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The Effects of Family Dynamics on Pediatric Intervention

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THE EFFECTS OF FAMILY DYNAMICS ON PEDIATRIC INTERVENTION

by

Michelle L. Jung
Bachelor of Science in Physical Therapy
University of North Dakota, 1994

An Independent Study

Submitted to the Graduate Faculty of the

Department of Physical Therapy

School of Medicine

University of North Dakota

in partial fulfillment of the requirements

for the degree of
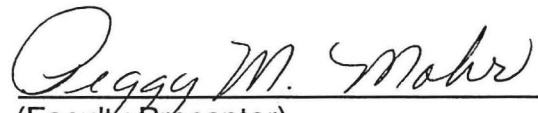
Master of Physical Therapy

Grand Forks, North Dakota
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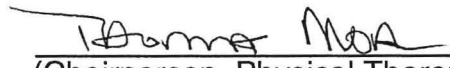
This Independent Study, submitted by Michelle L. Jung in partial fulfillment of the requirements for the Degree of Master of Physical Therapy from the University of North Dakota, has been read by the Faculty Preceptor, Advisor, and Chairperson of Physical Therapy under whom the work has been done and is hereby approved.

Peggy M. Mohr
(Faculty Preceptor)

Thomas Mohr
(Graduate School Advisor)

Thomas Mohr
(Chairperson, Physical Therapy)

PERMISSION

Title   The Effects of Family Dynamics on Pediatric Intervention

Department   Physical Therapy

Degree   Masters of Physical Therapy

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Signature   _Michelle L. Jung_

Date   _3-26-95_

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ABSTRACT

The family unit in America is becoming extremely diverse in its composition, perceptions, and capabilities. It is this diversity which challenges professionals to perceive and interact with each family as an unique entity. Most importantly, though, is the influence of family dynamics on the outcomes of therapeutic interventions for children with disabilities. Since the passage of Public Law 99-457, the focus of intervention has moved from treatment of the individual child to services involving the family as a single functioning unit. Services are then provided to the child and family, as the family needs influence the child's growth and development.

The purpose of this study is to address the issues facing families with children who have special needs. Specific questions to be addressed include:

1.) What characteristics of families promote intervention?

2.) What are the "stressors" that influence family involvement with intervention?

3.) What is beneficial for therapists to know to be effective in servicing families?

The procedure used for this study will be a literature review comprised of information on the structure and characteristics in today's society of "new" families. Also, a brief summary will identify the effects of culture and stress on several coping mechanisms. Finally, specific approaches, suggested by both professionals and parents, are incorporated for therapists to use in developing partnerships with families, which will enable the intervention team to work toward the best quality of care for a

child with special needs. The results gathered form this independent study will add to the knowledge of pediatric therapists on how to better communicate and function as a team member within each individual family system.

CHAPTER 1

INTRODUCTION

Culture has been the center of societies for thousands of years. Now of recent, it has become an integral component to early intervention for disabled children. Since culture is a broad "central theoretical concept" about which books can be written, this paper will refer to it using a general definition described by Sparling.[1] She defined culture as an unique behavioral complex which is socially created, readily transmitted to family members, and potentially maintained through generations. Thus, in reference to such a definition, families from generation to the next generation are contingent on the existence of their own unique culture of characteristics and values.

Unfortunately, it appears as the family composition changes, the culture from previous decades of American family life is slower to respond and adjust to such rapid differences. The family unit is becoming extremely diverse in its composition, perceptions, and capabilities. This is important to note, since these family dynamics influence the outcomes of therapeutic interventions for children with disabilities.[2] A review of current statistics indicated family transitions occurring from two-parent families to homes of single parents, growing minority representation, teenage mothers, families of abuse, possibilities of artificial reproduction, and even genetic altering of persons. Recognizing these family

changes, as well as the predominance of lower socioeconomic status and decreasing health coverage, is essential for the development and maintenance of quality early intervention services.[3] Now add to these families a child with a disability who requires additional support services and exceptional demands of the family. The stress under those conditions is magnified.[2,4,5] The recognition of the cultural dimensions of each family is a preliminary step to interaction with the family. Such recognition presents a challenge to the intervention system, from professional to parent, which is still adapting to the process of serving the family as a single functioning unit. Services are then provided to both the child and family, as the family needs influence the child's growth and development.

The purpose of early intervention is to provide services for young children to improve their quality of life to its fullest potential.[6] This does not suggest limitation of service provisions to health care facilities, institutions, or public and private schools, but requires service delivery within the context of their family environment and society.[3] Intervention is increasingly approached as a team effort. Parents, by law, are part of this team. This mandate is reflected in the provisions outlined in Public Law 94-142.[7] This law enacted in 1975, specified that parents must be invited to become part of the team, which formulates the involved child's Individualized Education Plan (IEP). That law has been in effect for almost two decades and many different approaches have been developed to generate parent involvement. Public Law 99-457 has been designed to assist states in facilitating a comprehensive system of early intervention services for

infants and toddlers with developmental delays and their families.[7] The Federal Register stated the regulations from this last mandate should have a positive impact on the family unit. The goals are to strengthen the authority of and increase participation of parents in meeting the early intervention needs of their children and all family members as they relate to caring for the child with a disability.

The traditional "medical model" approach to the early intervention process saw the child or family as having deficits which the professionals can "cure" or fix. In contrast, today the philosophy of early intervention is based on an approach which integrates parents, other family members, and professionals as team participants.[6] Many different labels exist to describe an interdisciplinary focus on families. Examples of such labels are family-centered care, enabling and empowering families, or family focused care, all of which share central assumptions regarding the importance of each family's values, needs, and expectations. Also, it is the professional's job to emphasize the importance of parents and siblings not simply as clients, but as active team participants. As participants, their valuable input will broaden the spectrum of information about the child or family, and therefore be of equal importance to that of the interdisciplinary team. This partnership between parents and professionals involves sharing of risks, responsibilities, and profits.[3]

The problem with implementing an appropriate intervention plan is that there are many types of families, each with a distinct family system. Professionals will

have to know how to interact with each family as a unique entity. Once each family's perceptions, needs, and goals are identified, communication and trust will be more readily established. Another issue, that of parent/child compliance, then becomes the next challenge.

