KW: So when they get to two and three

Pr: Yes, that was my experience anyway. And then, but I'd always involve them and bring them in, and then they always, we always had like homework workbooks, and I expected them to practice it at home, like communication folders with pictures, and they'd practice the pictures and I could tell if they practiced or not, and so I'd say, "Now, you have to practice because I know you didn't." (22302)

Some providers actually tried to discourage parents whom they thought were trying to do too much with their child at home or doing things inappropriately.

KW: What about, how do you feel about the parents as therapists? I mean, how much do you ask them to do or how do you decide that, or?

Pr: I think I try to be responsive to what they tell me or the cues that I read from that. I like to tell parents up front that I think it's very difficult for them to be both a parent and a therapist, and sometimes keeping those boundaries clear within the home environment helps us be more successful. Where I can make suggestions of things to incorporate but not a rigid set of activities to do. (21103)

KW: So parent as therapist isn't something you advocate. I mean, I just said that sort of a way to get into the topic.

Pr: Not in the strictest sense, no. Because I don't want to skew any more than necessary the development of, you know, a good parent-child relationship, and especially in those situations I'd rather that the child get frustrated with me and be angry at me about imposing certain motor limits than they would from their parents. Parents have enough to think about after they leave here in the total picture of their life that to continue to try to support the parent in making observations at home and incorporating some suggestions about positioning or certain toy appropriateness, that sort of thing. But I don't want them to feel that they need to do what I do. And at different times, depending on the parent and how the dialogue has gone, we'll articulate that in a variety of ways, I think, to them. Even to those parents that are really pushy about wanting to have more to do at home, I still try to temper that so that it's not, I'm not trying to have them be me. Not to say that they couldn't be, but again I think the relationship has to be different even for therapy to be successful, and I've tried to at different times or in different situations, point out the experiences that I've, and trainings, you know, that I've gone through to be where I'm at. And so therefore I can't expect them to be the same. It wouldn't be realistic. Lost my train of thought there. Did that answer some of the question? (21103)

For parents, balancing the role of therapist for their child with all their other roles was sometimes difficult.

Mo: [the nurse] was always the one who was a stronghold and always telling me to be mom first and not therapist, and make sure you do for the other, you know, [this child] as you do for the other kids. Make sure you do for the other kids as you do for [this child]. And always keeping that family unit more central and so she's really been a stronghold in that regard. (12104)

Another mother, whose child was cognitively normal, but severely physically handicapped and health impaired, said:

Mo: Hello. You got that right. Yes. I am no longer just a mom. I am a mom, a nurse, a therapist, a wife. I have so many roles and, you know, a lot of times I get to the point where it's like I don't want to do this any more. I just want to be me, you know. When did my life stop and I am now all these other people? I am no longer me. You know, we'll walk somewhere and, "Oh hi, you must be [Child's] mom." "Yes, my name's [Jane], but yes, I guess I'm [Child's] mom. It's like we've lost our identity because we're so wrapped up in him that we don't have any other, you know, it's almost like my life has been completely, I don't work anymore full time because I can't because of him. (12105)

Many parents wanted to do something to help their child, but sometimes felt unable because of time constraints due to their other roles, work or other children, or a feeling that they didn't know what to do. If the child also attended a preschool type program, they tended to rely on that to take the place of what they couldn't do at home.

KW: ...did they give you things to do at home with him or make suggestions to you?

Mo: Yes, they have given me sheets of the things, yes, and they tell me things, different things too. And it's hard to do at home now when you have another one also, you know. (12101)

KW: Yes.

Mo: I don't get a lot of time what I want with (Child), so. (12101)

KW: What sort of things did they suggest?

Mo: Well, just different activities to do during like meal time and bath time to try to help him to speak when we do certain things, or even sign language they want me to do some of. Just so he has another way of communicating before he talks. Stuff like that. Different, they gave me ideas for activities to put together. Different activities to put together that stuff that we have at home that he can do his fine motor skills with, stuff like that. But again, it's hard, you know. I kind of depend on (preschool) to do a lot of it because that's, you know, it's easier because then, because you're not there and they can just focus on (Child). And I think he benefits more from that, you know. I try to do my best, but it's hard. (12101)

In contrast, another parent avoided sending her child to additional programs because she felt that was her job.

KW: So this is really the only place you've had therapy for [Child] then?

Mo: Right. They wanted him to be put in a developmental preschool and I said I don't think so. "Well, he could have quality time with an instructor and do a teeth brushing time and all these different skills." And I thought "I'm his mother, that's what I do." And it takes a lot of time, you know, it takes more work, but it takes more work to teach your kids at home than to get them dressed and say "See you around", you know what I mean? (11107)

Some providers felt that parents weren't given enough hands on practice with their children during therapy to make them comfortable in doing much intervention at home.

Pr: I would actually prefer that they would give the parent a chance to do some hands on movement of their child. Some people are more open on that than others. I know we always do it if the child is too fussy for us to deal with him, but we don't tend to do it otherwise. I find that most of our parents are pretty clever and watch pretty carefully and go home and try these things, but I think that hands on help would probably be helpful for them. And that would be my preference although I don't usually say so because I don't think that's necessarily my business. So you know, it would be a good topic, I think, for discussion. (22403)

The role of Provider as Friend summarizes the personal nature of the relationships that tended to develop between the parents and providers. These relationships were not balanced when compared to outside friendships because the parents rarely knew as much about the personal life of the provider as the provider did about theirs. Although this fact was mentioned by some parents, it did not seem to be a problem for them. This mother had some concerns about the appropriateness of toys used in her child's sessions, but didn't feel she could say anything.

Mo: ...And so, those kinds of things are frustrating for me. And you know, I've gotten friendly with the gals, so, "Hey he's bored, let's, you know, think of something new." And he's been there for a long time, so it's probably hard for them to always come up with new ideas.

KW: So in a way getting friendly with them almost gets in the way of being able to

Mo: It does, but you pretty much, they're in your life, and they're such a big part of your life two days a week that it's hard to keep that

parent-therapist relationship strictly that way. They just become involved in your life. Moreso ..., they're involved in our lives. We're not really involved in theirs, you know. I know very little about their families and things like that, but they know every detail of our life, you know, which makes them seem like they're my friend and somebody I can confide in. (12105)

KW: But you don't feel like you can say anything?

Mo: Oh, no. Sometimes I don't. I feel like I don't want to cause any waves because I don't want it to be reciprocated onto [my child]. And I think that's a lot of it. A lot of things we keep, like them treating him in a way that we don't think, it's not harmful, you know what I mean, as long as it's not endangering his person, you know. But then by the same time is he benefiting the most from the therapy he's getting? But we don't say anything because I don't want anybody to have hurt feelings and then inadvertently, I don't think purposefully or anything like that, but take it out on him. And so, no, we don't say things that bother us a lot of times. We just kind of shrug it off. We know it's going on, but we don't really, you know what I'm saying. (12105)

KW: Yes.

Mo: And we did the same thing at the hospital for a while, and then it got to the point where at [the children's hospital], oh, Hon, if you ever wanted to interview me about that, do I have stories I can tell you about that. But at the hospital, we just, it's like "No, mom knows what she's talking about" and so many of the nurses know us now, it's like "If mom says, then that's what we'll do."

KW: So you had to finally get more assertive there?

Mo: Oh, very assertive, yes. It was like "Baloney, that is not going to happen. You have lost your mind, and you are not doing that to my child, and forget it." And just flat out telling them, "No, you will not do that, and he will not have this done," you know, and things like that. (12105)

This mother was able to be assertive when her child was in hospital and she felt he was in danger. She also told of being assertive and setting limits with school personnel about a bump on his head. Yet she felt unable to bring up her concerns to the therapists at the center about the most useful or appropriate toys to use in therapy.

Again, these relationships were negotiated on an individual basis, but they seemed to depend partially on the personality match between parent and provider and partially on the personal philosophies of the parent and provider. Another provider described how her level of self disclosure had changed over the years:

P: Yes. I don't either. I'm fine. So I feel, I mean, I think I've gotten to this point where I feel like I do have a personal relationship with many of my families. I may never certainly not see them socially outside of this office. I may not ever even speak to them socially outside this office, but I certainly think of them as definitely on the level of a friend. And I certainly think that for many of those cases that I know them better than many of the people who they socially would call their circle of friends.

KW: Umhm.

P: I have been more, the older I get the more I have, the more reluctant I've been to share a lot of personal information with people, although I certainly still do share some. I certainly don't as much as I used to.

KW: Why, do you think?

P: Partially because I think it's a little, it can be a little awkward. Partially because I think it changes the dynamic in therapy some. I know, it's like I'm a little wiser now that I have children of my own, and I'm amazed to think of the things that I used to say in front of children. I mean nothing terrible, but just personal things about myself in front of a three-year-old child who certainly is getting some of that. And I don't think I ever used to think about that. So part of it is definitely that. And

here we do have an older population so whereas before I did see many more infants who I didn't have to really think too much about what the child was hearing, now it's more, you know, three to six-year-olds, and yes, I definitely have to think about what I'm saying in front of children. And I think that I used to, again I'm not so sure about this, but I think that I used to interpret more interest in me personally by clients, and now I think that those same overtures or questions that I hear are not so much that the person really wants to hear of what, who I am or what I am, but they want to acknowledge in some way this connection, but it doesn't have to be about me so much. It can be and it should be much more about them. It doesn't need to be equal, and it still can feel fine. I'm kind of amazed at times to think of people who, you know, have been very, you know, I've seen for three or four years, you know, one or two times a week, and feel like I know about, and I feel like they know a lot about me in some ways, but they know nothing about certain parts of my life. So it's been kind of interesting. I also am much more careful about what I volunteer without being asked. I don't volunteer tons now, and if I tend to talk about something personal, it's usually much more about my kids than about anything else. But even not that so much because I feel such a difference in what I have in my life with my children than what these people have in their life with their children, and I don't like to emphasize that. So it's become in some ways a less personal area, the parent relationship with me.

Several providers mentioned being aware of how different their own experience with their children was than the experiences of the parents they worked with and wanting to avoid calling attention to that.

Both parents and providers frequently identified something about themselves (Self Characterization) when they described a particular relationship or how they approached relationships in this setting in general. This self characterization served to identify a degree of match between themselves and others with whom they were

interacting. In many cases, what the parents and providers said they liked about their relationships could be said to fit the category of normalization.

KW: It sounds like, I mean what I'm hearing is that you and [the therapist] know personal things about each other. So there's that kind of exchange.

P: But I'm really open. [...personal information...] I think it's just part of my personal make-up too. So that's a key to it that I'm me and maybe because I found a therapist like [her], it's a relationship that works for me. Because people that aren't like that, I never seem to do really well with. (11104)

KW: Like a therapist who doesn't share anything of their own or who doesn't respond to what you say? What is it that makes that work?

P: I think a therapist who doesn't share their personal -- not personal, but just the socialization skills, if they aren't there, then it feels like I have a professional dictating to me what to do rather than a professional helping me work through what we need to do. (11104)

KW: So it kind of puts you on an even --

P: Well, I don't know if even as much as respect that I am a part of this and that I also have insight into [child] that even though I don't have the professional background or the educational knowledge, that my part is important too. So it isn't like, I mean [the therapist], it isn't the fact that she [personal information about the provider] and shares that she [personal information]. It's just that social part of ... it isn't just a therapy session. It isn't just the medical part because I can't separate my life into those pieces. So I am drawn to people that. ... I look forward to going to the sessions with [her]. (11104)

There was a range of degree to which providers were willing to self disclose with the families they treated. Two extremes are illustrated here. The first is a

therapist who lives in the same community where she works and has developed a social relationship with one of her treatment families.

KW: "... I do notice that you have like it seems like a personal relationship with a lot of your families that you know. You talk to them about personal things about them, and also they know personal things about you, so I'd like to know how you feel about all that and how you see that.

Pr: For me, it makes me feel like more a part of, I guess that's just my personality. I can't, I guess I've been to some physicians and such where, I don't know if you've ever heard that commercial on t.v. where the doctor calls the patient's name by the wrong name and checks him out for something [he doesn't have], you know. (22101)

KW: Yes, yes.

Pr: You know, you've had some experiences like that, and it's like "No." I think knowing, having a sensitivity of where families are coming from and then letting them see your life and know where you're coming from, even if you're not coming from the same places and you don't have similar experiences. I think it creates more of a bonding. There's almost always something in common with different families, which it's nice. It makes it more comfortable and it gives you something to relate about besides just the fact that they have a child with a special need. But it's very comfortable for me, and I don't say anything I don't want them to know, but there really isn't anything that I'm hiding anyway. So I think it makes us seem both more human and less professional-parent level. (22101)

The next is a therapist who lives in a different community, but feels she would limit personal relationships:

KW: What about personal relationships with families? Do you sort of, do you ever get to know any of them outside of therapy or you do know a lot about their personal lives, I would assume.

Pr: I do. I don't think I would be resistant to it if I lived in the community. You know, it's not as though you turn your back on

people, but my life is full enough with my family and my other activities that I haven't felt the need to include that as an overlap, so there is pretty much a line that there's professional life and private life, but I don't, I never have been one to be, to not include examples from my personal life if I felt that they had an appropriate contribution to what I was able to accomplish professionally. So a lot of the examples I choose on how things have worked for me or things that haven't worked maybe have been in interactions with my own children. So socially, no, I don't plan things with families. (22506)

Regardless of the degree of self-disclosure on the part of the provider, there were other behaviors families took as cues that the provider really cared about them and their child. These included comments by the provider that she was happy about the progress the child had made. Several parents told me that the therapist had said she hadn't thought the child would make this much progress in such a short time. Two different parents told me that the therapist said their child was the reason why the therapist said "Never say never". Another indication that the therapist took a personal interest in them and their child was when the therapist saw a toy or activity appropriate for their child in a store and told them about it or purchased it. Therapists also frequently adapted ordinary toys and equipment for children using tri-wall cardboard and foam. Some of these efforts were seen as going "above and beyond" by parents.

Questions

A strategy which was used by both parents and providers for many purposes had to do with questions. It included both asking questions and evaluating the questions that were asked by the other. (Evaluation of the questions themselves will be

discussed in the following section on Reading the Cues.) Providers asked direct questions of parents to find out what their concerns, beliefs, preferences, and experiences were. They also used the technique of asking questions to broach subjects that were difficult to bring up. The following therapist describes that strategy.

Pr: I felt, that there were [specific] needs and there were some records of that that came with him from [the other center], although the parents never brought that up. They were a good example of an issue here that I didn't feel comfortable letting be left unsaid. So, because that isn't my style, I don't want to push or be disrespectful or not regard people's feelings, but I did want to share my concerns. I think how I did that, though, was I was very sensitive to the pacing of asking those questions or how I brought it up. I brought it up over several sessions in several different ways, very slowly asking about the reports, what was evals that happened [at the other center], what was their perception, say, in one session. Didn't say anything else. Maybe asked further questions on that the next time. (21103)

Another questioning strategy used by providers was questions to each other during treatment sessions as signals that they thought a topic should be explained more fully or in a better way to the parents, or even as a way to bring up an issue the other provider was not addressing. One provider described herself as asking "ignorant" questions for this purpose. This strategy was often used by the social workers and nurses. In some cases, they would be more direct and ask a question on behalf of the parent. Asking questions on behalf of the parents was also reported by providers who attended medical appointments with parents:

KW: So do you go like to appointments with [family] and people still, or?

P: I have. Yeah. We went over to [the children's hospital] for a couple things for her. Just to hear what they were going to say to her so I could kind of follow along. And it was helpful because [the parents] are still not, I mean I think they will in time be more assertive, but they still are not very assertive about asking questions that they have or asking for clarification. (21102)

KW: Do you just do that when you are there?

Pr: Uh-huh. Yeah. I'm sort of pushy, which I didn't used to be as well, but I think I sort of butt-in a little bit more. (21102)

Parents also used questions for various purposes. In this case, the provider describes how she viewed a parent as using questioning to gradually find out information at her own pace

Pr: ...Mom asking us just in back and forth a little tidbit of information here and there, like "What does a speech therapist really do?" and, you know, what, "He's doing this now, what do you think of that?", and until she felt comfortable enough. And I think concerned enough. (21304)

Parents used questions not only to get information, but also to determine how competent they thought the providers were.

