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A CLINICAL TRAINING MANUAL

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I. THE COLORADO HOME INTERVENTION PROGRAM (CHIP)

The Colorado Home Intervention Program (CHIP) operates under the auspices of the Colorado School for the Deaf and the Blind, which is part of the Colorado Department of Education. CHIP is designed specifically to serve families of children with hearing loss, from birth to preschool, in the secure surroundings of their own homes. At the heart of CHIP is the parent facilitator. Working with the family, the parent facilitator designs an individual program that fits both the family's needs and the child's learning style. The facilitator then helps family members to develop techniques to encourage their child's speech, language, and listening skills.

CHIP believes that the goal of family-focused intervention is to identify individual goals for each family and to provide them with the necessary supports to achieve these goals. In addition to sharing knowledge with the family regarding how to communicate with their child, facilitators provide emotional support to the family as they learn to understand the implications of their child's hearing loss. Facilitators make an effort to identify the unique dynamics among family members. With this understanding, information can be provided in a manner that is comfortable for each family member.

The guiding principles of the Colorado Home Intervention Program are:

- Making the program fit the family;

- Providing emotional support to the family;

- Helping the family navigate "the system";

- Making the facilitator accessible to the family;

- Putting quality first, quantity second;

- Being flexible and sensitive to the family's situation; and, measuring the effectiveness of intervention.

CHiP

Colorado
Home
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Program

For Familes of
Young Deaf & Hard
of Hearing Children
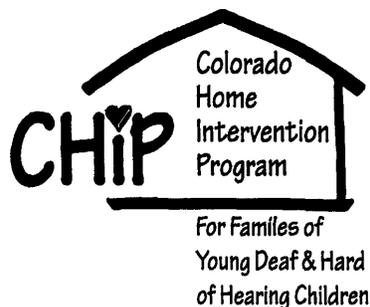
II. INTRODUCTION

An attempt has been made to include in this brief manual, some of the materials, articles and ideas that have been proven useful to interventionists working with the Colorado Home Intervention Program (CHIP). Most of this information has been presented to interventionists in various workshops over the course of a number of years. Thus, many interventionists have had the opportunity to ask questions and interact with the ideas. One comment that has been made by numerous individuals is that it often takes multiple contacts with this information before it begins to make sense. This manual is intended to serve as a reference guide, so that information can be reviewed and expanded upon when needed.

A number of topics are included that center around the type of clinical consultation that is provided to the Colorado Home Intervention Program (CHIP). CHIP is a program that provides services to families of deaf and hard of hearing children. The services are provided in the home and the focus of the intervention is family-centered services. Parents are provided with information related to hearing loss and the interventionist supports them as they make decisions regarding communication methodology, amplification, speech development, etc.

As interventionists work with families in a family-centered, home-based service delivery model, they are often presented with issues that fall outside their technical training related to hearing loss. The interventionists are not only dealing with the skills needed for their own discipline, they are dealing with complex and demanding dynamics of the family system. Interventionists are commonly required to trust their instincts as they counsel families about issues regarding hearing loss. These professionals are in need of support in dealing with issues outside their direct discipline scope of training. The interventionists interact with the family in a physical and emotional sense, attempting to teach the family new ideas and new ways to cope with the demands of having a child with hearing loss. Not only can families become empowered as the interventionist assists them in learning new information and providing them with resources, the interventionist can become empowered by learning new strategies for helping parents come to terms with the hearing loss.

This is a manual of empowerment because families are powerful. They may be resistant to change and desire to maintain the direction with which they feel most comfortable. They respond to trust and care. Like us, they will work hard when they are a part of the decision making process. It is hoped that this manual will encourage interventionists to feel more comfortable in the presence of families, so that this comfort will provide an atmosphere for growth and maximum utilization of all resources toward the best interest of the child with hearing loss. Families need support and compassion as they learn how to cope with the demands they face. And, interventionists need support in learning how to empower families.

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III. PHILOSOPHICAL BASIS OF FAMILY-FOCUSED SERVICES

It is important to talk about the beliefs that are the basis of family-focused intervention. DePree (1989) suggests that "What we believe precedes policy and practice." This statement suggests that before we become family-focused, we must believe in being family-focused. This belief is not a surface appreciation of families and their needs, but a belief that the family is at the core of the partnership. If an interventionist believes that families know what is best for their family and children, then this belief will shape a true partnership with the family. Conversely, if the interventionist believes that the professionals know what families need, this belief will be the foundation of the professional-family interaction. Beliefs have a great impact on how we think and behave.