The purpose of this literature review is to address the current issues facing families with children who have disabilities. Specific questions which will be addressed include:

1.   What are the "stressors" that influence a family's involvement with intervention?

2.   What characteristics of families promote intervention?

3.   What is beneficial for therapists to know to be effective when working with children and their families?

It will also address ways in which professionals can approach families of today's changed society. These approaches, suggested by parents and professionals, will enable therapists to better communicate and function as a team member within each individual family system. The intervention team can then work toward the best quality of care for the child with special needs.

CHAPTER 2

FAMILY SYSTEMS

As the "typical" American family has changed since the 1970's, so has the
way in which treatment facilitation is approached. Families cannot be
categorized in general terms of normal versus dysfunctional as they once were.
A family in the 21st century may have taken on a transformed definition. Today,
the term family no longer brings to mind the "traditional" nostalgic picture of a
mother baking cookies in the kitchen, a father mowing the lawn, and the kids
playing with their dog waiting for their grandparents to arrive. The structural
changes in the composition of the American family have been stressful for all
family members. Children are attempting to cope with divorce, step parents,
new siblings, episodic visits with natural parents, poverty, and violence, in
addition to the "normal" developmental problems associated with growing up in
our today's society. The statistical truth which historians are discovering centers
on the basis of families having their own unique system comprised of a series of
internal interactions and strategies.[4,7]

In 1986, William Bennett[8] in a statement directed toward public education,
regarding changes in family composition, reported out of 100 randomly selected
children, "Twelve have been born to unmarried parents; forty have been born to
parents who will divorce before the child is 18 years old; five have parents who

will separate; two have been born to parents one of whom will die before the child turns 18 years old. Only forty-one of these 100 children will reach their 18th birthday's in "tradition" family units." Bennett's observations illustrated the change that has occurred in the composition of families. This change challenges the traditional frame of reference held by teachers, administrators, and related-service personnel. Understanding and meeting this challenge requires analyzing how the American family has changed, what impact a child with a disability has on the family, and what services are required under P.L. 99-457.[9]

What does the American family of the 1990's look like? Predictions from Halpern[10] in 1987, were that by 1990, 75% of the children in this country under 6 years old would be receiving non-parent care.[10] As the 1990's began, the traditional family seemed to begin dismantling after several decades of economic and social hardships.[2] Only three in one hundred house-holds now conform to the "classic" family headed by a working husband with a dutiful wife and two children at home. Current statistics from the 1990 U.S. Census claimed only one in four families is made up of a married couple with children. This has fallen to the third most common scenario among the nation's households, behind people living alone and also trailing married, childless couples. Between 1970 and 1990, the proportion of children growing up with a single parent more than doubled, to over three in ten of American households. Nearly two thirds of black households are headed by a single parent. Out of these single parents approximately 39 percent are divorced.[11]

Roberts[11] stated, "From the beginning, America has been a nation on the go." In virtually every decade, except the 1930's, more immigrants have been coming into the country than emigrating. However, never before has this nation been so culturally diverse. He reported the 1990 Census found that Caucasians made up 80 percent of America's resident population; African-Americans constituted 12 percent of the population, an increase of 13 percent; Hispanic people rose to 9 percent of the population, an increase of 53 percent; and the Asians population doubled, to account for the final 3 percent of the total American population. Therefore, it is not surprising to find that one in eight people nationwide speaks a foreign language at home. Recognizing these changes in families is only the beginning of the process for development and quality of care for children who have special needs.[3,9]

Every family evolves their own method and pattern to deal with the daily demands of all its members and today's society.[3] Recent attempts to understand families have found it useful to define families as a system.[3,12] The family can then be analyzed in terms of a structure, function, and the processes by which the parts influence each other. Professionals and family members would benefit from learning about each individual family's major characteristics of all its members. Most importantly, there is a need to know the ways in which family members influence each other and the family as a single unit. This will enable them to promote the well-being and development of the child who needs services, as well as, aiding the rest of the family in support issues.[3]

According to Turnbull and Turnbull[4], the major characteristics of a family can be categorized by: size and form, cultural background, socioeconomic status, and geographic location. Although the number of family members and even their relationships may change over time, the family's cultural background and values or beliefs tend to remain more constant.[12] Success of interaction between professionals and parents requires recognition of each specific area. Failure to be sensitive to each family's unique characteristics can create additional barriers.[1, 12]

Family Size and Form

Turnbull and Turnbull[4] reported much of the research done on families with special need children indicated that larger families tended to be less distressed by the presence of such a child. Though it is unclear why this results, several authors have developed different theories on such an occurrence. Trevino[13] suggested two theories. First, that in large families there are more individuals available for assistance, where in smaller families the responsibility is not as well distributed. Or secondly, it could be that with a large number of children there is a greater atmosphere of normalcy. Another proposal by Powell and Ogle,[14] was that parents of large families may not feel as much at fault for the child with a disability as they might otherwise because the siblings tend to absorb the parents' expectations. Finally, in larger families other children may give the parents a chance to compare likenesses to siblings rather than the differences. Turnbull et al[15] noted one parent claimed the problems of a disability were no

greater, or perhaps even less difficult than dealings of adolescent rebellion, drug involvement, or pregnancy.

However, statistics reported by Sparling[1] showed the number of families with children decreased from 45% in 1970 to 36% in 1989. This decrease in family size was evident across all ethnic groups. Caucasian families with four or more children decreased from 9% to 2%. While Hispanic and African-American families also decreased from 18% to 6% all within the last 17 years. A decrease in family size, thus stimulates the further need for supporting services.

Another condition which may cause a difference in reaction to a child with special needs is the number of parents. Currently the divorce rate is reaching 50%.[7,11] Therefore, one is more likely to encounter a single-parent family. The majority of single parents with custody of children are women. Statistics reported approximately 13.5 million children live with their mothers, while 1.8 million with their fathers.[16] Similarly, Roberts[11] described 87 percent of children from single-parent homes living with their mothers. Due to the amount of responsibility facing these households to provide financial and child rearing support, the stress may be very high.

An opposite situation which has a high prevalence of occurring is that of having more than two parents. In 1982, Visher and Visher[17] found that 80% of people who divorce remarry. Thus, the likelihood of encountering this situation is quite high along with increased tensions due to personal issues between disarrayed family members. In such families with a variety of possible

configurations, it is difficult to develop any general rules for working with them, except for trying to stay in neutral territory and encouraging everyone's involvement.[4]

Cultural Background

A working definition of culture, describes a behavioral system which is socially created, readily transmitted to family members, and potentially maintained through generations.[7] In order for a professionals to relate within this system, they need to recognize each family's uniqueness, along with their own cultural characteristics, plus social biases.[3,4,7,18] One needs to be careful to avoid promoting stereotypes. While it is beyond this paper to review and analyze differences between cultures, a summary is necessary to assist with recommendations for professional interactions.