Fa: You know, some of them are competent and some of them aren't. So I am real into asking questions and trying to understand -- I'm the same way with my car. If I go into a mechanic, you know, I've got to find out, and it takes a while to figure out, does this guy really know what he's doing. So part of that sometimes is just asking small questions. You know, I don't want everybody to feel like I'm grilling them or testing them. So you just make conversation and learn from how they respond to things how knowledgeable they are. (11201)

Reading the Cues

Both parents and providers tried to read the cues in order to best get along and develop a therapeutic relationship, but providers talked about it more than parents.

One of the primary cues observed by providers was the questions the parents asked.

Pr: ...but, so how do I decide what I want to say? I think I take that some from the kinds of questions parents ask. When someone says, you know, "What's he going to be doing when he's five?", I mean, I take that to ask, you know, firstly what's his body going to be looking at, you know from a therapy standpoint, and also I think most parents are interested in the cognitive issues....(21205)

Later in the same conversation, this provider was talking about how much information she gave to parents during sessions.

Pr: ...And partially I think that comes from, you know, a parent who's responsive when I talk about anything or who asks questions, and if I have that experience a few times, then that just encourages me to being more communicative about it ongoing without them having to ask very much. (21205)

Other cues were also noted, but were sometimes difficult for the providers to quantify:

KW: So there's one that you feel like they don't want to hear it and they need to cling to the positive stuff. And one that you can be really comfortable saying things, and I'm trying to figure out how you know that.

Pr: I think that it's just really different personality styles, and I think that it's from what the family asks for and what they say. And I think facial expression and avoidance of answering questions directly. (21304)

The worst situation seemed to be when the provider couldn't read the cues

Pr: And then there are parents that you can't read, or I feel like I can't read at all, and I have no idea if in fact they want more information or less information, and I don't have a good sense of what's helpful and what's not. (21205)

Pr: And it seems like every situation is so different, and every parent is so different that sometimes it's difficult to read that initially. How much information they want to give, how much information they're comfortable in giving and how much they want to keep to themselves. (21304)

In other cases, the provider took the parent's behavior as a cue to what they wanted:

Pr: And I'll write that up and do a little notebook, and some people are great at bringing it back and some people are horrible. I know people who don't bring back the notebook, I figure they don't need the notebook, or they don't want the notebook. And the people who bring it back every week, I try to add something, or every other week, you know, I add something. (21205)

Managing the Sessions

Managing the treatment sessions was primarily done by the providers. It involved many activities such as planning, gathering equipment and toys, and scheduling rooms. Two strategies which were important in the parent provider relationship and the provision of therapeutic services were Working As a Team and Making Connections.

Working As A team. There are many different providers with whom parents need to interact. Working As A Team refers to the parents and providers at the center working together as a team as well as the providers at the center working with each other as a team. The providers at the centers in this study valued the team approach

within their centers. This was particularly important for Center B, which had nursing and social work in addition to the therapies and thus required more coordination of the team because of the number of people involved. In both centers, children who were seen by more than one discipline were often seen in co-treatment sessions where more than one discipline was present at once rather than in separate sessions. Sometimes the disciplines worked together with the child, while at other times, they took turns working with the child while the other observed the treatment or talked to the parent. These arrangements were negotiated between the disciplines based on how well the approach was working and what the priority for the child was at the moment. In discussing a particular session of co-treatment where there are a lot of people in the room, a lot of social conversation going on, one provider said:

Pr: "But it is difficult, it is difficult, and I think that that's something that I guess that we have to sort of negotiate person by person. But I still sometimes think that too much goes on in there. It's getting a little bit better, and part of it's probably I need to be a little more structured in what I do or attempt to be structured as much as you can with a child that age. I don't know, [other provider] and I have kind of sort of blended together of what we do, but you know, maybe it might work sometime to experiment with different things like, well, you have the first half hour, I have the second half hour. That's just something I probably need to do with [other provider] one on one to kind of let's try this certain thing, so."(22309)

In situations where more than two disciplines were involved, the logistics became even more complicated. For nursing and social work, the focus was often on the parent rather than the child. With these disciplines, conversations with the parent in

the corner during the treatment session were not uncommon. These side conversations were sometimes problematic and sometimes not. Most therapists valued the input from social work and nursing enough or saw its value for the parent enough to willingly cope with any distraction it caused. In some cases, however, there was a problem with distraction of the child. Taking the attention of the parent away from the therapy session was also viewed as a problem by some therapists and parents.

KW: What about, so that's as far as a child goes. What about as far as having the mother's attention divided up, is that a problem? I mean, I know that sometimes different sessions I'm in, social worker and nursing is talking to mom.

Pr: And therapists with the child. (22101)

KW: Yes, or two, and so the mother misses what's going on or either she's sort of back and forth.

Pr: Back and forth. It has advantages and disadvantages. The advantages would be that mom is able to talk with social work, to talk with nursing, to follow up on questions, get those answered, and maybe even work on some personal family problems that aren't directly related to the therapy that's going on. The disadvantage is she's missing whatever's being done with therapy and also I am not a very good double-minded person, in that I can't hear what's going on with the family and treat the child at the same time, and that puts me in a position where I need to make sure that I touch base with the social worker or the nurse, and say, hey, what did you guys talk about, and trying to get both sides of it. So I think it differs with different children. Some [children] it's easier to have mom and social work outside in a different room talking because it is very distracting. (22101)

Sometimes a problem with co-treatment was taking the child's attention from the therapy. This was most often true in the case of speech therapy.

Pr: And some kids, it doesn't matter, but when you want to work on cognition, the speech people are the ones that do that and attention, one of the main things in these kids. But then I've said, "You know, we have too many people in the room." Like the social workers can take the parents out, or one of them out, because when they're talking in the corner, it's distracting. So that can be problematic, but people are also flexible and they say, "Okay" you know. (22302)

Both parents and providers considered the parents part of the treatment team to some extent. Parent input to problem solving and decision making was highly valued when it occurred. One family seemed to reflect the ideal of teamwork for both parents and providers. One of the providers for the family said of them:

Pr: They are great people, you know. I think that's a nice dynamic. I don't feel like the expert in that situation at all as I'm sure no one does. It is so complicated. And I feel like that's really a team effort and I certainly don't take any offense if I'm told [by the parent] what to do or when to do it. I think, you know, I see our role for them as a little bit broader than the therapist telling them stuff they can do at home. I think it's a pretty mutually supportive role. (21301)

Making Connections. Making Connections refers to parents and providers making connections with providers and resources outside the center. It refers to the parents being referred to other resources and to the providers and the other resources keeping in touch with one another as well. To varying degrees, parents wanted to get connected with available services and resources. Some wanted to meet other parents, get additional funding or respite care. Often they found these connections through the centers, but sometimes this did not work out and they sought out these connections for themselves or found them through some other source. For parents who wanted to be

connected, this could become a highly charged issue. Parent desires for getting connected varied from one parent to another and also changed over time. Often, parents didn't even know of the existence of particular services, so didn't know to ask for them. In other cases, parents didn't realize all the aspects or implications of a service when it was first offered.

One family went to the resource center of the hospital where their newborn child had been sent for surgery and collected all the available information. They made their own connections with a parent support group and the local chapter of the advocacy group for their child's diagnosis.

Mo: Well, when [my child] was first born, you know, after a couple of days after the shock of it, we went up to the resource center at the hospital.... And you know, just got whatever information. We got information on the parent-to-parent program and I called them and got a parent. (11103)

KW: Was that helpful?

Mo: Yes. And then the [Advocacy Group], I called them ... and started getting their stuff. And then in one of the newsletters I saw they needed volunteers. So I went to that volunteer meeting.... And then I went through the parent-to-parent training program. (11103)

In another family, the father, who had been only peripherally involved in his child's therapy had what appeared to the providers to be a sudden realization that the child's problem was not going to go away. The providers identified a session at which he asked the therapist whether the child would eventually walk or need a wheelchair. The therapist, who was unprepared for the question, replied that she thought the child

would need a wheelchair. The providers said that the father became quiet for the remainder of the session, then came back the next week with lots of questions. They provided him with a book to read about his child's diagnosis, and he became very active in calling all agencies and organizations mentioned in the book. He soon became an authority on resources available in his community. His description of the situation was:

Fa: Yes, and then after, and then I'd say over about the last six months, I started realizing, you know, this is something that's going to be there all the time. And then when I started asking questions, you know, like about is he going to be able to feed himself, you know, and all these other things, they said, well let's read the book, here read the book. I highly recommend that book for anybody. (12203)

KW: So you're glad they handled, you like the way they handled that, when you asked your questions that they gave you

Fa: Oh yes, I mean, well, if there's not somebody there that's going to answer it, there's so many, I found that there's so many different places you can turn to, and so many different things. But the problem is with me, I had to accept that there was a problem to begin with. But once I did, I mean, I found so many places and things to just check into, you know, and it all depends upon what you want, you know. If it's information, why God, it's there. But there's so many different, there's group for parents and then the kids, and everything else. It's just, I got overwhelmed with, I got flooded with brochures and everything from everybody and all this information. (12203)

Other parents had more difficulty in seeking out resources and depended on the providers at the center and other health care settings to Make the Connections for them. For the most part, parents had no idea where to start, or what types of services and resources might be available. The providers, who had access to information about

resources, generally made referrals for the connections they thought were appropriate for or needed by the parent and child at the time, rather than providing a list of available resources from which parents could choose. One parent expressed frustration at this practice.

Mo: So I know there's other moms that have felt some frustration with, you know, like not knowing about [other center], not getting pursued in that direction, until we get it doing it on our own. I don't know if it's, I don't know if it's a money thing. I don't know you don't want to because [the other center] does outside therapy services....And you need that. Moms, Dads need that knowledge of what's out there and how to get it. (12104)

Managing Uncertainty

Reducing uncertainty versus maintaining uncertainty. The desire for reduction of uncertainty was by no means universal. Parents varied in the degree to which they wanted information. Some seemed to want to maintain uncertainty. Determining the parent position on management of Uncertainty was a judgment call on the part of the providers who had to determine from the family's cues what they wanted. With the following family, parents were asking whether the child would ever walk, but both providers judged that the parents didn't want to hear the answer. In this excerpt, the parents had been telling me in great detail how much they liked their therapist and how gentle she had been with them early on. They had only this one area in which she seemed "professional", which meant to them that she was non-

communicative. That area was when they asked her if she thought their child would ever walk.

Mo: But then again [the therapist], she won't -- I think sometimes she'll give a vague opinion, like what she thinks [Child] will, you know, "Will she walk?" "Well," you know, and no one will say, "Yes," "No," "She'll be in a wheelchair," whatever. And I'm sure no one wants to -- (11105)

Fa: Nobody wants to put their foot and say, "Yes, she will be," because if they don't, I don't know if it has any legal comeback. (11205)

Mo: When we ask her, "Will she walk?" "Ummm," you know. She might say, "Well, you know, she could." Or give a real vague of "Maybe down the line possibly with a prone stander to get her..." you know, but she --. (11105)

Fa: She won't, she does not, that is true, she does not come out and say what she --. (11205)

Mo: What she really thinks. (11105)

Fa: What she really thinks. (11205)

Mo: Yeah. (11105)

KW: For the long term?

Fa: For the long term. (11205)

Mo: Like she wouldn't come out and say, "Um, well I really don't think so." She wouldn't say that. (11105)

Fa: And I don't know if it's because her, for a couple of reasons is because -- we asked her those questions because we know she has been in her profession for quite a while and she's seen an awful lot of kids. And so she would have a better barometer to judge by looking at [Child] what's going on than we would because, you know, we don't have -- that's why we ask her. But on the other side I can understand why she doesn't want to do that because for one thing, she might not want to get our hopes too high. (11205)

Mo: Or crush us. Or crush the hope. (11105)

Fa: ... Or crush them. You know, stay real neutral. Um. So I can see that, but that is a little frustrating. (11205)

Mo: Yeah, it's not negative. It's just, you know, we just -- (Laughs) - - gives us something to more --. (11105)

Fa: I think it's because, I think it's because we're always looking for future hope too, you know, and we've learned a lot to just take her day by day. She amazes us. We feel that without her therapy, she would still be like this [indicates a curled position] and probably end up with more of a permanent curve because, you know, when she gets an upset stomach she curves an awful lot. (11205)

Fa: Yeah, as far as that goes, you know, professional things like that, she [therapist] won't come out and say what she sees in [Child's] future. For one thing, you can't tell anyway. From day-to-day, you don't know. You know what I mean? You never know. I've heard of kids all of a sudden there'd been something wrong with, you know, and all of a sudden almost a miraculous change. You know. So you never know. I think we always felt, we always hope for the best. So I think just having that positive attitude helps us out a lot too. And then on the other hand sometimes it's real hard because you just want her to be able to [walk] now. (11205)

From the point of view of the therapists working with this family, this was a very difficult situation. From their reading of these parents' cues, they felt hesitant to provide direct answers to questions about long term issues. One provider described it this way:

Pr: ...On the other hand, it's really frustrating because they are so positive and it seems like her outcome is not going to be very positive. But they are giving very definite cues that they need to be positive in order to maintain and to keep going, and so I feel like I need to be supportive of them so that they can kind of maintain pulling it all together, and yet I don't want to give them false hopes. (21304)

Later in the interview, she speaks of the same family again when she is talking about the cues parents give:

Pr: I think the [X family] may not be as direct in asking, in telling us what, how they want us to interact with her, but I think from them coo-cooing her and being real positive and saying "We're going to do it!" that they're telling us how to act around them and her. And, I don't know, I, it's so easy to know that they're just so fragile. (21304)

The other provider for these parents described her position in the following way:

Pr: How they feel. It's like they're going to feel how they feel and I can try and help it and I can try and be as sort of sympathetic or as careful about what I say, but I'm not going to go as crazy trying to, you know, sort of second-guess it all the time as I think we used to. Maybe I'm just getting old. I don't know. But you know, like [this family] is sort of an example. I know they are not at a place where they are being extremely realistic about how she's doing. I don't think they can be expected to be particularly realistic. They will at some point, and it's going to be pretty devastating, and they are gradually working into it I think. I mean there's the odd comment that let's me know they are kind of at times thinking along those lines, but I think they are in very different places. (21102)

When asked to summarize her position on giving information to parents, she said:

Pr: ... summarize it. I don't know. I guess the parents that I have, anyway, have given me pretty clear clues about where they are and I guess I sort of talk within those boundaries, sometimes push it a little bit or suggest new ideas, but just try and stay where they are, you know, where they are, because I don't see any need to cause great drama in anybody's life unless they are asking or unless it's causing a problem. You know. I mean I guess if somebody wasn't coming [to therapy] or wasn't working on stuff or they were getting ready to go to school and I knew they were going to be stuck in a multiply-handicapped [classroom] -- I mean I guess if there was a real need to do something, and as she gets closer to three, if we are still where we are right now, then we'll need to do something else. (21102)

As a result of Reading the Cues, these providers attempted to strike a balance between dealing with the Here and Now and the Future and between possible Competing Needs of parents, child and providers by Maintaining Uncertainty.

Another example of parental desire to maintain uncertainty was a mother who delayed bringing her child for treatment for weeks after referral and who has also declined to have genetic testing done. One mother decided to put off recommended genetic testing until the child “is done with therapy”.

Other parents wanted to know “up front” what the providers thought was in the future. That is, they wished to reduce uncertainty.

Mo: So we've been there two years, a little over two years. We have up and down times. I'm a type of mom that wants to know everything from the word get-go. If there's any suspicions down the road that you're thinking of, I want to know them as soon as you think about them. And I think that has been a tension between me and [the center]. From the word, day one, I wanted to know other parents. I wanted people I could talk to. I wanted to know everything that the doctors were thinking at the same time that they were thinking it, just so that I wasn't surprised at anything. I didn't want them to come down in a year and tell me “Your child's never going to walk”, you know. I wanted them to be as up front, you know. And they're not going to have any magical answers, I knew that, but I just wanted them to be as up front with me as they could. (12104)

As the parents differ in their desires for uncertainty reduction, the providers also differ in their views of their role in maintaining or decreasing uncertainty for the parents. Here, two providers who share the same opinion about disclosure take a slightly different approach to the rationale.

KW: Do you think, I mean, it seems like they vary in how much they want to know. Do you think that's true?

Pr: I think that's definite, but whether or not it is good for them and good for their child to allow them the security of not knowing, or just, I'm not so sure. Sometimes I think they need to be pushed to challenge themselves, and then can retrospectively look back and say it's better that I do know. And sometimes you wait and maybe not tell them quite in the order because you can just feel that they're not quite ready, or that they've got maybe an anniversary coming up on the weekend and what you're talking about is going to last a lifetime and please really could wait a week. (22506)

While the above quote indicates a view of what is best for the family and child, the following one is described as being based on feedback from parents in the past.