To determine if one is truly family-focused, one can ask the following questions:

- Was the program designed to incorporate family-focused beliefs?

- Is the program based on beliefs of true empowerment and a true partnership with families?

- Is the program attempting to have the family take as much control of their lives as possible?

One must be flexible delivering a family-focused program because, by the nature of being family-focused, the outcome for each family will be different. To be family-focused is to believe in the resources of families. To be family-focused is to join in a partnership with families with the ultimate goal of growth, independence and positive outcomes for all.

Perhaps one should examine his or her beliefs before deciding to be a professional who works in a family-focused model. Our beliefs may suggest that we will not be able to be family-focused because we do not believe the resources of the family will benefit the child. To be successful with families, we need to have beliefs that will allow us to adopt the policies and practices that will empower families.

Trout and Foley (1989) suggest that families who have children with disabilities have additional needs. These needs surpass those of families with more typically developing children. They encompass the specific needs dictated by the disabling condition, and a variety of needs in the emotional realm. Families who have a child with disabilities may experience feelings of disappointment, anger, frustration, dislike for professionals, sadness, fear of the future and what it holds for their family and their child, and the loss of hope. The families may also experience loss; loss of dreams and losing feelings of self-confidence. The family may be overwhelmed with information from professionals who are suddenly a part of their life. In general, the child with disabilities will affect the family dynamics. The guiding principal of family-focused intervention is that the interventionist attempts to address the variety of needs a family has. If habilitation is going to be successful, the interventionist that interacts with a child with disabilities will at some point in time have to address the family system. The goal is to support the family, their unique family configuration, and also to assist the family with their numerous tasks.

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The notion of professionals becoming involved in the lives of families of children with disabilities is not a new concept. It is not difficult to find references in training textbooks of disciplines that provide services to children with disabilities. These texts often address the need to consider family cooperation and involvement in educational and therapeutic services delivered to children with disabilities. While there may be a consensus on the desirability to involve families in the therapeutic needs of their children, there may not be as much agreement as to the degree and type of involvement.

Curriculum programs such as the Birth to Three Curriculum (Bangs, 1979), the Portage Project (Shearer & Shearer, 1972), Teach Your Child to Talk (Pushaw, 1977), the John Tracy Clinic (1983), and the SKI-HI Model (1993) are a few of the curriculums that have been designed to have parents involved in the direct instruction of their children. The use of these curriculum guides has also demonstrated compelling evidence that this sort of parent training is effective in terms of gains in skill acquisition, and educational gains made by the child being trained by their parents (Baker, 1976; McDade & Varneldoe, 1976; Baker, Heiferz & Murphy, 1980; Tizard & Rees, 1974; Fredricks, Baldwin & Grove, 1974).

There are some specific programs, such as the Mama Lere Parent-Infant Program, which encompass the family-focused approach (Fitzgerald & Fisher, 1987). As a family-focused program, it directs the parents to have direct involvement in the intervention process. This is in contrast to a child-focused program that directs most resources toward the child, somewhat in isolation, without the direct involvement of the parents (Knox & McConnell, 1968; Luterman, 1979; Fitzgerald & Bess, 1982). The family-focused programs work under the following premises; the family will interact with the child throughout the child's life, the members of the family are the real experts in terms of the child, families spend the bulk of their lives with the child, and families can be assisted in utilizing their own resources in the process of dealing with the many demands that the child with disabilities presents.

In general, the focus on parent involvement has had very positive results. Interventionists who understand these positive outcomes may find it easier to work in partnership with parents through empowerment of the family (Baker, 1983). The Colorado Home Intervention Program (CHIP) is a program that attempts to empower parents, and in a participative approach, attempts to place the interventionist in partnership with the family. With this dedication to being family-focused, CHIP commits to having interventionists who have some awareness of family functioning.

Espinosa and Shearer (1986) state that educators of today must possess a number of characteristics and skills that allow them successfully interact with a family. Teachers and interventionists have traditionally been trained in specific skills to facilitate the child's development. Professionals from many disciplines (e.g., special education, regular education, speech pathology, audiology) receive specialized training to deliver clinical services. But these well-trained professionals may not have the necessary skills to address the social-emotional and system needs of the family.