The most frequent way in which culture has been addressed in the occupational and physical therapy literature has been to equate it with ethnicity or race.[18] This narrow definition of culture limits the uniqueness within families, which many authors have already established exists. Consequently, we are left with preconceived ideas based on stereotypes. It is important to learn more about particular traits common to cultural groups in your local area, since cultural differences can play a role in how comfortable families are with "outside" support.[19]

Several guidelines noted by Sparling[7] may be used to help in identifying the individual cultural characteristics of each family with children who have special needs. They are as follows:

1.   Include the family as the unit of focus for health care and educational needs.

2.   Examine common rules which govern the way in which individual family members interact.

3.   Members have specific roles in the family, but these roles can be defined differently by different families and probably will change over time.

4.   Families can have similar experiences at times of crisis without perceiving and deciding things in the same manner.

5.   Inconsistency in caretaker behaviors may be one of the most critical variables affecting child outcome.

6.   Uncertainty in interaction, often based on a lack of information can create stress for the family.

In summary, successful partnerships with families require a great deal of self-awareness on the professional's part. An important aspect of culture is that the influence of it on behavior is not always conscious. Wayman, Lynch, and Hanson[12] have called culture the silent language and described cultural traditions and convention as largely subconscious. Most people do not recognize the effect of culture on themselves, yet their behavior is rigidly influenced by it.

Recognizing the role of culture in family assessment and treatment can improve rapport and communication, thereby increasing compliance and decreasing feelings of frustration, stress, and anger.[18]

Socioeconomic Status

A family's socioeconomic status (SES) includes such things as income, the level of education of its members, and status provided through occupations of its wage-earner.[4] This definition implies the higher a family's SES, the more resources available to cope with a child who has special needs. Once again the predictors are not that simple; higher SES does not automatically guarantee better coping or adaption. Family styles and values come into play, therefore shaping the overall reaction to the disabled child.

Some of the differences between higher and lower SES groups include the extent and knowledge level of resource networks along with the family's sense of control over both their environment and their future. Farber and Rychman[20] found that families which were achievement-orientated generally tended to be of a higher SES with their control of life based on personal goals and accomplishments. A traumatic crisis may be created when these families have to deal with the reality of their child's disability. This type of family may have a difficult time with the contradiction of being in control of their lives. A positive aspect, however, may be an advantage of financial security. The family may be able to respond efficiently and appropriately to support services for their child. In

such a situation, the child's and family's needs related to that child can be addressed as a high priority.

The opposite end of the spectrum includes lower SES families. In 1982, Lee[21] reported families of lower SES tended to value achievement less than other values such as family solidarity or happiness. These families may not experience a crisis due to the child's disability, but may have greater difficulties when they face the problem of how to care for the child financially and where to get support services. Many working-class families may not believe in the possibility of controlling their environment. Furthermore, such a belief can make these families less active participants in decision-making.[4] Some low SES families also have to deal with the harsh survival problems of poverty conditions. For such families, a child's support service needs may seem to be the least of their worries. Generally, parents who do not participate in supportive programs do not care less about their children than those who do, it just may not be their first priority.[4]

The need to understand the families' perspectives and develop value-appropriate services can help increase participation.[22] Therefore, whether a high or low SES family, they may be more willing to reach out for support services or information pertinent to their children condition. A strong rapport and trusting relationship are the keys to promoting cooperation within all socioeconomic groups.[4, 22]

Geographic Location

With today's world of mass multi-media and increased transit systems, regional differences in family values and forms are less than they once were.[4] Of the total population of children in year 1990, 46% live in suburbs, 30% in metropolitan areas, and 23% in rural and other areas.[7,11] Many of the metropolitan areas consist mainly of minority children.[7] Over a recent 12 year period, the percentage of Hispanics living in the city increased from 47% to 54% with poverty increasing in that group by 7%. The percentage of African-Americans living in inner-city areas remained constant at 56%, with their poverty level at 71%. In contrast, 25% of Caucasians live in the inner city with 33% of these living in poverty conditions. These statistics describe an ever-changing and high poverty level environment for city children. Reaching these families who have a child with a disability and finding financial aid for such services are the burden health care professionals have in urban areas.[10]

The children with special needs who live in rural areas face isolation problems. Providing services over such great distances to just a few families requires some creative professionals. The parents, with such little community resources, may have to provide a significant amount of care services by themselves.[4] This can be done through uses of video instruction tapes, self-instructional manuals, a WATS line, or a family newsletter. It is interesting to note that upon an interview with such parents,[23] they prefer not to get information by mail, unless they have requested it. They tend to have mounds

of information but a lack of time to read. Thus, when approaching training for parents, it will be beneficial if professionals remember their time constraints. Then parents may provide an effective treatment utilizing the necessary proper techniques.

In general, with the increased mobility of families, there is the stress of settling into a new community, plus problems of setting up new programs for their child with special needs. Statistics from 1980 to 1990 indicated that most people lived in different locations and/or houses, demonstrating the vast majority of mobile families.[11] For these families, the process of intervention begins again, with questions of past family history and their orientation to "new" professionals. Collaboration between interdisciplinary teams and parental involvement may ease such transitions, so the child's treatment plan can continue with limited delay or alteration.

Intervention team members have learned that it is not the parent, but the larger concept of the "family" that is the key in extending childhood services.[7] The family is important in terms of a system consistently surrounding and influencing the child, and in turn being influenced by the child.[1,2,7] Observing and understanding the major characteristics of a family permits professionals to assess the child and confer with their family, so that the child receives the most appropriate and beneficial services of care.