Pr: I think I lean on the highest side of disclosure than most other of my colleagues. Because I just feel like some of the most significant feedback I've gotten over the years from parents is an appreciation for saying the things that nobody else wants to say. And I think there's some evident things about various children that any professional who deals with them would say is "Of course this is going to happen." And yet nobody says that to the parents. And I can't stand that.(21205)

One couple whose child was followed by this provider, mentioned her giving them honest information as one of the things they liked about her. These parents were interviewed separately on different days. I spoke with the father first.

Fa: ...So we get a lot of straight information from her that way, and she's very honest and will tell us, you know, things that will actually happen, not so much as to paint pictures as you know hopes that, you know, some things will happen -- this is what's going to happen. This is the reality of it right now, the day-to-day reality of it. (11203)

I asked the mother whether she agreed that this provider gave them "straight information".

KW: So in terms of things about [your child] in particular, do you think she's really straight with you about that? It seems like your husband was saying something to that effect, that you can get straight information or something like that.

Mo: Oh yeah. Yeah, you tend to always believe what she says, you know, because we get a lot of different information about, you know, what his function ability is going to be. She was the first one who ever told us really, really what it was going to be like. (11103)

Strategies for managing uncertainty. Strategies for managing uncertainty varied according to whether the goal was to reduce it or maintain it. Strategies for reducing personal uncertainty included asking questions, reading cues and being vigilant. Strategies for maintaining uncertainty included the parents setting boundaries and giving cues and the providers reading the cues and making decisions about what was desired and what was the best course of action. When providers decided to Push the Boundaries and provide information to reduce parent uncertainty, they sometimes used strategies such as Setting the Stage. This was a process of gradually alerting parents to issues by asking questions and making comments. In several cases, parents were able to identify this strategy of the providers and appreciated it.

Mo: But they're really good at picking up how to communicate with each parent differently. So I really enjoy (12103)

KW: That's interesting.

Mo: Yes, I think they are anyway. I mean, because they didn't offer information to me that I wasn't ready for. I mean, they didn't talk to me about wheelchairs and braces and stuff because I'd never asked. And he was really not at that point yet, so they didn't offer that information. And then when we did ask they said, "Well, it's something that you might have to think about. He may need it full time or he may need it

part time.” and they offered just different situations where, you know, we'd have to think about it. You know, the possibilities there. So they didn't say, “Yes, he's going to do it” or “No, he's not.” And they didn't really put the information, I mean, you know the information is there if you want to ask. (12103)

KW: Umhm.

Mo: They're going to have some kind of comment, but without asking they didn't just start throwing it at you. “It's time for you to do this.” (12103)

KW: And you liked that.

Mo: I liked that, yes, I do. (12103)

Consequences of Striving for Therapeutic Relationships

Consequences included whether the provider's relationships with the parents and child were perceived as therapeutic, parent and provider perceptions of their own competence, and changes in child competence. Both parents and providers desired the achievement of therapeutic relationships. Relationships which were a good match were generally therapeutic for both parents and children and affirming for the providers. The goodness of fit of specific relationships varied across all these areas and over time.

Providers needed some indication that what they were doing was worthwhile and appreciated.

Pr: I think that that family is so rewarding because they give so much to their child and they care and they think about everything that you say and you can see that they are taking that and incorporating that at home. (21304)

P: The [family] are a real good example of a family that you can really talk with. And she called yesterday and she just had some

wonderful positive things to say about my style of working with [her child] when I've been really frustrated and feel like I come in and I don't do a thing for this kid because we're just on different wavelengths. And I feel like I don't read his cues real well and he's not real connected with me, but she was just extremely positive about how I talk, how I play with him, and that was real rewarding. (21304)

The degree of match between the perspectives of the parent and the providers as to whether a relationship was therapeutic and for whom varied. In most cases where the parent was dissatisfied with the services provided to them or to their child, the providers were unaware of this. All providers who participated in this study identified a family focus and a desire to communicate well and to provide services which met the expectations and desires of the families. Most of them identified consciously considering what they said, how it sounded, and how it might affect the family. In two cases where there had been an occurrence which caused the family concern, the providers were aware of the concern, but felt they had handled the situation fairly well and were unaware of the extent to which the parents were still upset.

It was important to both parents and providers that relationships be therapeutic, at least for the child, but usually for the family as well. There was a great deal of effort and many trade-offs on the part of both parents and providers to this end. Child progress varied extremely from child to child, depending on the severity of their developmental and medical problems. In cases where children made positive and steady changes, it was affirming for both parents and providers. In cases where gains

were inconsistent or nonexistent, both parents and providers had to look to other sources to determine their own feelings of competence and how therapeutic the relationships were. In these cases, the relationships between them became more important and were scrutinized more critically.

Uncertainty seemed to be an over-riding influence with which both parents and providers had to grapple. The provider goal for management of uncertainty seemed to be to maximize the parent's coping with the child and his or her disabilities and their ultimate acceptance of the situation. Parents varied a great deal on what they wanted and this also changed over time. Outcomes were the level of parent satisfaction with the amount of information they received, how satisfied they were with the therapy provided for their child and how competent they felt in parenting their child with special needs.

CHAPTER V

REFLEXIVITY IN METHOD

There is in any research endeavor an inevitable interaction between the researcher and the data. This interaction is addressed in quantitative research by attempts to distance the researcher from the data. In qualitative research, however, it is important that the investigator is intimately involved with the participants and the data as this is an integral aspect of the methodology. The question of how to address issues of investigator interaction with the data are discussed at length in the current nursing literature as well as that of other disciplines (Lipson, 1991; Robinson & Thorne, 1988; Wilde, 1992). For this study, the technique of reflexivity was used to explore the relationship of the researcher to the informants, the data, and the reader, in the manner suggested by Kahn (1993). This process of reflective thinking about the study will be discussed in this chapter.

Reflexivity

Reflexivity is discussed by Lamb and Huttlinger (1989) as:

...a kind of critical thinking that ...reflects the dynamic interaction and exchange between the investigator and the total research environment... and is a process in which an investigator seeks to understand how personal feelings and experiences may influence a study and then strives to integrate this understanding into the study. (p. 765).

As discussed earlier, this process, when explicated, should allow the critical reader to evaluate the trustworthiness of the data.

Relationship of the Researcher to the Informants

My relationship as researcher to the informants in this study was made more complex by several factors. First, as the parent of a daughter with a developmental disability, I may have been considered to some extent an insider to the parents who participated in this study. Second, as a professional service provider I had previously worked at one of the centers in the study with some of the providers who participated in this study. Thus, I was an insider to many of the professional participants as well. Third, I am a nurse, which brings to my research issues of how nursing knowledge affects the way I respond to the participants in terms of interventions and the way they respond to me as a member of a helping profession. In addition to whatever effects were produced by the degree to which the participants in this study considered me an insider, there were effects on me and my behaviors and interpretations as a result of these past experiences. A final factor which I considered to be significant is that my daughter's particular disability is mental retardation and she does not live with me, but in a group home. This dreaded diagnosis and the fact that she is placed outside my home was information which I believed had the potential to affect the interactions between me and the participants in this study. Each of these factors will be discussed in this chapter.

The Researcher as Parent

As the parent of a daughter who has mental retardation, I am always faced with the decision of whether to disclose this information to the parents with whom I work. I have always viewed this information as having the potential to either damage or enhance the relationship I had with parents. To the extent that it would make me seem to them to be an insider or someone who “really understands” the information has the potential to be helpful. However, for parents of very young children for whom a diagnosis and/or prognosis has not yet been established, mental retardation is not necessarily something they would view as a connection between us. In fact, because of the negative connotations of mental retardation, that diagnosis might be seen as a barrier to communication, especially if the parents thought I was suggesting that we had some kind of connection because of our children. Thus, sharing this information has always been a two-edged sword, the effects of which were partially out of my control and even my awareness.

The issue of personal disclosure was one to which I gave much thought to as I planned this study. It was my decision that I would disclose this information about myself and my daughter to parents for two reasons. The first was that I felt an ethical obligation to inform the participants in my study about my perspective in asking them such personal questions. The other was that it had been my experience as a clinician that when this information was disclosed to parents late in the formation of a close

relationship, there were sometimes feelings of having been deceived on the part of the parents. While I probably only had this experience once or twice, it has had a continuing effect on my behavior. One indication of the importance of such personal information to parents is the fact that many times in the early stages of an evaluation, parents have asked me and other providers who were present whether we had any children.

On one of my early trips to Center A, where I was to begin data collection, one of the therapists, who is a former co-worker of mine, brought up this issue. She and the other providers at Center A had been discussing what effect my disclosure would have on the parents in terms of their willingness to share information with me. Their concerns were related to the idea that the parents might think that I associated the diagnosis of mental retardation with their child. They were relieved to hear that I planned to tell parents that I was telling them my experience with my daughter as a way of explaining how I became interested in developmental disabilities, but that I felt all children and all parents were different and I was interested in their own experience. There is no way to really know what effect this information had on the parents who participated in this study. I found it very interesting, however, that these providers were also self-conscious about the use of the term mentally retarded, and vigilant about what effect it might have on parents.

Of the fifteen families with whom I did interviews, seven made reference to my disclosure during the interview. Four asked specific questions such as had it been hard for me or something more specific about what my daughter was like. Three more made some reference during the interview such as “ I’m sure that you, your daughter, it bothers her.” In the case of two of the parents who asked me specific questions about my daughter, I felt very uncomfortable. I realized that I have no problem talking to parents about what it was like for me or how I feel or felt. My problem occurs when the parents of young children ask me to tell them about my daughter so they can compare her development to that of their own child. I feel the desire to protect them from thinking their child might be as retarded as my own. The more similar their child is to how my daughter was at that age, the more uncomfortable I feel.

I was somewhat surprised that so few parents asked me specific questions. In retrospect, I might have also told them that I would be happy to answer any questions they had about my daughter at the end of the interview, but this might also have made them feel obliged to inquire about her. My final conclusion was that what I did was reasonable. It is not possible to know the total effects of such information.

The Researcher as Colleague

As a member of an interdisciplinary team in the past, I had been accustomed to discussing with my colleagues my conversations with and impressions of the families with whom we worked. Because many of the participants in my study were the same

colleagues with whom I had worked in the past, we had to inhibit our past habits of interaction during my research. While this was often difficult, it was accomplished. However, the constant awareness of what was permissible to discuss and what was not made me aware of how much personal information is routinely shared among professionals about families. I doubt that the parents have any idea of the extent to which the information they share with one team member is shared with other team members. For me, this experience raised issues for my own practice about informed consent and the relevance of personal information to health care.

Most information could not be shared between parents and providers simply because it was confidential, regardless of how innocuous it was. However, some information was also significant because of its nature. For example, when parents had problems or concerns about a provider or the service their family was receiving, or when providers shared sensitive information or critical remarks about a family, I felt the need to be extra vigilant in what I said or how I responded. I feel I was probably overly cautious and thus somewhat inhibited in my asking of subsequent questions because of the paired parents and providers. This is probably something that I would become better at doing with more practice, thus potentially enhancing the richness of the data obtained.

The Researcher as Nurse

Maintaining the role of researcher when one is trained as a nurse has been documented as a difficult task (Lipson, 1991; Swanson, 1986). The situation in which I found myself during participant observation was a very familiar one. At one center, the providers were those I had worked with in the past. At the other, the facility and some of the staff and providers were the same. In both cases, the treatment sessions were very similar. In my previous role as a Clinical Nurse Specialist, I usually sat near the parent so I could talk to him or her during the session and observe the therapy at the same time. As a researcher, I tried to sit away from everyone so as not to be intrusive. As the sessions progressed and the providers and parents discussed various matters, I had to exert extreme effort to overcome the urge to move in closer, ask questions or make comments, particularly when health related issues were discussed. This was more difficult when the provider was one with whom I had worked in the past. In some cases, providers with whom I had worked before tried to draw me into the conversation or began to provide me with more information about the child and family, explaining to the family that I was a nurse. This occurred in spite of the fact that I emphasized at staff meetings that I wanted to observe and not participate in the session. As time went by, this didn't happen as much, but it was clearly an ambiguous situation for others as well as myself.

In one case, I did allow myself to be drawn in to the session. The child was an infant who was medically fragile and the therapist was seeing her alone that day. The family had just moved to the area recently and was still in an evaluative process. Although the therapist was not one I had worked with in the past, we had developed a relationship during my stay at the center and she asked me several health related questions that arose during the session. As it turned out, this was the only session I observed for this family and I did not ask to interview them. I was surprised by how torn I felt between the roles of nurse and researcher in this situation.

During interviews, I frequently found myself focusing on the clinical aspects of the stories the parents were telling me about their experiences with their children rather than the communicative aspects. I would ask questions to elicit more information about the surgery or the symptoms or how the feeding was going and so forth. I sometimes had the urge to provide what I thought was a better explanation than what they had understood about some aspect of the child's care. My struggle in this aspect of interviewing was facilitated by developing questions which focused on the communication process and the relationship between parent and provider, such as "How do you handle it when you are given conflicting information like that?" Once I was refocused on my goal, framing the appropriate questions became easier and more spontaneous.

One of the mothers I interviewed (who was also a nurse) asked me why I did not take notes during the therapy sessions I was observing. I told her that I had considered that and decided against it for two reasons. One was that I thought my presence might be even more distracting to the participants in the sessions if I were taking notes while they were interacting. The other reason was that I thought it might distract me from what was going on in the session. I told her that I made notes as soon after the session as possible. This mother shared with me that she wouldn't mind at all if I wanted to take notes during her child's sessions. I did, in fact decide to do this at her next session as a way of responding to what seemed almost like a request from her. I also wanted to see how it worked for me, given the opportunity to do it with permission. I found it did distract me from what was going on, but during one session I began making notes of the vocalizations of the child, who didn't usually speak much during the sessions. With the mother's permission, I shared these with the speech therapist, who was not present that day and was preparing to evaluate the child's speech. In preparation for the speech evaluation, this mother also audiotaped some of her child's speech and made copious notes on his vocabulary at home. In an interview following the speech evaluation, she shared with me that the therapist gave more attention to the notes I took than the ones she took. She said she would take 'all the help I can get', but she was bothered by what she considered discounting of the worth

of her observations. This instinctive attempt of mine to get involved and “help” resulted in what I considered a disservice to the mother with whom I was working.

Relationship of the Researcher to the Data

The term ‘immersed in the data’ took on new meaning for me as I attempted to follow the guidelines for grounded theory analysis. Within two weeks from the end of data collection, I had 36 transcripts in various stages of analysis, two small notebooks full of field notes, and a growing set of theoretical memos. The volume of the data seemed to grow daily as I continued to make notes on the interviews, and on the literature I was reviewing at the same time. The analysis was a process of going through the data again and again from different perspectives and with different purposes. It eventually became necessary for me to take a break of several weeks from the data in order to regain my perspective.

I became very familiar with the taped interviews as I listened to many of the tapes prior to transcription and proofed all of them after transcription. I was struck with how much information is lost in the straight transcription of a conversation. As I made corrections on the transcripts, I also added underlining for emphasis in places where the informant stressed words in speaking. In a few cases I also made notes of what I thought was meant by excerpts which made sense when listened to on the tape, but were confusing when read from the transcript.

Typing my field notes and theoretical memos into the computer also made me more familiar with them. Once data collection was completed at the centers, I typed most memos into the computer, but I also used a large sketch pad to make diagrammatic representations of the data as I coded it. Each time a few of these sheets accumulated, I would organize them and type an outline of them into the computer also. As I typed, I often found that I had made essentially the same set of notes at different times on different pieces of paper. At many points as I read and re-read the transcripts, I felt I needed to do more interviews to ask the obvious questions I had missed the first time. I often spent time going through transcripts looking for instances I could remember, or looking for further instances of a category I found in a note or interview. During these times, I regretted my decision not to use a computer program to help me with this task. The process was definitely both inductive and deductive as well as non-linear.