The family-focused movement in treating children with disabilities parallels the movement in family therapy. Family therapy offers information about the way families are organized and operate. Family therapists are concerned with the family process, rather

than focusing on each individual. A healthy family is a balanced with a flexible mode of operation. The healthy family maintains a balance between cohesion and adaptability. The professional-family partnership can assist a family to adopt a more functional structure (Nichols & Everett, 1986). Structure is considered to be the way a family organizes itself to cope with the demands of daily living and the changes that are required to adjust and cope with the demands of life (Olson & McCubbin, 1983). The structure of a family has a great impact on their ability to deal with stress and change. It is critical for interventionists working with children with disabilities and their families to understand that it is not necessary for them to become family therapists. But, it is necessary for them to develop an understanding of family systems. If the interventionist maintains a family focus and gains knowledge about family systems, the interventionist can become empowered as well.

  A goal of this manual is to encourage professionals to be flexible and to acquire a variety of skills. Working with families is best accomplished by being eclectic. Those of us who work with families have a variety of skills to utilize as needed. We can have some specific skills and knowledge from several different disciplines. We can also know our limitations and have a good referral network. The goal is to maintain the beliefs that will make family-focused involvement possible and useful in theory and in practice.

IV. PRIMARY-SECONDARY PROCESSES

The question of whether professionals are trained to be family-focused is related to the concept of PRIMARY PROCESSES. A growing number of interventionists within CHIP are completely comfortable working with families and providing services in the families' homes. At one time, the interventionists involved with CHIP focused their work on delivering child-centered services. At one time, only a few interventionists had experience working with families. In a sense, the interventionists were all well trained in SECONDARY PROCESSES - the skills and knowledge about the disability. But, the family as a system evokes a need for a knowledge of PRIMARY PROCESSES. Primary processes is the knowledge of family systems, such as family joining issues and a variety of social-emotional needs of a family as it moves through its life cycle. The fundamental idea is that little can be accomplished in "therapy" until we understand the family and the family's system. For those who consistently work with families, the secondary processes of intervention are viewed as being subordinate to the needs of the family system, or primary processes.

Interventionists often find that their relationship with the family depends on having joined the family. It also depends on helping to create a family structure that allows intervention to be effective. Interventionists often find themselves helping to develop a family structure that is conducive to change long before they can address issues related to hearing loss, communication, and language development. Primary processes must be addressed when working with families. Yet, these primary processes are often missing in the professionals' training. Cartright and Ruscello (1979) found that while most university training programs indicated the need for training their students in family involvement, only half of these training programs have implemented such training.

In summary, there are a multiplicity of needs that exist within a family. If an interventionist is going to join with a family and empower them to utilize their own resources, then the interventionist must have some primary skills to accomplish this goal. In order to join with a family and encourage their utilization of resources, one must have some knowledge of primary processes. Without proper knowledge of primary processes, secondary processes will not be as effective.

This manual will discuss a number of primary processes. It will take a partnership between interventionists and families to successfully meet the many needs of the child and his or her family.

V. FAMILY EMPOWERMENT

We hear a great deal about family empowerment these days. Why would there be such interest in giving the family so much responsibility for the intervention for their child? In the past, professionals tended to view families as incapable of managing the complex requirements of their child's health and welfare. Perhaps the professionals were reluctant to give up the power they had over the family and child. There is a tendency for professionals to think they know what a child needs. After all, the professional has gone through a great deal of training to know a lot about what a child may need. If the family makes choices the professional feels are not the best choices, a difficult situation may arise. Therefore, family empowerment can be a difficult proposition for all.

There are as many reasons to empower a family as there are families. This section will discuss eight ideas regarding empowerment that help explain why family empowerment can be beneficial.

Idea One: The Life Cycle of a Child

It is most likely that the only group of individuals who will be around for the complete life of a child with disabilities is the family. Therefore, the family will be in an optimal position to ensure that there is consistency in meeting the health and intervention needs of the child. If the family has confidence in the intervention, they will be able to keep treatment consistent. Rather than one professional working with a family throughout the duration of intervention, a variety of professionals may enter and leave a family's life. A family who is empowered has the potential to maximize services and maintain consistency over the entire life cycle of the child.