CHAPTER 3

FAMILY REACTIONS

Undoubtedly the most commonly described effect of having a child with a disability is the subsequent stress imposed on a family. [2,6,7.] Professionals would benefit from learning the definition of stress, how it is assessed, and what factors contribute to reducing it in family settings. Research does support an increased stress level in parenting a child with special needs. [24] Although stress cannot be defined specifically, it is an attribute commonly used to account for variability in behavior. In a review of the literature on stress, Selye [25] defined it as the body's nonspecific response to any demand. Whether stress is pleasant and healing or unpleasant and painful, the body still requires an adjustment from its normal state. It is theorized, too much stress can be debilitating, but some stress is necessary for growth and change to occur. [2] Moreover, stress is not a single event, but rather a process that involves many factors. [2,6,11,26]

In 1958, Hill [26] was credited with the formulation of the family crisis model, ABCX, developed as a research project in sociology. This basic crisis model contained four factors A, B, C, and X. Factor A was the stressor event. It has a defined beginning and end which produces the crisis. Factor B was how the family utilized their resources to meet the immediate crisis or in other words the families style of coping. Factor C was the definition the family made of the

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event, with the possibility that each members' idea may be different. Finally, factor X was the crisis itself, which was the key concept of the model. This model examined the factor relationships and interactions. From this model, many others have been developed by expanding or reshaping the structure. Although the models vary in their idea of stress, they all agree on the system components of interaction and account for the many variations in a family's adaption capabilities.[26,27]

Stress may arise from a single event, but more often than not, it is caused by on-going factors which may have arisen from a specific event, but has had long-term ramifications. In general, a stressor is an event or set of events that requires some form of psychological or physical adjustment. The particular "change" of assimilating a child with a disability into a family causes nearly every aspect of family structure and interaction to be markedly altered.[6] Emotionally, the family and each of its members must come to terms with what has happened to them. The process of coming to acceptance is very similar to that of grieving, which includes experiencing the stages of shock, denial, anger, chronic sorrow, reorganization, and equilibrium.[6] It needs to be noted that different families or individual family members may have different perceptions of a given stressful event.

Generally, stress is assessed through self-report measures completed by a family member. Three commonly used measures are described by Bailey[2] as

the Questionnaire on Resources and Stress (QRS), the Parenting Stress Index, and the Impact-on-Family Scale.

The oldest and most frequently used measure of stress is the QRS, developed by Holroyd,[28] to evaluate the psychological costs to persons living with and caring for a disabled or chronically ill relative. This instrument is reported to be reliable and a valid measure of stress. Examples of its use have been to describe differential patterns for different disabilities and to examine the effects of various child and family characteristics on stress. [2]

The Parenting Stress Index, a screening and diagnostic assessment technique designed by Abidin[29] yields a measure of the relative magnitude of stress in the parent-child system. Either parent may complete the scale, although it was originally developed with the mother as the primary respondent. Several studies have documented the scale's reliability and validity. However, the extent to which the normative data represents the U.S. population is questionable, due to a predominantly Caucasian sample of 92%. [2]

Lastly the Impact-on Family Scale developed by Stein & Reissman[30] specifically assesses the impact of a chronically ill child on family life. It can be used for families with disabled children too. The developers provided reliability data on the measure and suggested that it be used in describing either the initial impact of a chronically ill or disabled child on the family or as an evaluation of the effectiveness of various interventions to reduce such an impact. [2]

Petersen and Wikoff [24] found that coping and adjustment seemed to be directly influenced by the resources available to the family. Families which reported higher levels of stress were more socially isolated. They had fewer contacts and meaningful relationships with extended family and friends. Also, they concluded that the adjustment within a family who had a child with a disability was affected by more variables than just the presence of that child. At different times, families experienced rapid periods of change and growth, while at other times relative stability was evident. Again such changes relate to the structure and function of the family. How such changes are brought about will depend upon the processes used by the family to communicate, make decisions, and to work together. [1]

There are various coping strategies utilized to enable individuals to get through stressful events. A general definition of coping is any strategy a person may choose to reduce feelings of stress. [4] There are five categories of coping styles developed by Olson et al.,[31] which include: 1) passive appraisal, which is ignoring a problem in hope that it will go away; 2) reframing or changing the way one thinks about a problem in order to solve it and/or to make it seem less stressful; 3) spiritual support, which is deriving comfort and guidance from one's spiritual beliefs; 4) social support, or receiving practical and emotional assistance from friends and family; and 5) support from professionals and human service agencies. Folkman and her colleagues [32] found that people employ different coping behaviors in response to different life events, and that the resources

people have available to them define their coping strategy. Therefore, in summary, it appears the process of dealing with stressful events is an individual personal cycle. Families with disabled children are clearly at greater risk for stress and its negative consequences. Thus, intervention professionals should be sensitive to the presences of stress and attempt to provide services in a fashion that decreases rather than increases it.[2]

Families also have a variety of types of strengths and competencies, which reflect the way in which they cope and grow.[2,4] There are many definitions of family strengths in published literature. In general, strengths are considered a pattern of interpersonal skills and characteristics of dynamic nature which create a positive personal sense, as well as an identity. These strengths encourage development and contribute to the ability to deal effectively with stress and crisis situations.[26] Since each individual family member has various strengths which they contribute to the family system, a uniqueness results in individual families.

Dunst, Trivette, and Deal[33] suggested that there are 12 major, non-mutually exclusive qualities of strong family units. These twelve qualities are as follows:

1. A belief and sense of commitment toward promoting the well-being and growth of individual family members as well as that of the family unit.

2. Appreciation for the small and large things that individual family members do well and encouragement to do better.

3. Concentrate effort to spend time and do things together, no matter how formal or informal the activity or event.

4. A sense of purpose that permeates the reasons and basis for "going on" in both bad and good times.

5. A sense of congruence among family members regarding the value and importance of assigning time and energy to meet needs.

6. The ability to communicate with one another in a way that emphasizes positive interactions.

7. A clear set of family rules, values, and beliefs that establishes expectations about acceptable and desired behavior.

8. A varied repertoire of coping strategies that promote positive functioning in dealing with both normative and non-normative life events.

9. The ability to engage in problem-solving activities designed to evaluate options for meeting needs and procuring resources.

10. The ability to be positive and see the positive in almost all aspects of their lives, including the ability to see crisis and problems as an opportunity to learn and grow.

11. Flexibility and adaptability in the roles necessary to procure resources to meet needs.

12. A balance between the use of internal and external family resources for coping and adapting to life events and planning for the future.