Because I was studying an area with which I am intimately familiar, I struggled with whether I was finding concepts in the data or whether they were my own previous ideas. I found that I was avoiding areas of the data that reflected what I had expected to find. For example, I believe that stigma is a very powerful force in the experience of having a child with developmental disabilities. I further feel that the worst stigma for many people in our society is mental retardation. When I saw instances of what I considered to be the effects of this stigma in the data, I questioned them and tried to

construct other explanations for them. For example, one topic that is very difficult for many parents is the point at which a wheelchair is recommended for their child. This was discussed by every parent in the study whose child had or was being considered for a wheelchair. I felt that to a great extent, the discomfort about the wheelchair was an issue of stigma, but decided to look for other explanations for why a wheelchair would be upsetting. The obvious reason is that it means that the child is not able to walk or is not expected to be able to walk for some time. This means the child will be limited in what he or she can do. If the child wants to play ball, for example, this may not be feasible. There might be places the child will not be able to go. There will be the need for expensive equipment, maybe a special vehicle to transport the chair. The family will need a one level house. All these are legitimate reasons for concern, but they don't seem to account for the degree of trauma of a wheelchair. When I went back to the data, I found several descriptions of getting a wheelchair that reflected stigma and confirmed my previous impressions and beliefs. These examples are discussed in Chapter VI. Thus, after examining the data again, I came to the conclusion that there was definitely evidence of the effects of stigma there, and it was not just my preconceived ideas. However, because the stigma of handicaps is so ingrained in our society, and often not explicitly acknowledged, I might not have noticed this evidence had I not been previously sensitized to the issue.

Relationship of the Researcher to the Reader

In a discussion of the relationship of the researcher to the reader, it is necessary to acknowledge that the researcher is making an argument and defending it. The writing is an attempt to influence others. In the case of this paper, I am not only trying to convince the reader to accept the conclusions and interpretations I have come to, but also that I have conducted an original and scholarly inquiry into a topic area of significance for nursing. In the following chapters I also have the opportunity and challenge to discuss my conclusions and interpretations in regard to their research and practice implications.

CHAPTER VI

DISCUSSION

Introduction

This study of the communication between parents and providers in two developmental treatment centers indicated that in general, these were very positive and nurturing environments for parents and their children. In many ways, the concerns and problems identified previously by parents in other health care settings such as hospitals and diagnostic and medical clinics were addressed by these centers. Parents were afforded respect, given information and encouraged to be involved in their child's treatment to whatever extent they desired, beginning with a basic minimum of bringing the child to therapy and incorporating basic handling and interaction suggestions. They were provided with information in a positive and understandable manner. There was a family focus and the atmosphere was friendly and comfortable. Their children were treated gently and in a playful manner. These are all characteristics which are recommended as best practice currently in the field of early intervention. Yet, this description says little about exactly how this communication process occurred on a daily basis and how issues of uncertainty and information are viewed and dealt with by the participants. Within this generally positive atmosphere for parents who found

themselves in a most difficult situation, there was still wide variety in the ways in which communication expressed information and the degree of satisfaction the parents and providers experienced. In spite of the positive aspects of the situation, bringing a child to therapy one, two, three or more times each week over a period of months or years is still a great commitment for parents and requires ongoing attention to communication between parents and providers.

This study led to the development of substantive theory, the core category of which is *Striving for Therapeutic Relationships Within a Context of Uncertainty*. As a part of the analysis of data, ongoing review of the literature was conducted, focusing on literature which was suggested by the content of the data. Several specific areas of literature were pursued during the analysis of data for this study. The Model of Guarded Alliance in health care relationships (Thome & Robinson, 1989), which was reviewed prior to the study was re-examined in more depth as it became clear that much of its content was reflected in the data from this study. In relation to the management of information in situations of uncertainty, literature on deceptive communication was reviewed briefly. Recent research and theory in the field of early intervention was also reviewed. And finally, the concept of stigma was explored in terms of how it affects the families of children with developmental delays and how it relates to the concept of normalization.

In the first section of this chapter is a discussion of the framework developed from the data, followed by discussions of trust, deceptive communication, and stigma and normalization. The remaining sections of this chapter will discuss limitations of this study and implications of the findings for nursing research and nursing science.

Discussion of the Core Category

The core category identified for this study of communication between parents and providers was *Striving for Therapeutic Relationships in a Context of Uncertainty*. This category is representative of the finding that it was through interpersonal relationships between the parents and providers that contributions were made toward the well-being of the family and child. The importance of such relationships has become increasingly recognized in recent years as evidenced by research on social support and the move toward family oriented approaches to intervention for young children with disabilities. Intervention programs where the parent waits in a lobby while the child is taken in a separate room for treatment are now rare. The mechanisms for efficacy of early intervention are now being investigated with a view toward a broader range of variables than just the developmental changes in the child (Marfo, Dinero, Browne, Gallant, Smyth & Corbett, 1992). It is recognized that family ecological factors play an important part in the outcome for the child and that these are influenced by communication interactions that occur in the intervention setting as well as other factors (Bernheimer, Gallimore & Weisner, 1990).

Enabling and Empowering families is an approach to parent involvement espoused by Dunst, Trivette & Deal (1988). They advocate assisting families to make use of their own informal resources as a principle way of meeting their needs, thus empowering them. Only when informal resources are exhausted are formal sources of help encouraged. Families are taught and encouraged to access the supports they need rather than having them provided by a helping professional, thus promoting dependence. Dunst, Trivette and Deal (1988) note that some families in their program came to identify providers as among their informal rather than formal support network. This phenomenon was also identified a number of times in the data from the present study. Providers were identified by their professional roles with the family such as advocate, teacher, therapist, but also as friend, "like family", "she mothers me". Some families and providers went so far as to see each other socially.

Story Line

The story of Striving for Therapeutic Relationships in a Context of Uncertainty begins when a concern is identified about a child's development. It might be identified by the parent or by someone else. If it is the parent, it may be some time before anyone listens. This can be very frustrating for parents. If it is the health care provider who raises the initial concern about the child's development, the parents may not agree or may be upset. Eventually, a referral for evaluation and/or treatment is made. Parents respond to referral in a variety of ways. The parent may have requested the referral,

may accept and agree with it, may accept it and disagree with it, or may resist it. How this all occurs affects the attitudes of the parents when they initially come to a treatment center. They generally do not know what to expect from developmental treatment, but they usually have some type of experience with the health care system in getting the referral. If they have not been satisfied with the health care system, they may be guarded. What is known of that initial experience by the providers also affects them and how they respond to the parents. If providers know that the parents have disagreed with previous providers or had a difficult time in the health care system, they are more sensitized to “be careful” with the parents.

Throughout the term of their involvement with each other, parent-provider relationships are permeated by uncertainty. As a general rule, the uncertainty decreases over time, but this is variable, depending on the child, the parents and the providers. Parents and providers differ in how they handle uncertainty, and a lot of energy goes into planning and managing uncertainty for both parents and providers.

Some provider uncertainties relate to the child and his or her development, diagnosis and prognosis, and temperament. Providers also have uncertainties about the parents, what their attitudes might be, what they want or need, how much they can understand, how much they want to be involved in the child’s care and treatment. Because the providers experience the uncertainty of this type of work routinely, they have somewhat developed ideas and ways of approaching the problem. They look for

certain cues from the parents, they use particular strategies to get information. In many cases, the providers rely on reading the cues of the parents, but are unable to articulate what those cues are. The approaches of the providers vary by the discipline in which they were trained, their years of experience, whether they have children of their own, and their personal belief systems.

Parents and providers each have their own perspective, influenced by their past experiences and roles. The parent perspective focuses on the well-being of their own child and family while that of the provider views the child and family as one of many on their caseload and in their professional experience.

Because parents have little experience with parenting a handicapped child, they do not have readily available criteria with which to judge the therapy situation and the skill of the providers. They tend to depend on their evaluation of how the provider relates to their child, to them and how well their needs are met. Parents generally value a personal relationship with the providers and any evidence communicated to them that the provider cares about and respects them and their child. They find evidence of the provider's care and respect for them and their child in things the providers does for them, both routinely and "going above and beyond"; how the providers give them information; how well the providers meet their needs both expressed and unexpressed; how the providers follow through on what they said they

would do; how well the providers keep in touch with other providers involved with the family.

Parent and provider interactions are further complicated by the fact that there are many processes which change over time. In order for the relationships to be therapeutic both parents and providers must constantly be vigilant for change.

Parents and providers have many strategies by which they attempt to form therapeutic relationships. These include Balancing of needs, roles and perspectives, Reading Cues and Questioning to decrease Uncertainty and Managing the sessions and relationships. Some degree of therapeutic relationship is the consequence of all these strategies used in the face of the particular contexts and conditions. The relationships are therapeutic to the child and family differentially, but how therapeutic they are to the child may depend to some extent on the relationship between parent and provider. One provider said she thought that the only children who make significant gains in therapy were the ones where the parent and provider had established a significant relationship. The providers strive for this therapeutic relationship by trying to match what the parents want or need, within the limits of the provider's beliefs about her role. They Read the Cues of the parents and adjust their interactions and interventions accordingly.

The parents strive for a therapeutic relationship by trying to get their child's and their own needs met without jeopardizing the relationship with the provider. Parent

views of how careful they need to be with the providers vary. Parents evaluate the relationships for their therapeutic value for themselves and their child. If they have concerns, they weigh them against the positive aspects of the situation and make trade-offs based on these judgments.

Identification and Referral

Although Identification and Referral had already taken place in order for the child to arrive at the Center, the effects were still felt, as evidenced by the parents discussing at length their initial experiences as a necessary beginning to describing their current experiences. It seemed that the manner in which the initial concerns had been handled was very important, but the style of the provider making the initial referral also needed to match with the parents' preferences. The parents' telling of this story was elicited by the providers in their history at intake, and was not only an opportunity for the parent to share the story with sympathetic and informed listeners, but also had an effect on how the providers approached the parent in the future.

Uncertainty

Uncertainty was pervasive for both parents and providers, and was made significant by the negative implications of developmental disabilities. It was uncertainty combined with the stigma of developmental disabilities that made it necessary for both parents and providers to adopt strategies for action and interaction in their

communication. Uncertainty was cited by providers as one reason for not sharing with parents their perceptions of the child's potential or prognosis. It was also cited by some parents as a reason not to believe negative information they were given. Parents were in the uncomfortable position of wanting information about their child, but not knowing if the information would be positive or negative and not knowing whether to believe the information in either case. In some cases, both parents and providers avoided this situation by focusing on the Here and Now and assigning responsibility for information about the Future to the physician. Sometimes, however, the physician's information was negative or provided in a negative way, and parents needed to rely on the positive and normalizing approach of the providers at the center for a positive outlook about their child's future.

Differing Perspectives and Change Over Time

Intervening Conditions for the core category were identified as Differing Parent and Provider Perspectives and Change Over Time. Regardless of how much the parents and providers had in mind the common goals of a therapeutic relationship for the family, they saw the situation from Differing Perspectives. Parents perspectives included their initial experience of Identification and Referral, how they felt about their role as a parent, how they felt about their child's problems, their previous experience with handicapping conditions and their attitudes about handicaps, their experiences

with their other children, and their views of the role of the parent and how parents should relate to providers.

While some parents and providers were less aware of these differences in their perspectives, others were very aware. Throughout the data were examples of how both parents and providers consciously and unconsciously attempted to understand the point of view of the other. For the providers, there was the risk of becoming ineffective for the child if they saw the situation too much from the parent's point of view. This is one example of Balancing Competing Needs. For parents, looking at the situation too much from the point of view of the provider led to the risk of not being able to voice concerns about the child's treatment.

Providers were aware that parents had different perspectives, and were generally prepared to respect them, but this varied from one provider to another. This variability was somewhat circumscribed in these two centers by the fact that both were operated under a family oriented framework. Thus, providers who had a view of working with families that was different than the family oriented approach still had to function within a family oriented framework. One example of this was how providers felt about having parents in the sessions during therapy. Some providers had worked previously in settings in which the parents waited in the lobby and came in at the end to be instructed on what to work on at home. Some of them felt that the children worked better without their parents present, but this was not considered an option as a regular

practice at these two centers. On the other end of the continuum, other providers felt there was little use in seeing children without their parents present so they could carry over in the home. Even within the practice of always having the parents in the sessions, providers varied in their feelings about how much the parent should function as a therapist for their child. Several said their practices had changed over the years from providing extensive written home programs which they expected the parent to carry out daily, to teaching by modeling those things the parent could incorporate into the daily activities of the child.

Change Over Time was also an Intervening Condition. Because there were many processes involved, such as the developmental process for the child, the adjustment process for the parents, and the relationship development process for the parents and providers, there was constant change occurring. There were obviously changes in the child, both from the normal process of development and from the interventions of the parents and providers. There were parallel changes occurring in the parents in terms of their concerns, understanding and goals. Providers also changed as they gained experience with children and families, had children of their own, and developed relationships with individual families. Providers were sometimes more aware of parent changes early in the relationship than later on. As they got to know families better, they asked fewer questions, and assumed things were the same unless a

concern was voiced. This became a problem when parents were unable for whatever reason to voice their concerns.

Under other conditions, providers assumed Change Over Time for parents and relied on its occurrence. This happened particularly in terms of parent understanding of the child's limitations. Providers often did not make these limitations explicit even after their own Uncertainty was reduced, but relied instead on the parents gradually coming to realizations as the child changed or failed to change.

Strategies for Action and Interaction

The data from this study revealed multiple Strategies of both parents and providers for developing Therapeutic Relationships. These strategies were interrelated with each other and related to the other parts of the paradigm. Balancing, one main category, consisted of four aspects of balancing. The other main categories, Reading the Cues, Questions, Managing the Sessions, and Managing Uncertainty occurred throughout these balancing categories. Several of these also had layers of sub-categories.

Balancing

Balancing was required in the areas of Competing Needs of parents, child and providers, Competence of child and parents versus the Need for Intervention, the Here and Now versus the Future, and Parent and Provider Roles.

In terms of their roles, providers and parents varied in how they saw these.

Both parents and providers identified many roles that the providers filled. The balancing of the personal relationship between them and the role of parent vs. provider seemed most critical. While parents varied somewhat in the amount of personal disclosure, the level was generally high. Providers varied more widely in their level of personal disclosure, but it was overall much less than that of parents. Both parents and providers varied in how they felt about the role of parents as “therapists”.

Another area which required Balancing was issues of the Here and Now and the Future. The Here and Now included everyday issues of what is going on with the child right now and what does the child need right now, and the bringing up of issues which were perceived as problematic or potentially upsetting right now. For example, the provider could simply talk about the child’s swallow being poor today or she could go further and talk about whether the worsening swallowing ability was related to the child not being fed orally on a regular basis.

The Future included issues of diagnosis and prognosis and the future implications of what is going on in the present. In general, Providers tended to focus on the Here and Now issues and leave the issues of the Future until the parent brought them up or there was some necessity for bringing them up. Thus, in the above example the provider probably would not say to the parent that the child’s decreasing swallowing ability indicated that the child might not ever be able to feed orally unless

the parents asked, or unless it was necessary to address the issue for some other reason.

Balance between acknowledging and affirming the competence of both the child and the parents and documenting the need for ongoing services was accomplished through such strategies as normalizing, affirming and taking one step at a time. Providers focused on what the child was doing at the time and what to do to reach the next step. They went back and forth between recognizing what the parent was doing with the child that was helpful in promoting development and making suggestions of adjustments or further activities. They watched for Cues from the parents to indicate how much to say, when to stop.

Between the family members and providers there were often Competing Needs to balance. While some providers came from backgrounds where the child needs always came first, both of the centers in this study had philosophies with a family focus. Therefore, the need for balancing of child and family needs was inevitable. When these needs were in conflict with each other, providers were influenced by their own beliefs and professional background. At times, a provider's need for time with a child or parent came into play in this balancing. For example, one speech therapist reported difficulty in getting to know a particular child's abilities, because much of the session was taken up with interaction between the parent and other team members in regard to family issues.

Questions and Questioning

One strategy which appeared in the data, both in transcribed interviews and my field notes, was that of questions. Both parents and providers asked questions as a strategy with various purposes, and both also evaluated the questions asked by the other and drew conclusions from these evaluations. Both parents and providers asked questions for the information content of the answer. In the initial stages of the relationship, providers asked questions designed to reveal how much the parents had been told about their child's problem, how they felt about this information, and what they expected or wanted from the provider, both for the child and for themselves. They were generally asked what types of information they found most useful (written, verbal, pictures). At the same time, the providers evaluated the questions the parents asked to help them determine the level of the parent's understanding of the child's condition and how interested the parent was in the technical aspects of the diagnosis and treatment and in the prognosis. Some providers believed that parents might not have enough information to ask relevant questions and attempted to educate them and encourage them to ask questions. As the relationship developed over time, some providers also used the strategy of asking questions to bring up issues they thought the parent should become aware of or think about in a way that was gradual, and encouraged the parent to ask their own questions about the topic.