The family is also the expert about the child. The family knows the child on an intimate level. They interact with the child in a variety of situations and places. They, better than anyone, have the potential to understand the specific and individual needs of the child with disabilities.

Idea Two: Time Efficiency

An interventionist is relatively limited in the amount of time he or she can spend with the child with disabilities. If the parents of a child can initiate follow-up activities in the absence of the interventionist, the child will benefit from intervention services throughout the day. If an interventionist sees a child for one hour a week, that therapist is involved in that child's life for about .59% of a week. If one includes 12 hours for sleep, the interventionist still only sees the child for 1.2% of the week. If an interventionist has the luxury of seeing a child for 3 hours a week, this is still only 1.7% of the week (or 3.4% allowing for sleep). An interventionist's time with families is very limited. If the parents and family can carry the responsibility for intervention, it is in the best interest of the child.

Parents interact with a child during the 99% of the time that the child is not with an interventionist. If the family is empowered to be an active part of services, the parents will create a team with the interventionist. As a team member, the family can more accurately report on the child's progress, their concerns, and their goals. Families become active participants in the process, rather than passive observers who are unaware of the "secrets" leading to their child's success.

There are intervention strategies that are best modeled within the home, rather than in a clinical environment. And, there are a number of daily routines that can be integrated into intervention. New skills are continually introduced, implemented, and reinforced. Who is better suited to provide this consistency than the family who is with the child the majority of the time? Some strategies will be successful only when there are used continuously. If these strategies are integrated into the normal routines of the family, the likelihood of their success increases.

Idea Three: Socialization Needs

The family plays a critical role in the socialization of their child. The intervention can provide the family with ideas for socialization opportunities. When a child has a hearing loss, socialization can be affected because communication is affected. A child with hearing loss needs to be taught all the necessary data about the rules of interpersonal interaction. They most likely will not learn this incidentally on their own because the hearing loss limits their opportunity for incidental learning. They are left to make assumptions about what they see unless provided with explanations about the complex world in which they live.

Suárez, (2000) suggests that children with hearing loss are immature in their social knowledge, often many years behind their hearing peers. They tend to be overprotected by parents. They are often unaware of their own feelings and the feelings of others. Children with hearing loss need to understand the same emotions and feelings that we all need to understand. It is only through interaction with feelings and emotions that any child becomes comfortable with his or her internal world of emotions, and becomes healthy in terms of overall emotional adjustment. A child with hearing loss needs to know how to label feelings and how feelings impact the world. Parents need support in learning how to give their child this information. The parents will be central to the socialization of their child.

Idea Four: Individualization needs

Families and parents have an enormous impact on the self-concept of a child in his or her early years. To be healthy as adults, children need to become separate people who understand their worth as individuals. A great deal of this worth and sense of control of their own lives comes from their early experiences in the family. These experiences reflect back to a child the acceptance or rejection that will be the building blocks of what they will feel about themselves throughout their lives.

Not many of us remember what our parents said to us or how they interacted with us when we were one, two, three or four years of age. Yet these interactions became very much a part of our confidence and our self-concept as we grew older. These interactions are a part of us long before we have the cognitive ability to evaluate their accuracy or intent. The same is true for our individualization. We are either encouraged to think for ourselves or discouraged to be individuals long before we realize what is occurring.

Families are so powerful in these processes. Yet, often with a child with disabilities, the parents are afraid to allow freedom and individualization to occur. The family needs to utilize their love and support to allow the child to grow in positive ways by spending time with the child and accepting him or her as a valuable individual.

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Idea Five: Preventing Dependency and Enmeshment

If a child is to grow in healthy and functional ways, the child must not be dependent or enmeshed within his family. Enmeshment and dependency do not foster independence.

The concepts of dependency and enmeshment have ramifications for the whole family. The family members and the interventionist all need to examine their involvement. The family members will not have healthy interactions with each other and with the child with disabilities if they are enmeshed or detached. The interventionist will not have empowering interactions with the family if he or she is enmeshed with or detached from the family members. As a part of their personalities, interventionists must have a desire to help others. But helping others does not mean being enmeshed, over-involved or fostering dependence. Dependency and enmeshment are not healthy for proper growth and development of individuals, families or professionals.