The presence of these different qualities and all the possible combinations, defines what Dunst, Trivette, and Deal have called "family functioning style." The use of the term family functioning style is preferred, since using strengths implies that at the opposite end there are weaknesses. Though there exists a difference in family strengths, there are no absolute right or wrong styles. In reviewing literature on family strengths, many scales have been developed. In 1988, Trivette, Dunst, Deal and Associates developed the Family Functioning Style Scale (FFSS).[33] They then studied three additional scales including: the Family Strengths Inventory by Stinnett and DeFrain; the Family Strengths Scale by Olson, Larsen, and McCubbin; and the Family Hardiness Index by McCubbin, McCubbin, and Thompson. Results showed the FFSS to be the most comprehensive in terms of the range of qualities it attempts to measure.

Today, the process of family assessment plays an important part in service delivery and is imperative that it identifies the family's strengths, as well as their needs.[26,34] There are a range of family assessment tools, which professionals should become familiar and comfortable with in order to apply them properly. This will enable them to choose which tool will best identify both the strengths and needs of a family.

In an article by Whitehead, Deiner, and Toccafondi[34] recommendations for service delivery are discussed based on the Delaware FIRST project. This project was a model study done in 1990 that was initiated for the purpose of making specific recommendations for supportive delivery systems for better

implementation of the mandates from P.L. 99-457. The Delaware FIRST project

selected four assessment tools for use in evaluating families. They were as

follows: 1) the Survey of Family Needs by Bailey,[35] which assesses six major

categories, including needs for information, support, explanation of conditions,

community services, financial help, and family functioning; 2) the Family Support

Scale by Dunst, Jenkin, and Trivette, which measures the availability of 18

possible sources of social support as well as the family's judgment on each ones

usefulness; 3) the Parenting Stress Index by Abidin,[29] which rates parental

stress related to child's characteristics and parents' functioning; and 4) the

Family Adaptability and Cohesion Evaluation Scale (Faces III) which measures

family adaptability and cohesion as the family currently perceives them and how

they ideally would like them. This project found the Survey of Family Needs to

be of greatest resource in generating family goals.[34]

During discussion after each assessment tool of the Delaware FIRST project

was administered, it was found that parents generally were agreeable and very

cooperative about the items, but any negatively worded items were sometimes

not responded to honestly. Overall, the Delaware FIRST project specified two

recommendations.[34] One, that there was a need for families to be heard and

regarded as valuable to the team process, and secondly, the appropriate

assessment tool which is estimated to be truly responsive to their needs should

be implemented. This would limit irrelevant information and make better use of

the empowerment time. The project recommended the child's assessment

should proceed the identification of family strengths and needs. Then, before a formal family assessment is done, a general relaxed interview should be implemented to help the family focus on their unique strengths and needs.

In relation to any professional administration of family assessment tools, service providers need adequate training in early childhood special education and development.[34] Although skilled practitioners with experience find better results due to informal assessments, there is a need for beginning or inexperienced professionals to first understand the purpose of each assessment tool by using them in their formalized measures. As professionals attempt to provide intervention in ways that reflect the mandate of P.L. 99-457, the search for models and strategies to guide efforts will continue.[19] Conceptualizing the intervention process, with emphasis on how families define what is normal for them in the context of their daily lives, may enable professionals to provide the framework for an appropriate family-centered treatment plan.[34]

CHAPTER 4

PROFESSIONALS AND FAMILY RELATIONS

Professionals and families with children who have disabilities have vital

information to share with each other. The success of this interaction requires

developing a strategy which will enable professionals to become members of

each family's team. Families cannot be changed to fit in with the team;

therefore, this team works best if it is a "family driven" system. [7] To be an

effective team, many prerequisites are needed. Professionals should learn to

recognize family diversity. They must develop a detailed understanding of its

size, structure, cultural background, values, interaction styles, and child rearing

practices.[2] Professionals also require effective communication skills. Such

communication skills have been defined as a process by which people exchange

and transmit information. Unfortunately, Sonnenschein[36] found communication

among families to be frequently less than adequate to sustain an ideal

relationship.

A survey of professional education programs providing service to families,

including the disciplines of physical, occupational, and speech therapy, was

conducted by Wayman et al.[12] It revealed that few hours of course work or field

experience focus on family dynamics and systems, nor any studying of

assessment through family interaction. These concepts are needed for building

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mutual respect, trust and positive communication within an individual team. Without all of the previous information and sensitivity to it, the vital information shared between parent and professional will be lost. Research conducted by Bensky et al.[37] has indicated that teachers ranked communication with parents as a major source of job stress and likewise, parents reported the same feelings of stress when working with teachers or other communication intensive professionals. This may lead to increasing the level of stress for the family and frustration of the professional.

There appears to be a developing consensus in the literature that certain factors influence team functioning.[7] Each member brings with them a different perception and judgment, which has been developed based on their own life experiences and individual personalities. These attributes often change as new personal experiences are encountered and their personality matures.[38] Personality development is a lifelong process which often changes with each new experience.[2] The best way to ensure effective teamwork would be in appreciating and using the strengths of each type on the team.[8, 39] Certain personality types are more amendable than others in determining and solving the problem, while others are better able to facilitate a solution. Any member who is perceived to be inferior eventually realizes this and withdraws from active participation, thus depriving the team of input. This is an area of concern, due to the fact that the intervention system, as well as the parents, generally empower professionals with more expertise and capabilities than parents, themselves,

have with their own children.[7, 40] In reference to a professional working within a family system, parents implore you not to strip them of their knowledge and expertise.[2, 4, 6] Bailey has stated that under ideal circumstances, each team member's role is relatively equal in power and influence.[35]

The ultimate goal of the team should be to balance the needs of all family members with those of their disabled child or sibling.[6] To complete this task, the various talents of each individual team member is needed. Some individuals are naturally better leaders than others, but all team members should choose or be assigned tasks which fit their area of expertise.[7, 38] There are positive and negative attributes associated with diverse teams. For instance, a group with many different perspectives will reach decisions more slowly, but the final decision will usually be more preferable, because more viewpoints have been incorporated.[38] When a team, such as this, is successful, all members benefit in their own development, as they learn from the skills of others.

A review of the literature on multi-disciplinary teams indicated that there is a process and structure change that occurs over time. Therefore, team structure needs to be defined in a cross-sectional view to illustrate what the team looks like at any one point in time.[7] Structure can be considered from an external and an internal perspective. The external structure of the team refers to the environment of the system in which it works. Since the team depends on the organization for its survival; teamwork can be effective only when it is supported by that organization. The teams' internal structure includes factors such as

members' roles, team goals, team norms and members' values. Lowe and Herranen [41] suggested that team process dysfunctions occur when there are problems with the team's structure.