Parents identified using questions to find out information, to assess the competence of the provider, and to test the waters when they had concerns but didn't want to rock the boat or put up walls in terms of communication with the therapist. They judged how well they might be able to work with the provider by the provider's responses and openness to questions. Parents on a panel I listened to during the pilot phase of this study expressed the need to have providers ask the questions as a way of helping them to identify issues they weren't aware of, a need which seems consistent with those expressed by the parents in this study.

Reading the Cues

Providers spoke frequently in their interviews about trying to read parent cues, or get a "feel" or a "sense" for "where parents are" in regard to their needs and knowledge levels. Cues included facial expressions, body language, questions asked, and comments made by parents. In many cases, providers couldn't articulate exactly what the cues were that told them a parent wanted or did not want certain information. In other cases, they were very clear about what they watched for or what they had observed that led them to their conclusions about parent needs.

Parents looked for cues regarding how the provider viewed their child and his or her abilities and them as parents of a special needs child. Cues that the provider cared about them and their child were especially valued. When providers went out of

their way or “above and beyond” what was required, parents felt this indicated personal caring.

Managing the Sessions

The way in which the centers and treatment sessions in this study were organized and carried out their work generally provided a good setting to meet needs of parents which have been identified in the literature. For example, parent participants in one study (Knafl, Breitmayer, Gallo, & Zoeller, 1992) advised providers to offer accurate and complete information, not dwell on the negative possibilities, explain in terms they could understand, and provide the opportunity for them to ask question. There was evidence that these practices were being followed by the providers who participated in this study.

The treatment sessions themselves were the setting where most of the communication in this study took place, although there were also telephone and written communication. In the beginning, the providers managed the sessions, and the parents accepted them more passively, assuming that the providers knew best about what should be done. Uncertainty was decreased as time went by and parents learned more about their child, the disability and the treatment. Parents began to have opinions about the treatment sessions and were sometimes disappointed or felt the sessions were not providing all they might. Sometimes parents were bothered by sessions starting late or being very routine with no new ideas. However, fears of hurting the feelings of the

provider, or of there being unintended repercussions to the child were given as reasons for not speaking up. These seemed to be the costs of a close personal relationship. Parents weighed their concerns against the possible repercussions and made tradeoffs based on their assessment. The same was true of situations where the parent wished to change providers or centers. Costs were weighed against benefits and action taken accordingly. Parents sometimes felt vulnerable, even in situations where there was a very positive relationship with the provider. Although most parents had positive feelings about the relationship they had with their primary provider at the Center, very few felt completely free to say anything to the provider that concerned them.

Managing Uncertainty

The effects of uncertainty were pervasive in the relationships between parents and providers and colored all their interactions. Parents varied in the degree to which they wanted to decrease uncertainty, and providers varied in the degree to which they felt it was their job to decrease parent uncertainty. Most providers consciously tried to read parents' cues and stay within the perceived boundaries as much as possible. A few providers felt they should provide a certain level of information to parents even if they were not asking for it. Parents generally expressed satisfaction with the amount of information they were given. In the case of one severely involved child, the parents gave mixed messages about what they wanted to know and the providers found the situation very disconcerting.

Most providers found that there were times when they needed to encourage parents to consider unpleasant information or make difficult decisions. When found it necessary to Push the Boundaries, they put much effort into approaching these topics carefully by Setting the Stage. This included warning parents in advance of topics that would need to be discussed in the future, asking alerting questions of the parents, and making comments about child needs or changes. Some parents were aware of these provider efforts to be gentle with them and were very appreciative. Very few parents felt the providers in this study had been less than forthright with information.

Therapeutic Aspects of Developmental Treatment

The end result of all the communication processes that occurred was some degree of therapeutic benefit to the child and parents and some degree of satisfaction or feeling of accomplishment for the providers. Parents reported feeling increasingly competent as parents as time went by and they learned more about their child and the system. Some of them gave credit to the providers for helping them to be better parents. Parent views of whether the relationship with the provider was therapeutic for them and their child was quite variable. All parents reported satisfaction with the early stages of treatment, the kindness and the information they were given. However, some became disillusioned as time went by due to various circumstances. Their dissatisfaction was always specific to certain circumstances and they often offered reasons for why the providers might behave in the way that was disturbing. All of them

emphasized that the helpful aspects of the relationships and experiences outweighed the negative ones.

Providers attempted to identify ways in which they were therapeutic to families and children and ways in which they could tell that their efforts were appreciated. It was difficult for them when the child did not respond to treatment or was severely impaired, and in these cases positive feedback from the family or indications they were being helpful to the family were much valued. Positive child change was therefore not always required for the relationships to be perceived as therapeutic and affirming.

Establishing Trust

Trust has been demonstrated to be a salient issue for persons with chronic illness and their families. They have identified their relationships with health care providers as very important in their lives (Thorne, 1993). Thorne and Robinson (1989) developed a model of reconstructed trust that describes the different ways families are able to go on working with health care providers after their initial trust has been shattered. Because the experiences of families who have a child with a developmental disability or delay differ in so many respects from that of families who have a child with chronic illness, I could not assume at the beginning of this study that this model would be appropriate for this population and the setting of interest. It was notable, however, that many parents related to me experiences with the acute care medical establishment that reflected the Thorne and Robinson model very well.

Similarly, the parents in this study identified the relationships with their providers as very powerful influences in either a positive or negative way. It was important to them that the providers be good communicators as well as competent clinicians. Lacking the skills or information to judge the provider's skill level, parents relied on evaluation of provider communication skills and interpersonal relationships with them and with their children, as well as with other providers involved in the child's care.

As discussed in Chapter II, the Thome and Robinson (1989) model describes three stages of trust in the relationships that persons with chronic illness and their family members have with health care providers. The first stage, naive trust, is followed by disenchantment and finally, guarded alliance. Guarded alliance has four distinct patterns, hero worship, team playing, resignation, and consumerism. These patterns are represented by the intersection of the two dimensions of Trust in the health care provider and Confidence in self. This model was clearly reflected by parents in their descriptions of their previous experiences with the health care system and could also be identified in some of what parents reflected about their current relationships with the providers in the developmental centers.

Thome (1993) describes clinical competence and communication skills as being necessary qualities of a trustworthy provider. Active listening and the ability to explain things understandably were identified as components of good communication. Based

on the data from this study, these were also things that were important to parents of children with developmental disabilities. Without exception, these families came to their developmental treatment center with past experience with at least one medical professional, generally a physician. Although I did not ask specifically about these early experiences, I told parents to talk about anything they needed to in order to tell me about their communication experiences with the professionals at the center. Most informants described their past experiences with physicians at some point in the interview. These stories reflected both positive and negative experiences. The stories often described the initial naive trust in the physician, erosion or shattering of that trust, and some type of reconstruction of trust. One mother described her experience with her child's pediatrician when she expressed a concern about a physical feature which later proved to be significant

Mo: ...and so I was concerned , but I never went for a second opinion. I thought , well, you know, he must know what he's talking about. And I was a nurse and I should have questioned it, but there comes a point where you just trust, you know. You just have to."
(11101)

After a succession of trust shattering experiences with physicians, this mother said, "...and that really took our confidence totally away and we never have been back to him since" (11101)

This family experienced a succession of incidents which totally eroded their trust in health care providers. As a result of these experiences, they became very

methodical about evaluating potential providers of care for their child. Both parents described these experiences explicitly as having destroyed their trust. They had chosen the center where they were receiving services for their child after interviewing staff at several other centers. One of their criteria for their choice had been how the providers at each center responded to their questions. They wished to avoid service providers who felt threatened by parents asking many questions. The husband clearly identified his current approach to health care as that of a consumer in new situations until trust was earned by the provider. Both parents desired a team .playing relationship. In a situation at the Center, where there was disagreement between them and the providers about the service needs of their child, the mother felt that the parent-provider relationship was in jeopardy, and thus the highly valued therapy services for her child. She took active steps to offer the providers positive affirmations and attempt to repair the possible damage to the relationship. While the providers were aware that the mother was concerned, they expressed no knowledge of the extent of the concern and felt they were being very accepting of their difference of opinion with the parents regarding the child's service needs.

Another mother, talking about her family physician's minimizing of her concern about her child said "I just assumed that the doctor knew best". When the child was two the physician told her to wait until he was three. When he was three, she took him to a different physician, a pediatrician who began the referral process. Although the

child has received therapy and special education since age three, this mother still experiences intense feelings and wonders if beginning a year sooner would have helped her son. Her approach now is “I know what I want and I just go after it”, definitely a consumer perspective.

In describing their relationships with the providers at the Center, parents frequently mentioned characteristics of the communication of the provider. Even the competence of the provider was often evaluated in terms of their communication skills and their affect in handling and interacting with the child

Deceptive Communication

In developmental treatment situations, as in many health care settings, providers are in possession of a great deal of information that is of interest to the clients. This is true in spite of the uncertainties involved. Davis (1991) indicated that health care providers sometimes feign uncertainty long past the time when it actually exists. Providers in this study reported that they avoided giving information to parents in a number of situations, thus maintaining uncertainty. This was almost exclusively information about the child’s potential for the future. In some cases, the providers felt it was not their responsibility to provide prognostic information, but should be left for the physician. In other cases, they felt the parents weren’t ready to hear the information or didn’t want to hear it. Some felt that parents would learn the facts soon enough and

there was no reason to upset them unless they were asking specifically for the information or unless their not having the information was causing some type of harm.

Although this type of decision about interactions with parents or other patients is generally considered clinical judgment rather than deceptive communication by health care professionals, it does have many characteristics which have been described in the literature on deceptive communication. One type of deceptive message is called disqualification (Bavelas, 1985). It is said to be used when "...communication is required but all possible messages are negative...". The theory states that in this situation, all the obvious possible negative messages will be avoided and "...a deflected message will be sent instead, one that 'says nothing while saying something, or says something without really saying it.'" (Bavelas, 1985, p. 192). The current view of deceptive communication is that deceptiveness is a functional adaptation to a difficult communication situation in which the communicator is faced with competing goals of conveying information and at the same time minimizing the damage that such information might produce (McCormack, 1992). Deceptive messages are thought to be covert deviations from the principles that underly conversational understanding. The Cooperative Principle (Grice, 1989) represents an assumption that the speaker will adhere to certain maxims or standards about quality, quantity, relevance and manner of presenting information. The speaker can produce deceptive communication by covertly

manipulating any of the four maxims. This theory is called the Information Manipulation Theory (McCormack, 1992).

The results of the study suggest that providers make decisions about what information to share and under what circumstances to share that information with parents. Some providers were more straightforward than others and more comfortable with sharing less than positive information. The above mentioned theories suggest that disqualified messages and deceptive messages may be the result of the communicator being in a communicative position that seems to have no good options. That is, all the available communication options seem equally undesirable. The purpose of this study was not to examine the content of the communication between the parents and providers, but instead, to examine the communication experience from the perspectives of parents and providers and develop a substantive theory about how it evolved. However, it would seem that further study of the content of messages in the developmental treatment setting would be revealing in regard to strategies of communication used by providers with parents. Use of the extant literature on deceptive communication would strengthen such studies.

Stigma and Normalization

The term stigma was not mentioned by either the parent or provider participants in this study, yet its influence was heard in the interviews, both in terms of the parents trying to deal with their own attitudes and those of the public, and the providers trying

to minimize the effects of stigma on children and families. Normalization is a term used to describe the response to a situation in which a family member has an illness or disability (Knafl & Deatrck, 1986). It has been discussed by Davis (1972 and 1991) and includes behaviors such as "...engaging in usual parenting activities, limiting contacts with similarly situated others, making the child appear normal, avoiding potentially embarrassing situations, and controlling information" (Knafl & Deatrck, 1986). Normalization is distinguished from denial by the fact that the family acknowledges the reality of the situation.

In this section, I will attempt to highlight the ways in which stigma was influential in much of the communication that went on between parents and providers and also accounted for much of the necessity for deceptive communication when it occurred. I will also argue that an important function of the providers in a developmental treatment center is to assist parents with normalization. The following paragraphs will review some of the literature on stigma and illustrate my arguments with examples from the data of this study.

Stigma occurs in response to the perception of deviance, or characteristics that vary from what is considered normal. Deviance is not inherent, but depends on what a particular society defines as deviant and under what circumstances. The definition of stigma given in the *Thesaurus of Psychological Index Terms* (Walker, 1991) states that stigma is:

Perception of a distinguishing personal characteristic or condition, e.g. a physical or psychological disorder, race, or religion, which carries, or is believed to carry, a physical, psychological or social disadvantage (p. 211)

The parents and providers in this study gave evidence that developmental disabilities are stigmatized conditions in our society and that both parents and providers were affected by these attitudes. The data also suggest that one of the major activities of the providers was normalization, or destigmatization of the condition.

Erving Goffman's history of the concept of stigma (Goffman, 1963) is the classic work on the subject. He describes the concept as beginning with the Greeks, who used bodily signs to expose something unusual and bad about the moral status of the person. One example was a brand to identify slaves. Later, the Christians used two layers of metaphor for stigma. One was that stigmata were bodily signs of holy grace expressed in eruptive blossoms on the skin. The other was a medical allusion to the above religious allusion which identifies stigma as bodily signs of a physical disorder. Goffman says that the way stigma is used today is more like the original Greek usage, except the bodily sign itself is the focus rather than a moral implication.

Goffman talks about stigma in terms of social identity and describes two types, the virtual social identity, which is the identity a person is expected to have, and the actual social identity, which is the identity the person may actually be proved to have if his stigma becomes known. When a person is actually identified as a less desirable

kind, he is deeply discredited as a worthy person. Stigma is a relative attribute, depending on the virtual identity, or what is expected of a person in a particular setting. Stigma occurs when there is a discrepancy between a person's virtual and actual social identities. A very important aspect of Goffman's conceptualization of stigma is that in most cases, the individual holds the same societal values as those who judge him, and therefore is likely to feel shame. Beuf (1990) refers to this as self-stigmatization.

There are two methods by which societies stigmatize illness: cultural symbols, and social institutions/structures for handling certain deviances (Fabrega, 1990). Cultural symbols are certain forms of behavior, action and accomplishment, some of which are symbolically valued positively and others of which are symbolically valued negatively. The writhing movements of athetoid cerebral palsy are an example of a negatively valued cultural symbol. Social institutions and structures such as hospitals, asylums, and religious homes set up for various groups for well-intentioned reasons can also have unintended negative effects on social identity. Group homes for the retarded are an example of such a structure. While created for positive and progressive reasons, they are seen as undesirable by local communities, and their inhabitants are stigmatized by living there. Developmental disability treatment centers are another example of stigmatized social institutions or structures. Two parents in this study articulated concerns about bringing their child to a "wheelchair place" or a "place where people go who have something wrong with them".

Mental Retardation As Stigmatized

In his history of mental retardation, Scheerenberger (1983), describes a long litany of oppression of the retarded rooted in fear and ignorance. Mental illness, mental retardation and poverty were often equally stigmatized and those people tended to be blended together in the various hospitals, asylums, and on the streets. Violence and harsh treatment were justified either on the basis of fear and danger or in order to drive out the evil spirit or influence which was believed to be present.

Health professionals can be stigmatizers or destigmatizers of disease in their roles of legitimizers of the sick role and labelers of illness (Volinn, 1983). In non-psychiatric illness, the labeling by the medical profession of symptoms and signs as a particular illness provides social melioration, restoration and neutrality. In psychiatric illness, on the other hand, the labeling can lead to social discrediting, rejection and/or condemnation (Fabrega, 1990). Mental retardation seems to fit in the category of psychiatric illness, being an unwelcome diagnosis which leaves a permanent effect. In medical decision-making, it is generally considered better to overdiagnose rather than underdiagnose, because the consequences are worse for disease left undetected. However, in mental retardation, clinicians are sensitive to the social implications of the diagnosis and tend to be reluctant to make this diagnosis without strong evidence or "proof" (Mercer, 1973). Mercer (1973) quotes Binet, "It will never be to one's credit

to have attended a special school. We should at the least spare from this mark those who do not deserve it." (p. 12).

Stigma and the Family

Being stigmatized has a significant effect on the life of an individual and requires adaptation of some form. Many of the articles and studies on stigma discuss the effects of stigma on individuals and individual coping strategies. In the case of young children with mental retardation or handicapping conditions, it is the family members who experience stigma rather than the affected child, who is unaware. Parents and siblings, who are aware of the discrediting effect of the diagnosis, behaviors, or appearance must be the ones to feel and deal with stigma. A study of siblings of children with chronic illness (Gallo, Breitmayer, Knafl & Zoeller, 1991) indicated that siblings struggled with issues of revealing, passing and covering. For parents, this is more than the courtesy stigma spoken of by Goffman. They themselves are stigmatized as parents of a handicapped child.