A healthy interaction among all members of the intervention process is a balance between detachment and enmeshment. Either extreme on the continuum between detachment and enmeshment is not a healthy interaction. Interventionists can practice their own healthy balance by maintaining a functional interaction with the family and the child with disabilities. This can serve as a model for the family. The family needs to be empowered to learn a healthy balance with their own child, their own family and the agencies that will serve them in the future. We want families, and the children who grow up in these families, to learn to take care of their needs, to feel they can evaluate their needs, find needed services, and participate in the delivery of these services. The most functional relationship is for families and interventionists to work together in a partnership.

Idea Six: How to Create Non-Victims

Model ABC-X (McCubbin & Patterson, 1983) suggests that one way to create a dependency is to set circumstances in place that make that individual view him or herself as not having the power or resources to manage a situation. If an individual believes s/he does not have the ability to deal with a situation, s/he may become dependent and feel powerless. Likewise, if the family of a child with disabilities does not see themselves as capable of dealing with the demands of that child, they will look to professionals to take on the responsibility. They could become a victim in the sense that they are now at the mercy of those who make decisions for and about them. This behavior is a variation of learned helplessness (Abramson, 1978). On the other hand, if families see themselves as having the ability and resources to cope with a variety of demands, they will not be in a dependent role and will maintain control of their lives.

In many ways, the interaction pattern of the will encourage or discourage the family to become or avoid becoming dependent. Interventionists could reinforce the belief that families and parents are not able to deal with the problems their child with disabilities presents. The interventionist could encourage the family to think that they must always go to a professional for services, decisions and assistance. But, when the interventionist is empowering, they position the family to become independent. The real basis of empowering is to allow families to make their own decisions, whether we agree with them or not. Modeling this behavior will also help the parents to allow their child to begin the process of making decision. As interventionists, we need to encourage the family to see that they can learn and utilize resources. We want families to see that they

can deal with the demands of their child. We must encourage children and families to utilize their wide variety of resources and strengths. We want families and children to view themselves as being capable and able to make decisions. This will only come about if they view themselves as having resources of their own.

Idea Seven: Obtainment of Resources

Some families need to obtain many new resources, while other families do not. Resources can be defined as economic, physical and emotional support. Resources can also be defined as the strengths and abilities the family has to cope with and adjust to the demands of life. The more resources they have, the more control of their lives they will have, the more functional they will be, and the more knowledge they will have to share with their family members. The same holds true for professionals. The more resources we possess, the more we can model for families and assist families with their needs and concerns. Both families and interventionists need to be flexible enough to adjust to the new and unexpected demands that life presents. If they are able to adjust and adapt, they will be healthy. The challenges presented to interventionists and families are reciprocal.

In a number of situations where therapy is needed, especially with very young children, interventionists have a choice of doing the therapy themselves, teaching the family to do the therapy, or a combination in which the interventionist and family share the responsibility. In the process of teaching the family to take responsibility for intervention, professionals are doing a number of things. We are showing the family how to avoid becoming dependent. We are showing the family that interventionists do not have all the information. We are helping the family to understand the processes that are involved in their child's intervention. We act as role models for the family as we encourage independent interactions and provide opinions and feedback.

As we work with families, we enter into their world to a much greater degree than when we were doing child-centered therapy in the clinic setting. The family may or may not understand the structural needs of their family, such as the needs of family members or the discipline needs of the children. As they learn about the structural needs of their family and children, they will gain more control. As interventionists, we can assist families in learning more functional ways to structure their familial interactions. The interventionist can assist by providing parenting information and parenting ideas. Parenting issues can be modeled and discussed. The ultimate goal is for the family to incorporate new ideas into their daily routines.

In general, the more resources we have as interventionists, the better. In addition, the more resources families have, the better. Empowerment means that we provide resources and allow families to use them in their own way.

Idea Eight: Trust and Change

How does one build trust between interventionists and families? How does therapy progress without trust? How do families trust each other and risk change? Can change occur without trust? All of these basic questions are common elements of the interactions between interventionists and families, parents and children.

Trust is built on empowerment and mutual respect. Through the process of empowering, we build mutual trust between families and the professionals. This trust allows risks to be taken; the risk necessary for growth and change to occur. A family will not trust their

child to an interventionist when the foundation of trust does not exist and has not been integrated into the professional-family relationship. In addition, a family will not have confidence in themselves if the interventionist does not have confidence in them.