The team process then, is how the factors of decision making through open communication can accomplish team goals, objectives, and tasks. Such goals should reflect the desires, needs, and experience of the family, supplemented by the knowledge and expertise of professionals.[7] The establishment of a healthy communication network on the team is crucial for active family participation.[4,7,8]

When families and professionals interact, a whole host of variables come together. These variables range from varied social, economic, and educational experiences to ethnic, racial, and religious backgrounds. Turnbull and Turnbull[4] reported the first step on learning to communicate effectively and work with others is learning to know and work with ourselves. The attitude that favors understanding of ourselves favors understanding of others. Wayman et al.[12] defined language as the expression of thoughts and feelings by which people communicate with one another. In accordance with Wayman's definition, Turnbull and Turnbull defined interaction style as the specific manner in which language is expressed, and that it varies individually and by family. This distinctive style of interaction per family is shaped by cultural background and values.[4,12]

The ability to communicate and to demonstrate appropriate personal qualities are highly inter-related with professional competence.[4] There are six key

aspects described by Cunningham and Davis[3] to developing successful partnerships:

1. Respect

2. Genuineness

3. Attending

4. Getting Parents to Talk

5. Empathy

6. Challenging Skills

Simpson[42] believed without mutual trust and respect, the probability for the development of meaningful and productive communication among families and professionals is severely compromised. Among the qualities of trust-worthiness is the ability to nurture open communication with families. Professionals with such qualities are personified to be "approachable" people who tend to listen closely and make direct eye contact with individuals.[6] Respect then, is the belief that the families are valuable and important. This implies not only that professionals are prepared to give help willingly, but also that they believe that the family can cope, change and be strong. Respect can be shown in many ways, but perhaps the most powerful may be in attending to the family, which simply stated is quality listening.[3]

Another reason for the importance of development of trustworthy and respectful relationships among professionals and parents is that of treatment compliance. Compliance is defined by Gajdosik[43] as the primary means to

which the parent or care-giver of the child adheres to or follows through with the
prescribed treatment. Parents of children with disabilities are at risk for low
levels of compliance due to the characteristics of the home programs, which are
complex, continue over many years, and require the parent to make changes in
his or her lifestyle.[3] Five factors noted by Clopton and McMahon[44] which may
influence the level of compliance with a treatment regimen are as follows:

1. The family's psychological make-up.

2. The family's environment.

3. The nature of the treatment regimen itself.

4. The quality of interaction between the parents and professional.

5. The quality of the family education and involvement provided by
the therapist.

They further concluded that the most important factor influencing the
parent/patient compliance may be their own perception of the professional. For
optimal adherence, the parent, in situations concerning child services or a minor,
must view the professional as trustworthy, competent and empathetic.[3]

The study conducted by Gajdosik and Campbell[45] also reported factors which
influenced compliance. These factors included personal characteristics and the
perception of the parent, program characteristics, and professionals-client
relationships. Though no one factor was proven to be a reliable predictor of
compliance, therapists appeared to judge family compliance by each family's
socioeconomic status. However, this factor was not found to be a predictive

value for compliance either. Several variables which were associated with poor compliance were medical debts, lack of hospital insurance, lack of transportation, and when parents considered the cost for medicine or treatment too great. On the other hand, high frequency of follow through may not always be a positive sign. It may indicate that the parent is overly involved with the child, perhaps at the expense of other family members and him or herself. The parent could also be falsifying the data collecting records, perhaps in order to meet the therapist's expectations. [46]

What a parent does with the child at home may affect the child's rate of development. [1,2,22,46] Thus, when assessing the effects of the treatment on child development, the therapist should measure how often the parent practices the activities and their accuracy related to such treatments. Several methods of measuring compliance that pertain to pediatric therapies have been reported in literature. [46] One of the more creative methods for measuring compliance was the idea of counting disposable treatment items, such as paper or cotton swabs that are incorporated into the child's program. The problems with such a method is that a parent may reuse or forget to use the items, or use more than the appropriate number of items per day. Another method, that of asking parents to record in a journal each day whether he or she carried out the home program, has been used to measure compliance. This, however, requires a further time commitment on the part of that parent.

When the two methods were compared, the level of compliance measure was approximately the same. [46] To obtain a general idea of compliance levels, clinicians may also use interviews, but it should be kept in mind that parents are likely to over-estimate what was really done.

Therapists can affect parent follow through with a home program in several ways. [46, 47] However, before they attempt to increase compliance, he or she should decide if the level of follow through is really low and, if so, why it is low. To improve it, therapists could reduce the complexity of the regimen, number and frequency of exercises, and consistently monitor the program with the parent.

At times working with parents can be a delicate and challenging experience, yet even "difficult" parents have positive traits that should be reinforced. [48] Difficult behavior on the part of parents includes behaviors that are uncooperative, belligerent, detached, or overpowering. Boutte et al [48] discussed six parenting behaviors while addressing specific suggestions for working with each one. It covered such behaviors as the antagonist, "know-it-all", complaining, negative, shy/unresponsive, and illiterate parents. Although, it is beyond this paper to review all the suggestions per behavior, one is commonly suggested throughout all six categories. It is the importance of maintaining mutual respect for each parent as a human being who has his or her own feelings, beliefs, and mind set.

Further investigations of documentation concerning the frequency of parent compliance, what factors affect their ability to comply, and what therapists can do the support parents in their efforts of home treatment programs, would be beneficial for the whole intervention system.

CHAPTER 5

PARENT'S PERSPECTIVES REGARDING INTERVENTION

Primary among the catalysts which facilitate the development of family and professional partnerships is trust. [6] When a family feels trust in a professional, it tends to diffuse the confused emotional reactions that parents often face as they go about seeking and implementing services for their child. As a parent seeks help for their child, they are admitting to themselves and "the world" that their child has a problem. For most parents that admission is an excruciating step.