Goffman (1963) discusses a number of aspects of individual adaptation to stigma. The discredited, those whose stigma is apparent or known, must deal with the responses of others to their deviation. The discreditable must practice information control, or deciding when, where, to whom and under what circumstances to tell. Not disclosing discrediting information is called passing. Parents of handicapped children face these issues daily. For example, if the child's defects are not obvious, they may

pass by lying about the child's age (if the child is small for age, or behaving as a younger child might). If the child does not answer questions because her or she does not understand, or does not yet talk, the parent might say the child is shy. Davis (1991) describes a situation where the mother of a child with polio who is wearing a cast allows a cab driver to assume the boy broke his leg playing sports. This was an example of passing for both the boy and his mother.

There is a set of sympathetic others who may share the point of view of the stigmatized person and consider him or her essentially normal. These are described as the "wise" and are of two types. The first type includes those who become wise through their work with the stigmatized group. The second includes "...the individual who is related through the social structure to a stigmatized individual--a relationship that leads the wider society to treat both individuals in some respects as one" (p. 30). Goffman considers the parents of a handicapped person as an example of the second type of "wise". Voysey (1972) conducted a study in which she interviewed parents of handicapped children about how they handled interactions outside the family regarding their handicapped child. Voysey maintains that parents are critically different from this wise group in that they did not choose their position, yet are expected to welcome it.

While Voysey emphasizes and perhaps exaggerates the difference between the wise, as Goffman describes them, and parents of the handicapped, it is true that parents are different. In addition to being members of the wise, parents are also stigmatized. If

one assumes that there must be an awareness of stigma on the part of the stigmatized for it to exist, then it is often the case that parents are stigmatized in place of the child, who may simply be discriminated against. Voysey (1972) goes on to describe impression management, deviance disavowal, breaking through, and information control by parents of the disabled, all of which are described by Goffman as individual coping strategies of the stigmatized.

Fred Davis (1972) studied the visibly handicapped and how they manage social interactions with normals. Like the work of Goffman, Davis' work is considered classic and is frequently referenced in discussions of stigma. The type of interaction he studied was defined as a social encounter with a person such as one might have at a party, on an airplane, or meeting neighbors. He analyzed the rules of normal social interaction in Western society and how the visible handicap upsets the process.

Davis (1972) described four means by which the handicap poses a threat to the sociable encounter. First, the handicap has a tendency to become the focal point of the interaction. Second, it tends to place constraints on social boundaries such as concern about what to say or not say. Certain words become taboo for fear of saying the "wrong thing". The third means by which the handicap poses a threat to the interaction is the discordance between the handicap and the person's other attributes. Finally, there is the ambiguity of the handicap as a predictor of social activity. In response to all these interferences, the normal and the handicapped must both find ways to interact.

Davis proposed that the handicapped person uses a process of deviance disavowal, the goal of which is to "break through" so that the normal sees him as a person first.

There are three stages in the process of deviance disavowal or normalization (Davis, 1972). These are fictional acceptance, breaking through, and institutionalization of a normalized relationship. In fictionalized acceptance, polite manners prevent normals from acknowledging that they have noticed the handicap. In breaking through, the handicapped person tries to project aspects of himself that are normal so the normal person may identify him with these instead of the handicap. Once a normalized relationship has been instituted, there are numerous instances in which the handicapped person must instruct the normal in what to do and how to handle aspects that may be problematic because of the handicap. The following excerpt illustrates an attempt by parents in this study to get past fictionalized acceptance and break through on behalf of their child at a family picnic, and then at a church bible school.

Mo: ... So everybody camped for the weekend at her house, and those kids, you know, there's nine of them running, eight of them running around and playing and jumping and hooting and hollering, and they had a little red car that the kids would get in. One would get in and the other three or four would pull on the rope and some would push it behind. Well, [child] was "Please, car", [signing] you know, and I was like "How are we going to do this?" Well, two or three of the kids pulled the rope and my brother, my back, I was pregnant with her [refers to baby], it was like "You've got to be kidding. There's no way I'm going to be able to bend over and push him". So my brother, it was wonderful, because he has three of his own kids. He got behind the car with [Child], kind of gave [him] enough support, and pushed while the other kids were pulling him, so [Child] was included right in that. And it's so nice when they include him. We took him to vacation Bible

school last summer, because I wanted him exposed to the three year olds before we put him in a school setting. (12105)

KW: Yes.

Mo: We didn't know how he'd do. He did terrific except for they passed over him a lot. The teachers would and the other kids. Everybody got a turn kicking the ball but [him]. So my husband and I both helped teach the Bible. We didn't really teach, we were more like helpers. And I wanted both of us to be there so one could deal with [Child] and the other could help the other kids. Well, it was like, well, "[Child] gets a turn", and we'd pick him up and hold him so he could kick the ball when we were learning how to play soccer. (12105)

KW: And they were probably afraid to do that.

Mo: They were, they were. And like they played duck, duck, goose. Well, when they came to [him] you know, the kids wouldn't pick him because they knew he couldn't run, and then one little girl, can I pick [Child]? I said, "Yes, pick him!". She picked him goose, [he] got all excited, and I picked him up and we ran and tried to chase her. You know, and it's, "Okay, he needs a little more help doing it but please include him" you know. So I, that's why I like this school so much, you know. (12105)

These parents and one provider also had a social relationship outside the treatment setting. As she describes this relationship, the mother demonstrates breaking through and normalization

Mo: Oh, personal relationships you have? We have an outside friendship with [provider]. We go to the same church, we went out for Valentine's through our church with them. And we've developed a really nice friendship, my husband and I. Another couple that know our special needs with our children, and, you know, they're still our friends, you know what I mean. We're still invited to do things and then we enjoy their company as well. And it's nice because a lot of things you might not mention you would because they're like a friend. (12105)

Both professional and lay literature about children with handicapping conditions and their parents reveal many stories of dealing with everyday social encounters (Kupfer, 1980; Tisdale, 1990). Normal conversation between people at the level described frequently involves questions and comments about children, whether they are present or not. If the child is present, parents are very aware of the reaction of others to his or her appearance or behavior. Parents often become the educators of the community on whatever handicap the child has. They decide whether to bring up the child's handicap or to focus on his or her normal characteristics. They seek to manage impressions of the child just as they would for themselves. One mother in this study said:

Mo: ...But you know when you have, I don't know if you have experienced this, but when you had, but when you have a kid who's not totally perfect according to the world, people don't come up to you and say, "Oh, can I hold your baby?" They just say "How old is he?" Or something like that, you know. It bugs me. (11107)

KW: Or ask you weird questions, did you ever have that?

Mo: Umhm. "So does he have Down's Syndrome?" No. "Oh, what does he have?" Well, nothing that I can tell. But nobody told me anything, you know what I mean. And he's been tested for all kinds of things, but nobody has said anything. All they say is he has a big head, "Really? Isn't that amazing". He had an MRI done and all of his brains are there and the whole brain is full of, I mean, the whole head is full of brains and it has all the water pockets where they belong. Nothing is larger than it's supposed to be. So I don't know. But I think that's weird too, the way people treat you when you have a kid who isn't, because, I mean, to you, to me, [he] is different than other kids but he's still mine and he's still perfect to me, do you know what I mean? Isn't that weird? Don't you think that's true, though? (11107)

One mother had talked at the center once about how her child's wheelchair looked like "a big black tomb" to her at first. As she continued, she used the wheelchair as representative of the abnormality of handicap:

Mo: Okay, so it was very shortly after we got out of the hospital. And in the hospital I didn't know that we were going to be doing all this stuff. I had no idea what we were doing when we came home. I never knew therapy existed like this, okay.(12102)

KW: Yes. How would you know?

Mo: I wouldn't. And I didn't like it, I didn't want to walk there. I, what are we doing here? What's, what am I....[begins to cry] (12102)

KW: Do you want me to turn it off, no? [participant shakes head no]

Mo: I just didn't want to be there because it was a wheelchair place and a disabled place, and it was a place where normal life just doesn't go. Now I couldn't live without it. Well, I could now, but in the middle of it all I couldn't. I learned to appreciate it, but not at first. So anyway, that's how I felt when I first went there. (12102)

Noticeability of a child's speech and behavior and the reactions of others to the child have been found to be very stressful to parents of mentally retarded children (Baxter, 1989). Providers in this study were aware of the stigma of appearing handicapped and attempted to minimize this in the adaptive equipment they provided and recommendations they made, strategies which were characterized as normalization for this study.

Pr: Usually the first equipment a child needs is something to support them in sitting, and I purposefully often will suggest the Tumbleforms because it's a very visually appealing piece of equipment. It's that kind of material, and it's just molded, and even though it may not position the child perfectly, I think it's a very family-friendly, very family-friendly.

And so that's really on my mind quite a bit with early, and you know, and we're thinking, when I talk about this, I'm thinking of the child who's eight to ten months old. I mean, the young baby, really, fairly young baby. Often we don't have a diagnosis at that point. The parents really are just going a day at a time. (22205)

KW: And so by family friendly you mean

Pr: Accepted by the family. It doesn't even look like, you know, an adapted piece of equipment, you see. And actually it's one of the better things on the market too. But you know, and this is something that's changed, I used to like make my own little infant seat, and I'd measure all the foam, and I'd be sure that everything was perfect. But it looked so, you know, strange. And it was hard to keep clean, you know. If you can imagine little blocks of glued-in foam and a piece of tri-wall, yes, you know. And to me it's just like that gives the message that a child is, that there's something really wrong with a child. (22205)

This mother recognizes that the providers are focusing on the normal aspects of her child and trying to help her avoid having him look abnormal or handicapped.

Mo: ... So she's always concerned about [Child] and she says, "Oh, [He's] two years old. He's kind of getting out of the diaper bag state", so, you know, I don't think of those things. And she mentions to me, so I put it in the backpack, you know. (12104)

KW: Oh, yes.

Mo: It's much more convenient, and you know, "Gee, [his] hair is getting kind of long," you know, and she's concerned about his look as a child and if it gets too muffled then it looks more disabled, you know, was her feelings. Boy, it's really nice to have that, somebody else's opinion on that, you know. And [other provider] likes, [she] has mentioned to me before about equipment. She likes to make sure everything you can adapt like normal baby equipment first off before buying a whole ton of stuff that doesn't look so equipment sized in the house. (12104)

In terms of the stigmatized person's relationships to others, Saylor (1990a) listed six responses. First, the person may choose to disregard any stigmatizing reaction. Parents may do this by ignoring the stares or questions or discomfort of others. Second, the stigmatized person may choose to isolate herself from social interaction with normals and associate with other similarly stigmatized persons. Parents may do this by avoiding contact with friends who have normal children and either remaining isolated or seeking out other parents whose children have similar problems. A third possible response is to seek secondary gains from the stigma, such as by being dependent. Fourth is resistance to the stigmatization, such as through political action. Parents may do this by becoming involved in one or more of the many support/political action/information groups available to parents of children with various handicaps. The fifth response is passing, or avoiding detection of the stigma, and the sixth is covering, which is an attempt to minimize the consequences of the condition so as to decrease tension.

Saylor (1990b) discussed the attitudes of the person with chronic illness toward herself in terms of cognitive belief patterns. What the person thinks about the self and self worth influences his or her responses to the disease. Saylor (1990a) lists the responses of normals to those with chronic illness as devaluing, stereotyping, and labeling. Unfortunately, health care professionals display these same responses. Their values are shaped by the society they live in, including their professional training and

their personal experiences with stigmatizing conditions in their clients and chronically ill acquaintances. Health care professionals, says Saylor, have a responsibility to obtain a thorough understanding of responses to stigma in order to overcome the effects of stigmatizing behavior. Suggestions are made for helping the stigmatized individual cope. As well, a model of mutual participation is suggested for intervention. Saylor (1990 b) uses the Nerentz and Leventhal Model of self regulation in chronic illness (1983). This model suggests that individual coping is determined by how one represents chronic illness, the self and the body. These representations influence how the person participates in medical regimes and also the person's feelings of self worth.

In the case of the parents of child with a developmental disability, these suggestions should be applied to them as they would to an adult with an illness. How the parent represents the birth of a child who is judged to be lacking will influence not only how the parent adjusts, but also how the child is treated. If the parent can be helped to represent the child's handicap in a more positive way and cope with stigma, the outcome for the family and the child will be improved. There are several ways in which the communication between providers and families at these centers was destigmatizing. Parents efforts and stresses in caring for their child were acknowledged and appreciated in a specific way. There were no embarrassing mistakes about the child's age or abilities. Positive comments were made about the child, regardless of his or her disability, appearance or behavior. Equipment and other paraphernalia were

neither stared at nor ignored, but commented upon as a normal part of the family's life. For example, a newly acquired wheelchair was cause for everyone to gather and talk about the color, how well the child looked in it, how much easier it was to travel, and so forth.

One mother talked about how her feelings had changed about wheelchairs. A lot of her feelings had to do with looking normal and having people stare at her child and ask questions about what was wrong with him. Her experience is consistent with the findings of Baxter (1989) that parents find noticeable differences in a child's speech and behavior and the responses of others such as stares to be very stressful.

Mo: Umhm, exactly. Yes, and that was another reason we, I had a big thing about getting him a wheelchair. We came home from the hospital with a loaner wheelchair when he first had his [disability]. There's a picture on the refrigerator of him. He was so little, but he, it was a dinosaur. There's another little girl with him, but see, he's in a wheelchair there, but he was so little. He was only a year and a half old, and he only weighed fifteen, sixteen pounds, but he was still so tiny. I could put him in a stroller that we adapted with a little bit of foam and Velcro and he looked more normal. (12105)

KW: Yes.

Mo: And to me him looking normal with a, I mean, that was horrifying for me. They took my normal looking child, and turned him into, well, the accidents that happened during surgery, he became disabled, handicapped, special needs, all of these things overnight. So we went from someone walking and talking and pulling on my shirt, "Mommy, juice" to you know, all this flailing movements, blind, couldn't do anything, couldn't even suck on a pacifier or drink out of a bottle any more. So for a long time I didn't want a wheelchair because I was determined he was going to walk again. This [disability] had to go away. They said 98% of them it goes away. So of course his was going to go away. We don't need a wheelchair. I don't want this wheelchair.

I got rid of that wheelchair because I hated it, because I took him for a walk and everybody would stare at us and, "Ooh, what's wrong with him?", and that was so horrifying. So for the longest time I didn't want a wheelchair, you know, and so I put him in the stroller. But then he was three and a half, he's getting ready to start school, and everybody would see him like at the stores. "Oh, how old's your baby?" And then little two year olds would be looking at [Child] who's older, "Look at the baby, look at the.." And I was like, they think he's a baby because he's in this stroller. (12105)

KW: Yes.

Mo: He's too big for this stroller. So my husband said, you know, we have to do age appropriate things for his (12105)

KW: Right.

Mo: And I thought, okay, so we went ahead and got the wheelchair. And you know, his wheelchair's cute. It doesn't look like that one. That one was a dinosaur of a wheelchair. It was a clunker; it must be eighty years old. So his new one's nice, and you know, (12105)

There was also an instance where the child's mother was resistant to the wheelchair because of the stigma associated with it, while the child's father wanted the wheelchair to provide more opportunities for the child than he had without it.

Mo: My biggest thing with the wheelchair is the social issue of the wheelchair, as far as out in public. My personal issue is, you know, me thinking that [child's] not going to get out of the wheelchair. And then there's also the social issue of what people are going to think, what they're automatically going to assume when they see him in a wheelchair. Are they going to give him a chance? (12106)

KW: And what do you think that'll be?

Mo: Well, from friends of mine who have, has a son in school in a wheelchair, who's mainstreaming, has problems with other parents there who automatically assume, "Well, you're in a wheelchair, you must be mentally retarded" or, you know, "I don't want to have anything to do

with you.” People are scared of handicapped people. I know before I had a handicapped son, I was scared of handicapped children or even adults, you know, to where, I mean, I would look but I'd kind of look like this, you know. I wouldn't stare or anything, but I would always wonder and I'd be scared to go talk to them. (12106)

This child's father, on the other hand, was more concerned about enabling his child to move around in the world

Mo: Oh, you still get resentful and stuff when he's on the floor all the time. (12106)

Fa: Yes, because I want him in his chair, I want him outside with the world. I mean, yes. (12206)

Mo: And I want him to stay in the house. (12106)

Fa: Right. [his mother] wants to shelter him in his little world right here between here and there, which is her feelings. And I'm saying, wait a minute, but there's more to the world than the living room and his bedroom. Maybe he won't cry so much when he gets to go outside, you know. (12206)

The next excerpt is from an interview with a mother whose daughter has mental retardation and cerebral palsy and is older. In speaking of her son, who has attention deficit disorder, she said she didn't want her son to take Ritalin because he knew his sister took pills for seizures, and she didn't want him to think there was something wrong with him. To me this gets at the heart of the stigma issue. Something is “wrong” with you. That is a separate issue from the inconvenience of not being able to walk or the risk of being injured during a seizure. Having attention deficit disorder is not having something “wrong” with you to the extent that having mental retardation,

cerebral palsy or seizures is. The generic idea of having something “wrong” is the essence of stigma.

Mo: So, anyways, in what grade was it, seven? Must have been first grade, the school psychologist told me, first grade, age seven, I don't know. (11108)

KW: If he got held back a year, that

Mo: That's right, that's right, it would make it right. She told me that he was a Ritalin kid, and I should put him on Ritalin. At the time I didn't know what it was, but I just flat out said no, because [his sister] was on medication and he knew [his sister] took medication for seizures. And I didn't want him thinking there's something wrong with him, you know, taking this medicine. So I never thought twice about it. (11108)

Another mother identifies the possibility of cognitive problems as her worst fear for her child. She also mentions cerebral palsy, and it is not clear whether she associates this with cognitive problems or not.

KW: Were you ever concerned about his cognitive abilities, about whether he would have learning problems or?

Mo: Oh yeah. Always. Always and because he's always been slow. He was always behind. And he's caught up now and he does have. there are some quirks about him, but he's pretty --(11103)

KW: Normal.

Mo: Uh-huh. You know, which is, so I hate to say it, but it's like -- and I was reading this article once about how, you know, it's like you rate disabilities and handicaps and it's like “at least this isn't affected”, well at least my son has his brain, you know. It's like mental would be way worse. I mean I'm even judgmentally about that. (11103)

KW: What do you mean judgmental?

Mo: Well that like when you go out and see other disability families and you like kind of scope them out and see what their scene is, you know, it's like, "phewww." Like if you see a CP person or something. (11103)

KW: But you sort of feel like the mental, the cognitive stuff would be like the worst?

Mo: Yeah. (11103)

Limitations of This Study

Limitations identified for this study may be discussed in three categories: limitations produced by the characteristics of the setting and participant group; limitations of the methodology and design; and limitations of the researcher.

Characteristics of the Setting and Participant Group

All research is limited to some degree by the characteristics of the sample or participants. While generalizability and replicability are not generally claims of interpretive research, it is still important for the reader to be aware of characteristics of the participants and setting that would be important in determining usefulness of the findings. Several characteristics of the two centers and the participants in this study will be mentioned here as limitations.

The two developmental treatment centers with which the participants in this study were connected were both health care settings with a medical rehabilitation perspective and provided individual clinic type sessions. The degree of commonality of experiences these participants would have with those associated with other settings, for

example, an educational facility where children were seen in groups, cannot be ascertained from these findings. In addition, all the parents in this study were able to arrange to bring their children to sessions during normal week-day work hours. The experiences of both the parents and providers might be different in settings where the child stayed all day or part of the day with no parent present. There was no formal parent support program in either of the two settings through which parents were able to make contact with each other. Such a formal program might make a difference in the relationships formed between parents and providers. Theoretical sampling from other types of programs might have enriched this data.

Limitations of the Methodology and Design

A primary characteristic of interpretive methods is that the researcher is the primary instrument used not only to collect the data, but also to interpret it. How the researcher is seen by the participants affects the data they provide. These effects may be unavailable to us, in spite of attempts to be aware of them, though again, experience of the researcher may enhance this awareness. The researcher attempts to become more aware of herself and how she is perceived with conscious effort (Lipson, 1991).

The use of both providers and parents in this study was both a strength and a limitation. I was constantly aware of the necessity to maintain confidentiality between the parent participants and the provider participants. In some cases, this made me avoid asking questions that came to mind out of concern that the question would reveal

what the other person had told me. These decisions had to be made quickly and were often conservative, possibly resulting in less informative interviews. Concerns about protecting confidentiality also limit the reporting of my results. Some situations and interactions which would be identifiable to the participants as well as to others were altered to conceal the identity of the participants or excluded from the report entirely. This is particularly true in the case of social work and nursing because only one center had these disciplines and their numbers were so small. Although the intent was not to change content, this alteration or elimination changes context slightly for the reader from that of the researcher. Hopefully, the gains from direct parent provider discussion outweigh any losses caused by concealing identities.

A sampling practice which is useful in grounded theory is sampling in a population which is different from the population of interest, but has some related characteristics. This was not done in this study and is therefore a limitation.

Most participants in this study were interviewed only once in an interview that lasted from forty minutes to two hours. The study would have been improved by doing more lengthy participant observation, by conducting the interviews over a longer period of time and by conducting repeat interviews with many of the participants. To some degree, these limitations were produced by financial and time constraints. However, more extensive interviews with fewer participants might have improved the study without adding to time or cost. Other possibilities would have been to add a

longitudinal component to the study in order to more fully describe the development of relationships between the parents and providers over time.

This study was also limited by some missing data caused by errors in recording several interviews. One was completely ruined and was replaced by notes made within hours after the interview. One contained numerous gaps in recording and the third sounded disjointed, but was useable. In addition, one provider was unable to be interviewed because of vacation time and other scheduling difficulties at the last minute. Fortunately, she was only working with one of the participating families.

A limitation of this study which is particularly relevant for nursing is that there was only one nurse employed by the two participating centers, and thus, only one nurse participant in the study. Unfortunately, this is not an unusual circumstance in developmental treatment centers. Thus, the experiences of nurses in these settings is represented in a limited way in the findings of this study. It would enrich the data from this study to interview nurses from different developmental treatment settings.

Limitations of the Researcher

As a doctoral student, I had essentially no previous experience in using the methods of participant observation and unstructured interviews for research purposes. Although learning by doing can be very effective, it does have an effect on the quality of early efforts. While the activities of participant observer and interviewer in this setting were very familiar to me as a clinician, my purpose and role in these activities

were different as a researcher and I had to struggle to stay focused. As I read and re-read my transcripts, I could identify points at which I must have felt anxious and did not ask the obvious question or follow up on particular comments by participants. It came as a surprise to me that these points were just as obvious in transcripts of interviews with providers as in those with parents.

Another limitation which is similar to the issue of confidentiality is that of being perceived as having a certain amount of clinical expertise, and therefore information, by virtue of being a nurse. I was very aware of the fact that parents might view me as a person who was knowledgeable about their child and I was very concerned that my questions not sound suggestive of any particular impression of the child. For me, this was especially true in the case of children who were suspected to have mental retardation. These concerns made me self conscious and some of the interviews less informative and more awkward.

Implications for Nursing Practice

Based on the results of this study, there are several suggestions for nursing practice. Because nurses are usually employed by only the larger developmental centers, their functions are frequently consultative. This is unfortunate because of the high level of health concerns in this population. Nurses are needed in early intervention programs to better integrate health related services into Individual Family Service Plans (Godfrey, 1991) and to offer firm grounding in the family oriented approach to care.

The results of this study should be useful to Nurses in early intervention programs in advising and informing other members of the team about considerations in therapeutic relationships with families. The information gained about the development of therapeutic relationships should also be helpful to nurses in evaluating their own practice with families and in considering the effects of their interactions on families. The direct implications of this study for nursing practice are not essentially different for nursing than for any of the other professional disciplines that provide services to children and parents in developmental treatment centers. As more and more focus is placed on families in the arena of early intervention, nurses must continue to increase the depth and breadth of our knowledge of families and the communication that occurs between family members and providers in order to continue to be advocates for families and resources to other disciplines in working with families.

While there was only one nurse participant in this study, there was no indication from the interviews that her experiences in communication with families were significantly different from those of the other providers overall. In general, occupational and physical therapists were the primary providers for the families and the other disciplines such as speech pathology, social work and nursing were adjunctive or secondary. Although the nurse was not the primary provider for any families, her services were highly desired and positively received. In addition to the fact that she had health and medical information that was both practical and timely, her family focus

and attitude of normalization was highly valued by several families. A disadvantage of her consultant role was that she had a very large case load and didn't always have the opportunity to develop close relationships with families. In spite of this, however, some families felt very close to her and valued her presence and input in their sessions as much as or more than that of their other providers.

Several specific suggestions for clinical nursing practice as well as that of other disciplines in developmental treatment centers can be made based on the results of this study. They are intended as areas to consider in working with families, rather than prescriptions for specific situations. First, the role of the provider as a normalizer and destigmatizer for families with a child who has developmental problems seems very important. This seemed to consist of attending to the normal aspects of the child and family and to allowing them an opportunity to normalize the abnormal aspects. Normalization efforts must be distinguished from denial, in which the fact of the disability is denied.

Second, the role of questions and questioning as a strategy for both parents and providers was striking. It appears important that providers not rely too heavily on the questions parents ask as cues to the parents' knowledge level or desire to receive information. Although this seems appropriate with many families, there are those who are hesitant to ask questions for various reasons or don't have an adequate knowledge base from which to formulate questions. Often parents express their needs and

questions in veiled ways which may sound like simple requests for reassurance (Sabbeth & Leventhal, 1988). Providers must continue to be alert for veiled requests for help. This practice was exemplified in this study by a mother who mentioned repeatedly how she would “put out little flares” to bring up a topic or question in a non-threatening way. Her efforts were often overlooked, much to her distress.

Third, although the personal relationships between parents and providers are very important and therapeutic for many families, there are still constraints on communication by virtue of the fact that the parent is dependent on the provider for services for their child and themselves. Even in situations where the provider feels very comfortable in the relationship with a family, the family may have areas in which they feel they cannot speak up about concerns for fear of causing hurt feelings or negative repercussions for the child. It would seem that providers should continue to ask questions of the parents about their concerns and preferences and offer opportunities for change, even after a good relationship has been established. Concerns such as treatment sessions starting late or ending early or becoming very routine and unimaginative may be more difficult to bring up in an established relationship. Programs might also provide parents the opportunity to periodically speak with a provider who is not providing direct services to the parent and child in order to facilitate communication of difficult concerns by the parents.

Finally, providers must remain cognizant of the effects of the process of change on the needs, knowledge levels and concerns of parents. Resources offered at one point in time may not be remembered when needed at a later point in time. The relevance of specific information or services may be obscured by grief or lack of knowledge. Provider should revisit previous offers of information and services which might be helpful to parents. For example, the offer of an educator who makes home visits might sound ludicrous to the parents of a young infant just beginning a developmental program. The same offer might sound very helpful and desirable to the same parents after six months of experience and increased awareness.

Implications for Nursing Science

As a discipline which has long advocated a family approach, Nursing must continue to pursue research to benefit the population of children with disabilities and their families. The results of this study confirm that the relationships between parent and provider are very important and that there is a wide variation in the interpretation of the term "family oriented intervention". Content on working with families is being introduced into the curricula of more professional disciplines. Research is needed to determine how critical aspects of developmental treatment can be assured in upcoming health care reform. Can therapeutic relationships with providers be established and maintained with monthly contact rather than weekly contact? Is it necessary to have an initial intensive period of contact for relationship building prior to going to a more

periodic schedule? Would study of the experience of transition from developmental treatment centers to the school district shed more light on the most critical aspects of the parent provider relationships? My data suggest that it is not the discipline of the provider that is important to parents, but the nature of the relationship and how information is communicated. Among the strengths espoused for nursing have long been a family orientation and skills in interpersonal communication. Researchers who are nurses have a great deal to offer to service providers and families of very young children with developmental delays and disabilities.

Several rich areas for further research are suggested by this study. First, interpretive studies using a similar population of informants, but utilizing more extensive interviews would increase the richness and complexity of the data set. The target groups could be expanded to include centers where the model was based on an educational rather than a rehabilitation model, or to those where children attend a classroom setting without their parents. This study suggested that stigma and deceptive communication were concepts that might be active in the developmental treatment setting. These concepts should be pursued more directly in future interpretive studies to shed further light on the parent-provider communication process.

Neither of the sites for the current study offered parent support groups. It would be useful to learn how parent-provider relationships might differ when this support was available in a formalized manner and utilized by parents.

Difficulty of transition to school district programs was experienced by some parents in this study, and not by others. Fruitful areas for further study might be parent perspectives of transitions and comparisons of the experiences of parents for whom transition was difficult versus positive.

This study indicated that some providers are more direct and active in their communication with parents and others are more passive, and avoidant. Case studies in which two providers with different approaches were studied over an extended period of time might be more revealing about the process of developing and maintaining therapeutic relationships and managing uncertainty.

In contrast to the above suggested interpretive studies, research is needed on the actual content of communication between parents and providers in developmental treatment settings. Such a study could be a triangulated component of one of the above mentioned studies. The scant research which has been done on the actual content of communication in diagnostic situations indicates that information gained from such an effort would have the potential to be very useful.

Summary

This study of the communication experiences of parents and providers in a developmental treatment setting reveals that the participants are all Striving for Therapeutic Relationships in a Context of Uncertainty. Through their communication with each other, relationships are developed which have potential for being therapeutic

for parents and children and rewarding for providers. This study reveals a framework of strategies used by parents and providers in developing and maintaining these relationships. Implications of the study are that the communication process between parents and providers is important to families and should be studied further so it may be better understood. This improved understanding can lead to strategies to develop and support these therapeutic relationships as major changes in our health care system occur in the near future. Improved understanding of parent-provider relationships in development treatment settings can also lead to improvement of the communication process for families of children with developmental delays and disabilities in other health care and educational settings.

References

- Amir, M. (1987). Considerations guiding physicians when informing cancer patients. Social Science and Medicine, 24(9), 741-748.
- Atwood, J.R. & Hinds, P. (1986). Heuristic heresy: Application of reliability and validity criteria to products of grounded theory. Western Journal of Nursing Research, 8(2), 135-154.
- Baxter, C. (1989). Investigating stigma as stress in social interactions of parents. Journal of Mental Deficiency Research, 33, 455-466.
- Bavelas, J.B. (1985). A situational theory of disqualification: Using language to "Leave the field". In J.P. Forgas (Ed.), Language and social situations, (pp. 189-212). New York: Springer-Verlag.
- Bernheimer, L.P., Young, M.A. & Winton, P.J. (1983). Stress over time: Parents with young handicapped children. Developmental and Behavioral Pediatrics, 4(3), 177-181.
- Bernheimer, L.P., Gallimore, R. & Weisner, T.S. (1990). Ecocultural theory as a context for the individual family service plan. Journal of Early Intervention, 14(3), 219-233.
- Beuf, A.H. (1990). Beauty is the beast. Philadelphia: University of Pennsylvania Press.
- Blackard, M.K. & Barsh, E.T. (1982). Parents' and Providers' perceptions of the handicapped child's impact on the family. TASH Journal (Journal of the Association for the Severely Handicapped), 7, 62-69.
- Blumer, H. (1969). Symbolic interaction: Perspective and method. Englewood Cliffs, New Jersey: Prentice-Hall Publishing Company.
- Bradford, R. (1991). Staff accuracy in predicting the concerns of parents of chronically ill children. Child: Care, Health and Development, 17, 39-47.
- Burr, W.R., Leigh, G.K., Day, R.D. & Constantine, J. (1979). Symbolic interaction and the family. In W.R. Burr, R. Hill, F.I. Nye & I.L. Reiss (Eds.), Contemporary theories about the family: Vol. II (pp. 42-129). New York: The Free Press.