In many ways, the traditional service systems seem to set families and professionals up as opponents, instead of teammates. Since the intervention system usually begins service provisions with a formal developmental evaluation of their child, parents immediately face a team of professionals likely to give them more dismal news. The family is probably trying desperately to recover from the initial diagnosis and to shield themselves, as well as their families from more pain. The initial evaluation by the team, unless it totally contradicts the original diagnosis, may inflict more pain. However, if professionals can show parents when they first meet with them, that they see their child first and the disability second, this does much to dismantle all the protective defenses that are in place. [6] This can lay the foundation for establishing a trusting relationship

in which families and professionals know they are members of the same team with one, overall goal: Nurture the child's development.

Thus, a situation which had the potential to seem very intrusive to the family can be made to feel less so. A common comment of parents who have had extensive experience with early intervention programs is, "If I see acceptance of my child in the teacher or other professionals, if it is obvious that they like my kid and that my kid likes them, then I will do everything in my power to make the relationship work. We may have to 'agree to disagree' on some issues, but if I know the people truly care, that's what is most important to me." [6]

Perhaps the best way to learn what fosters effective partnerships with families is to listen to what "veteran" parents have said and their advice to professionals given throughout various literature. [6, 40]

In a study by Summers et al, [44] which compared family and practitioners preferences for the family service process, demonstrating sensitivity to families was by far the top priority. Comments by these respondents suggested that families look to the early intervention practitioner as an important source of emotional support and friendship. The implication is that early intervention involves families and practitioners forging personal, informal relationships. Therefore, parents at least in the early stages of adjusting to their child's disability, want practitioners who can perform the dual functions of formal (i.e. knowledgeable, capable, and professional) and informal (i.e. emotionally responsive) support systems.

In The Helsels' Story of Robin [47] additional insight for professionals about needs of families with exceptional children was shared. In view of the many needs of each family, professionals should recognize early that they too, are going to need help. [6] No one person has God-like powers to know what is best for a particular family, yet countless professionals assume this role. Families need and want professionals who are well qualified in their fields, but who have humility and empathy. They desperately need to have their emotions listened to and validated. Then they can proceed to learn how to channel their emotional energy into constructive outcomes. Turnbull [48] stated, "Emotion can be healthy; emotion can be energizing; emotion is human." Early intervention professionals should begin to teach families how to channel emotion to its greatest potential.

Sensitivity was one of the top priorities in a Parent Focused Group Interview done for the Personal Preparation Subcommittee, Interagency Coordinating Council and Department of Human Services of North Dakota. [23] A group of parents, all being mothers of a child with a disability, were asked what they felt were important skills that early intervention service providers needed to have when working with families. The unanimous response was that of being sensitive to parent/child needs, priorities, and skills including: listening, communication, understanding, empathy, confirming of parent's feelings, compassion and utilizing a non-judgmental approach. Jim Hinojosa's [49] study on how mothers of preschool children with cerebral palsy perceive Occupational and Physical Therapists and their influence on family life, reported to emphasize

the importance of open communications, sensitivity and trust. All the mothers felt their relationships with therapists were personally important. Often, it appeared that the therapist, as a person, was more important than the therapy itself.

There are several qualities of early intervention programs and the professionals who deliver such services, which serve to fulfill the development of sensitive and trusting partnerships with families.[3,6,33] Professional sensitivity to the needs of all members of a family, simply means thinking about what each family's life situation is like, and then taking the time to make a comment or an adjustment in scheduling, will mean a great deal to everyone.[6]

Perhaps in the professional world of early intervention, we have viewed emotionalism and professionals as incongruent, thus we describe formal and informal support as entirely separate. Apparently, families do not make that distinction.[44] Harriet Able-Boon et al[50] reported research findings of an interview study conducted with parents of young children with special needs. Research was conducted to assess parental perceptions of infant and family services as proposed in P.L. 99-457. A total of 30 families were interviewed. The sample included 30 mothers and 28 fathers, but the fathers did not participate in the interviews due to work, or unwillingness because they viewed the mother as the primary care-giver for their child. Four major categories emerged from the interviews. They were:

1.   Understanding Family Life & Family Service Needs

2.   Family Assessment

3.   IFSP (Individual Family Service Plan)

4.   Case Management

Parents were able to discuss how their family life had changed since their child with special needs was born. Three major issues raised concerning family life or functioning styles included: disrupted family schedules, caretaking demands, and lack of time, as well as attention, for other children in the family. Turnbull[48] found it critical that families be taught through continual encouragement, to think broadly about the priority needs of each family member and to establish balance with their time and attention. It is also important for professionals to learn, through each family, balance in giving attention to different functions within the family.

Able-Boon et al[50] indicated that family service needs were expressed by parents as they noted their goals for their child, their expectations of professionals and infant services, and their difficulty in accessing the service system. The goals for their child included: independence, acceptance by other children, realization of the child's potential, ability to communicate, and becoming "potty-trained". From the interviews, it became apparent that those goals varied according to the child's special needs and the family's situation. The over-riding concern of the parents was their need for information regarding their child's special needs and available community resources. This concept was also

addressed by Gallagher and Gallagher,[40] who reported that parents need and want adequate knowledge of the range of support and treatment facilities available for their child's particular disorder. It is rare for a parent to even have the slightest knowledge of where to go or how to get help for their child. Perrin et al[23] found an over-resounding need to establish a mechanism for the exchange of information, such as a clearinghouse with information concerning: medical information and research, support group information, assisting services available, financial support available, equipment suppliers, resource listings, regional meetings, general information, networking, training opportunities, workshops (cross disciplines and around the region), listing of names of parents willing to be trainers or support personnel, etc.

Sontag and Schacht[51] investigated ethnic differences in parent perceptions of their information needs and their sources of information. Statistically significant differences among Caucasian, American Indian, and Hispanic parents were reported for both parent information needs and sources of information. American Indian and Hispanic parents reported a greater need to receive information about how to get services, when compared with Caucasian parents. A greater percentage of American Indian parents identified doctors (88%) and public health nurses (24%) as the individuals from whom they get the most information, when compared to Caucasian and Hispanic parents (75% and 70%, respectively, for doctors, and 11% and 8%, respectively, for public health nurses). More significantly, American Indian and Hispanic parents selected

therapists as a source of information much less frequently that did Caucasian parents. Caucasians reported a higher rate of using agencies (other than hospitals and doctors' offices) as a source of information more frequently than did the other two groups.

Furthermore, Sontag and Schacht[51] found ethnic group differences were identified with regard to the kinds of problems parents had getting information. American Indian parents reported significantly more often that they were not told why a service could not be provided than reported by Hispanic and Caucasian parents. On the other hand, Hispanic parents were much less likely, than the other two groups, to feel that they had been told what could be done for their child.