- Charmaz, K. (1990). "Discovering" chronic illness: Using grounded theory. Social Science and Medicine, 30(11), 1161-1172.
- Cottrell, D.J. & Summers, K. (1990). Communicating an evolutionary diagnosis of disability to parents. Child: Care, Health and Development, 16, 211-218.
- Davis, F. (1960). Uncertainty in medical prognosis-clinical and functional. American Journal of Sociology, 66, 41-47.
- Davis, F. (1972). Deviance disavowal: The management of strained interaction by the visibly handicapped. In F. Davis (Ed.), Illness, interaction and the self. Belmont: Wadsworth Publishing Company. p. 388-397.
- Davis, F. (1991). Passage through crisis: Polio victims and their families. New Brunswick: Transaction Publishers.
- Denzin, N. (1970).. Strategies of multiple triangulation. In N. Denzin (Ed.), The research act. New York: McGraw-Hill.
- Dunst, C., Trivette, C. & Deal, A. (1988). Enabling and empowering families: Principles and guidelines for practice. Cambridge, MA: Brookline Books.
- Fabrega, H. (1990). Psychiatric stigma in the classical and medieval period: A review of the literature. Comprehensive Psychiatry 31(4), 289-306.
- Francis, M., Korsch, B.M. & Morris, M.J. (1969). Gaps in doctor-patient communication. The New England Journal of Medicine, 280(10), 535-540.
- Gallo, A.M., Breitmayer, B.J., Knafelz, K.A. & Zoeller, L.H. (1991). Stigma in childhood chronic illness: A well sibling perspective. Pediatric Nursing 17(1), 21-25.
- Glaser, B.G. (1978). Theoretical sensitivity: Advances in the methodology of grounded theory. Mill Valley, CA: The Sociology Press.
- Glaser, B. & Strauss, A. (1967). The discovery of grounded theory. Chicago: Aldine Publishing Co.
- Godfrey, A.B. (1991). Providing health services to facilitate benefit from early intervention: A model. Infants and Young Children, 4(2), 47-55.

- Goffman, E. (1963). Stigma: Notes on the management of spoiled identity. Englewood Cliffs, New Jersey: Prentice-Hall.
- Grice, H.P. (1975) Logic and conversations. In P. Cole and J.L. Morgan (Eds.), Syntax and semantics (Vol. 3). New York: Academic Press.
- Guba, E.G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. Educational Communication and Technology Journal, 29, 75-92.
- Guba, E.G. & Lincoln, Y. (1981). Effective evaluation. San Francisco: Jossey-Bass.
- Hutchins, V.L. & McPherson, M. (1991). National agenda for children with special health needs. American Psychologist, 46(2), 141-143.
- Kahn, D.L. (1993). Ways of discussing validity in qualitative nursing research. Western Journal of Nursing, 15(1), 122-126.
- Knafl, K., Breitmayer, B., Gallo, A. & Zoeller, L. (1992). Parents' views of health care providers: An exploration of the components of a positive working relationship. Children's Health Care: Journal of the Association for the Care of Children's Health, 21(2), 90-95.
- Knafl, K.A. & Deatrick, J.A. (1986). How families manage chronic conditions: An analysis of the concept of normalization. Research in Nursing and Health, 9, 215-222.
- Komblatt, E.S. & Heinrich, J. (1985). Needs and coping abilities in families of children with developmental disabilities. Mental Retardation, 23(10), 13-19.
- Korsch, B.M., Gozzi, E.K. & Francis, V. (1968). Gaps in doctor-patient communication: I. Doctor-patient interaction and patient satisfaction. Pediatrics, 42(5), 855-871.
- Korsch, B.M. & Negrete, F. (1972). Doctor-patient communication. Scientific American, 227, August, 66-74.
- Krahn, G.L., Hallum, A. & Kime, C. (1993). Are there good ways to give "bad news"? Pediatrics, 91(3), 578-582.
- Kupfer, F.Y. (January, 1980). A place for Zachariah, Redbook, pp. 31, 137-139.

- Lamb, G.S. & Huttlinger, K. (1989). Reflexivity in nursing research. Western Journal of Nursing Research, 11(6), 765-772.
- Lincoln, Y.S. & Guba, E.G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Lipson, J.G. (1991). The use of self in ethnographic research. In J. M. Morse (Ed.), Qualitative nursing research: A contemporary dialogue. Newbury Park: Sage.
- MacKinnon, J.R. (1984). Health providers' patterns of communication: Cross - purpose or problem solving? Journal of Allied Health, February, 3-12.
- McCormack, S.A. (1992). Information manipulation theory. Communication Monographs, 59, 1-16.
- McIntosh, J. (1974). Processes of communication, information seeking and control associated with cancer: A selective review of the literature. Social Science and Medicine, 8, 167-187.
- Marfo, K., Dinero, T.E., Browne, N., Gallant, D., Smyth, R. & Corbett, A. (1992). Child, program, and family ecological variables in early intervention. Early Education and Development, 3(1), 27-44.
- Matheny, A.P. & Vernick, J. (1969). Parents of the mentally retarded child: Emotionally overwhelmed or informationally deprived? The Journal of Pediatrics, 74(6), 953-959.
- Meeropol, E. (1991). Parental needs assessment: A design for clinical nurse specialist practice. Pediatric Nursing, 17(5), 456-458.
- Mercer, J.R. (1973). Labeling the mentally retarded: Clinical and social systems perspectives on mental retardation. Berkeley: University of California Press.
- Mishel, M.H. (1981). The measurement of uncertainty in illness. Nursing Research, 30(5), 258-263.
- Mishel, M.H. (1983). Parents' perception of uncertainty concerning their hospitalized child. Nursing Research, 32(6), 324-330.
- Mishel, M.H. (1988). Uncertainty in illness. IMAGE: Journal of Nursing Scholarship, 20(4), 225-232.

- Mishel, M.H. (1990). Reconceptualization of the uncertainty in illness theory. IMAGE: Journal of Nursing Scholarship, 22(4), 256-262.
- Mitchell, E.M. (1986). Multiple triangulation: A methodology for nursing science. Advances in Nursing Science, 8(3), 18-26.
- Mulhern, R.K., Crisco, J.J. & Camitta, B.M. (1981). Patterns of communication among pediatric patients with leukemia, parents, and physicians: Prognostic disagreements and misunderstandings. Journal of Pediatrics, 99(3), 480-483.
- Nerentz, D. & Leventhal, H. (1983). Self-regulation theory in chronic illness. In T.G. Burish & L.A. Bradley (Eds.), Coping with chronic disease. New York, NY: Academic Press.
- Northouse, P.G. & Northouse, L.L. (1992). Health communication: strategies for health professionals (2nd ed.). Norwalk, Connecticut: Appleton and Lange.
- Pope, A.M. & Tarlov, A.R. (1991). Disability in America: Toward a national agenda for prevention. Washington, D.C.: National Academy Press.
- Quine, S. & Pahl, J. (1986). First diagnosis of severe mental handicap; Characteristics of unsatisfactory encounters between doctors and parents. Social Science and Medicine, 22(1), 53-62.
- Richardson, H.B. & Guralnick, M.J. (1978). Pediatric residents and young handicapped children: Curriculum evaluation. Journal of Medical Education, 53, June, 487-492.
- Richardson, H.B., Guralnick, M.J. & Tupper, D. (1978). Training pediatricians for effective involvement with handicapped preschool children and their families. Mental Retardation, February, 3-8.
- Richardson, S.A. & Koller, H. (1994). Mental Retardation. In I.B. Pless (Ed.), The epidemiology of childhood disorders (pp 277-303). New York: Oxford University Press.
- Robinson, C.A. & Thorne, S.E. (1988). Dilemmas of ethics and validity in qualitative nursing research. The Canadian Journal of Nursing Research, 20(1), 65-76.
- Sabbeth, B.F. & Leventhal, J.M. (1988). Trial balloons: When families of ill children express needs in veiled ways. Children's Health Care, 17(2), 87-92.

- Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances in Nursing Science, 8(3), 27-37.
- Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. Advances in Nursing Science, 16(2), 1-8.
- Saylor, C. (1990a). Stigma. In I.M. Lubkin (Ed.), Chronic illness: Impacts and interventions. Boston: Jones and Bartlett.
- Saylor, C.R. (1990b). The management of stigma: Redefinition and representation. Holistic Nursing Practice 5(1), 45-53.
- Schatzman, L. (1992). Dimensional analysis: Notes on an alternative approach to the grounding of theory in qualitative research. In D.R. Maines (Ed.), Social organization and social process: Essays in honor of Anselm Strauss. New York: Aldine de Gruyter.
- Scheerenberger, R.C. (1983). A history of mental retardation. Baltimore: Paul H. Brookes.
- Seitz, V. & Provence, S. (1990). Caregiver-focused models of early intervention. In S.J. Meisels & J.P. Shonkoff (Eds.), Handbook of early childhood intervention. New York: Cambridge University Press.
- Sloper, P. & Turner, S. (1992). Service needs of families of children with severe physical disability. Child: Care, Health and Development, 18, 259-282.
- Stein, R.E. & Jessop, D.J. (1982). A noncategorical approach to chronic childhood illness. Public Health Reports, 97(4), 354-362.
- Strauss, A. (1987). Qualitative analysis for social scientists. New York: Cambridge University Press.
- Strauss, A.L. & Corbin, J. (1990). Basics of qualitative research. Newbury Park, CA: Sage Publications.
- Strauss, S.S. & Munton, M. (1985). Common concerns of parents with disabled children. Pediatric Nursing, 11, 371-375.
- Svarstad, B.L. & Lipton, H.L. (1977). Informing parents about mental retardation: A study of professional communication and parent acceptance. Social Science and Medicine, 11, 645-651.

- Thomas, R.B. (1986). Ventilator dependency consequences for child and family. Unpublished doctoral dissertation, University of Washington, Seattle.
- Thorne, S.E. (1993). Negotiating health care: The social context of chronic illness. Newbury Park: Sage.
- Thorne, S.E. & Robinson, C.A. (1988). Health care relationships: The chronic illness perspective. Research in Nursing and Health, 11, 293-300.
- Thorne, S.E. & Robinson, C.A. (1989). Guarded alliance: Health care relationships in chronic illness. Image, 21(3), 153-157.
- Tisdale, S. (June, 1990). Neither morons nor imbeciles nor idiots: In the company of the mentally retarded. Harper's Magazine, 47-56.
- Tuckett, D. & Williams, A. (1984). Approaches to the measurement of explanation and information-giving in medical consultations: A review of empirical studies. Social Science and Medicine, 18(7), 571-580.
- Turner, M.A., Tomlinson, P.S. & Harbaugh, B.L. (1990). Parental uncertainty in critical care hospitalization of children. Maternal-Child Nursing Journal, 19(1), 45-62.
- Volinn, I.J. (1983). Health professionals as stigmatizers and destigmatizers of diseases: Alcoholism and leprosy as examples. Social Science and Medicine, 17(7), 385-393.
- Voysey, M. (1972). Impression management by parents with disabled children. Journal of Health and Social Behavior, 13, 80-89.
- Wachs, T.D. & Sheehan, R. (1988). Issues in the linkage of assessment to intervention. In T.D. Wachs & R. Sheehan (Eds.), Assessment of young developmentally disabled children. New York: Plenum Press.
- Walker, A. (1991). Thesaurus of psychological index terms (6th Ed). Arlington, VA: American Psychological Association.
- Walker, D.K., Epstein, S.G., Taylor, A.B., Crocker, A.C. & Tuttle, G.A. (1989). Perceived needs of families with children who have chronic health conditions. Children's Health Care, 18(4), 196-201.

- Widrick, G., Whaley, C., DiVenere, N., Vecchione, E., Swartz, D. & Stiffler, D. (1991). The medical education project: An example of collaboration between parents and providers. Children's Health Care: Journal of the Association for the Care of Children's Health, 20(2), 93-100.
- Wilde, V. (1992). Controversial hypotheses on the relationship between researcher and informant in qualitative research. Journal of Advanced Nursing, 17, 234-242.
- Wikler, L., Wasow, M. & Hatfield, E. (1981). Chronic sorrow revisited: Parent vs. professional depiction of the adjustment of parents of mentally retarded children. American Journal of Orthopsychiatry, 51(1), 63-70.

APPENDIX A: PARENT LETTER

September 28, 1993

Dear Parent:

I am a registered nurse who is currently working on an advanced degree in Nursing at the University of Washington. I am interested in learning more about how parents and professionals work together and communicate with each other in treatment settings like this one. For the next few months, I will be spending time at this center, observing treatment sessions and conferences and talking with both parents and staff at the center. I want to learn as much as I can about what it is like to be a professional working with parents at a developmental treatment center. I believe the best way to do this is to simply ask people about their experiences.

In addition to observing activities and talking to people, I will be doing some individual interviews which I will audiotape for further study. Taped interviews will only be done with people who agree to this and sign a consent form. Enclosed is a consent form for your information. If you are willing to participate in a taped interview, you may sign the form and return it to your treating therapist at your child's next appointment and I will make arrangements to meet with you at your convenience. If you are interested, but have questions, let your therapist know and I will be available to provide answers to your questions.

Participation with me in this study is completely voluntary. All information will be kept strictly confidential. I will not talk with therapists about what parents say to me or to parents about what therapists say to me. Anyone who participates in the study is free to drop out at any time for any reason. I will always identify myself to you as a researcher so that you may decide not to talk with me or have me in your session if you would rather not.

Please feel free to ask any questions you have about this study. You may talk to me while I am at the center or leave a message for me with the receptionist or one of the therapists, and I will get in touch with you as soon as possible. I look forward to the opportunity to talk with you and hear about your experiences.

Sincerely,

Kathy Clotfelter, R.N., M.S.N.,
Predoctoral Nursing Student

CURRICULUM VITA

Kathleen Clotfelter Watson

EDUCATION:

Doctoral Candidacy, University of Washington, School of Nursing, December, 1993 to December, 1994.

Predoctoral coursework, University of Washington, School of Nursing, Spring 1990 to Spring, 1993.

Master of Science in Nursing, Maternal Infant Nursing, University of Alabama at Birmingham, August, 1976.

Bachelor of Science in Nursing, University of Alabama at Birmingham, 1974.

PROFESSIONAL EXPERIENCE:

Predoctoral Research Assistant II, Critical Care Nursing Systems Study, Department of Physiological Nursing, University of Washington, October, 1993 to June, 1994.

Predoctoral Research Assistant I, Critical Care Nursing Systems Study, Department of Physiological Nursing, University of Washington, October, 1991 to October, 1993.

Per Diem Staff Nurse, Perinatal Nursing, University of Washington Medical Center, August, 1990 to June, 1994.

Predoctoral Teaching Associate I, Department of Parent and Child Nursing, University of Washington, September to December, 1991.

Predoctoral Research Assistant I, Department of Parent and Child Nursing, University of Washington, April to June, 1991.

Research Nurse, Newborn Eye Prophylaxis Study, Departments of Pediatrics and Epidemiology, University of Washington, October, 1988 to September, 1990.

Per Diem Staff Nurse, Perinatal Nursing, University of Washington Medical Center, February to October, 1988.

Clinical Nurse Specialist, Developmental Disabilities, Providence Hospital Children's Center, Everett, Washington, October, 1983 to December, 1987.

Staff Nurse, Perinatal Nursing, University Hospital, University of Washington, August, 1981 to October, 1983.

Clinical Nurse Specialist, Developmental Disabilities, Experimental Education Unit, Child Development and Mental Retardation Center, U of WA, February, 1978 to June, 1981.

Instructor, Department of Maternal-Infant Nursing, University of Alabama at Birmingham, September, 1976 to December, 1977.

Clinical Associate, Department of Maternal-Infant Nursing, University of Alabama at Birmingham, September, 1974 to August, 1975.

RESEARCH:

Weed, Kathleen Clotfelter. A study to develop and pilot a tool to assess the attitudes of mothers of handicapped children. Unpublished research study, University of Alabama at Birmingham, School of Nursing, Birmingham, Alabama, 1976.

AWARDS, HONORS, SPECIAL RECOGNITION:

University of Washington School of Nursing Hester McLaws Nursing Scholarship, awarded September, 1993.

Washington Association for Retarded Citizens Trust Fund stipend awarded April, 1993.

Maternal and Child Health Bureau, Children and Adolescents with Special Health Care Needs grant traineeship, October 1992 to December, 1992 and April to June, 1993.

Professional Nurse Traineeship Program Award, October, 1991 to August, 1992.

Preparation of Related Services Personnel: Interdisciplinary Teams for Serving Young Children with Disabilities in Family Systems (FITT) grant. Stipend and tuition waiver, October, 1990 to May, 1991.

Clinical Instructor, Department of Maternal and Child Nursing, University of Washington, unsalaried position, September, 1978 to June, 1981.

Inducted into Sigma Theta Tau, Nu Chapter, Nursing Honor Society, 1976.

National Institute of Health Professional Nurse Traineeship, 1975-76.

CURRENT PROFESSIONAL MEMBERSHIPS:

American Association on Mental Retardation

Sigma Theta Tau, Psi Chapter

Western Institute of Nursing

RECENT PROFESSIONAL MEMBERSHIPS

American Nurses Association

Association of Women's Health, Obstetrical and Neonatal Nurses