The need to provide all parents with information about what services are available was clearly identified as an important requirement by several authors.[4,6,7,18,49,51] The kind of information parents are more likely to receive about their child appears to be related to the child's medical or disability condition, such as the type of information the medical doctors, as the primary source of information, would provide.[51] Information about other kinds of services including rehabilitative, educational and family support services, does not appear to be as readily available to parents. Physicians may not perceive this as their responsibility. Incidentally, parents suggested that they want information about the service delivery system so they can make their own decisions about what the child needs, rather than more information about the needs of their child.[23,51]

In the study by Able-Boon et al,[50] parents were asked their opinions of family assessment, IFSP development and implementation, and case study services. They examined the specific aspects of P.L. 99-457 concerning these topics. Although all families were involved in early intervention, only 33% of the families reported prior knowledge of P.L. 99-457 and its provisions. Parental reactions to family assessment indicated that is could be helpful if conducted with sensitivity.[50] They saw the need for understanding family dynamics, values, and priorities in order for staff to better understand their child. Families did express some concerns about intrusiveness and privacy. The parents gave several beneficial aspects of family assessments:

1. The consideration of families' financial resources so that the infant program would know how to best assist them.

2. Observation of the home environment in terms of other toys or children.

3. Getting to know the whole family, especially fathers, who often are less involved.

Fathers and their importance in families with disabled children are often over-shadowed as they are not the primary care-giver.[19, 50] They have been described by Hinojosa[49] as responsive to their handicapped children, interacting and playing with them. Although they did not assume routine child care responsibilities, they were there when help was needed and to provide companionship, emotional support, and understanding for their wives.

Overall, Turnbull[48] summarized that family assessments should teach families skills for coping successfully, as well as negotiating the service system. Taking charge of a child's education and development involves many skills, including problem-solving, collaboration, home teaching, and community organization.

When addressing the IFSP process, parents stressed the importance of active parental involvement.[50] Reaction to the IFSP included:

1.   The goals for a child are family goals.

2.   The plan should be written with suggestions rather than definite goals (i.e. not "Mom will do that", or "Dad will do that"). It should be a working plan and be reviewed frequently.

3.   The plan should be designed to help families understand options for services, so that they can intelligently chose which services they want.

In terms of the meeting to develop the IFSP, families felt that only those people involved with the child and family should be at the meeting. This would exclude administrators and those who do not know the child and family.

Finally, parents expressed some concerns about case management.[50] They derived that the case manager should help families access and utilize resources. Further, the case manager should have no specific allegiances, so as not to "color" information about services. It should be their responsibility to help parents become co-case managers. Parents stated that they did recognize how

their informational needs changed over time. Initially accessing the service system, they needed someone to offer advise and information, however, as they become more knowledgeable about the service system, their need for professional advise and informational support decreased. Researchers reported that parents in particular defined case management as collaboration management, where there is a networking of information passed between other disciplines, parents, and within the medical community. [23]

The service delivery system works best when professionals and families alike recognize that we need each other in order to provide optimal services for children with disabilities and their families. [6,23,50] The insight into parental perspectives of family-centered intervention strategies is an important component and not recognized nearly enough. It requires additional studies to address an unanimous view across various cultures and demographics. [51] The conclusion from these parental studies emphasized that parents need to become knowledgeable about their child and available services. The importance of professionals relaying information and empowering families to become their child's informed decision maker was also stressed. [6,23,40,48,49,50, 51]

CHAPTER 6

CONCLUSION

Professionals in the field of early childhood intervention are increasing their use of home visits, as a means to deliver services to children with special needs and their families. [48] Therefore, reconceptualization of all aspects of assessment and treatment is needed if the multi-cultural nature of today's society is to be acknowledged in the rehabilitation field. Throughout the whole process of intervention, professionals need to recognize families as ever-changing systems with their own unique structures, distinct roles, and functions for each of its members.

For all special families, the ultimate goal should be to balance the needs of all family members with those of their child with a disability. For professionals who address the needs of those children, an awareness of individual family dynamics can help them to choose a style of service delivery which has its primary focus on the developmental needs of the child, yet is also supportive of the broader goal of family equilibrium. [6]

Family stresses and coping strategies have become more pronounced, due to the significant alteration in the structure and composition of contemporary families and the nature of supports available to them. Examples of such changes include rapid expansion of mothers in the work force and families with

two working parents, rising numbers of families with single head of the household, more out of wedlock births, increasing geographic mobility resulting in isolation of young families, [42] growing poverty, and increasing minority cultures. [7] Stresses such as those have heightened demands for resources and created urgent need for effective approaches.

A family-centered approach to early intervention allows families to gain a sense of control over their lives, while strengthening its existing internal and external supports. [42] The successful implementation of P.L. 99-457 demands flexibility in services and supports, as well as fostering parental autonomy in order to meet the dynamic needs of families and their children with special needs.

Therapists as service professionals may be experiencing difficultly with the "new" family-centered process of early intervention, where they relinquish traditional roles of decision maker to a consultant. [38] Leviton et al [52] described an ideal model of family-centered consultation. The role of a professional then would be to provide the parents with "all" possible options, not just those the professionals or experts believe would be effective in achieving the family's goals. This avoids giving specific recommendations which could limit the child and family for meeting goal objectives.

In summary, the majority of the literature implied that parents want a service consultant, someone who provides expert advice about the policies, procedures, eligibility requirements, and other aspects of the service providing system. This

person ideally would serve as a link between two cultural systems, the family and the service providing community, with the expressed intent of changing the system to meet unique family needs. Families may seek information about the empirical validity of different approaches to their perceived needs. Also they may ask for the professionals' biases in meeting those needs. Though, ultimately, they want the decision to be theirs, and this is as it should be. The service delivery system works best when professionals and families alike recognize the need for each other in order to provide optimal services for children with disabilities and their families. [6]

A therapist's effectiveness in providing quality early childhood services is influenced by their sensitivity to the cultural background of the families with whom they intervene. [48] Such sensitivity means respecting differences between family's values, beliefs, customs, practices, and traditions, as well as knowing their own. Culture is the "mosaic" of such things; it is not simply a matter of a family's race, language, or geographic location. [48]

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