Both families and individuals have a tendency to resist change. Even though their patterns and cycles of operation as a family may not be working, their routines may be comfortable and familiar. It may be the way things have been done in their family for generations. As families acquire resources, they begin to change. Never underestimate the risk that change can create. As agents of change, interventionists should be sensitive to these risks. Change only occurs through an environment rooted in confidence and trust. When the interventionist listens, encourages, and reflects, the family has an opportunity to identify the resources they need to adjust and cope.

There are a variety of reasons to empower a family. It can be a challenge for interventionists to create a partnership with the family based on empowerment and allowing. It is also difficult for families to change their dreams and adjust to their roles as primary care providers of a child with disabilities. By practicing allowing and empowerment, families and interventionists can create a positive relationship that will benefit the child with disabilities.

VI. FAMILY RESOURCES

The ultimate goal of the Colorado Home Intervention Program is to have the family become the depository of as many resources as possible. If the family is in command of their own resources, their decisions and actions will be efficient and directed. Olson and McCubbin (1983) speak to the need for families and individuals to have an ability to function with balance and flexibility as they face the numerous challenges of life. One way for families to individualize to their maximum potential is to have a number of resources to draw from. In a sense, families need to be like the country doctor who has a black bag of remedies and resources. The more remedies we have in our bag, the more situations we can treat. In a sense, a family's knowledge of resources becomes their "black bag," allowing them to effectively cope with challenges. For a family who has a child with disabilities, their bag of resources will need to encompass issues and remedies beyond those needed by most families because there may additional stressors. If the family possesses a complete "black bag", they will be more prepared to deal with difficult issues.

Early intervention views the role of the professionals as one who attempts to mobilize existing family resources. There are often a great number of resources within a family, and these resources can be utilized in a variety of ways. Utilization may require some additional education, support, and direction. And we see the professional as one who helps the family to identify their existing strengths. We want to view families as being capable. We as interventionists will draw upon the strengths and resources that each family has as a part of their individual and distinct mode of family functioning. We will work with their style of resource utilization to jointly plan for the needs of their child with disabilities. The concept of resource utilization is actually two-fold in that both interventionists and families need to acquire additional resources, and they need to have the confidence to use the resources they already possess.

There is a symbiotic nature to the professional-family relationship. Not only are families empowered, but professionals are empowered as well. As many more professionals are moving from child-focused to family-focused intervention, the interventionists confront a variety of situations that test their resources. Like the family, professionals utilize their own skills, acquired resources, and pursue additional resources. As a team, families and professionals direct their joint resources toward the expressed needs and perceived needs of the family with a child with disabilities.

Resources are defined not only in terms of financial or physical aspects. Family resources can also be the characteristics in a family that promote coping, that limit destructive patterns, and that enrich the daily life of the family. A list of such resources would include the flexibility of the family, the cohesiveness of the family, communications within the family, the attitude of a family, the ability to parent, the quality of the marital partnership, the support structure, the ability to tolerate individual differences, awareness of limits, acceptance of the past, the ability to formulate new dreams, assertiveness, understanding service delivery, and social skills (Karpel, 1986; Olson and McCubbin, 1983). This list is incomplete, but it captures the variety of resources that a family may need to possess in order to cope with daily life.

While the family of a child with disabilities may have additional stressors, as with all families, they deal with the issues of change.

Friedman (1986) views families as having their own resources for healing and surviving. He conceptualizes the role of the interventionist as being that of a mobilizer. While families benefit from outside professional expertise, this assistance most likely has less to do with the knowledge the interventionist has injected into the situation and more to do with what the interventionist has tapped, catalyzed or promoted from within the family. This mobilization of resources within the family often happens unwittingly rather than by design. Friedman further suggests that the educational degree of the professional is not the crucial factor in creating positive outcomes for families. Rather, positive outcomes depend on the capacity and desire of the interventionist to promote the utilization of the family's resources. If interventionists are to be family-focused, there must be an appreciation of the family's resources. Interventionists can help the family to view their own resources as being useful, to utilize these resources, and to see the tasks that lie ahead as being surmountable.

According to Luterman (1979), in most cases the family who has a child with disabilities becomes their child's own medical, educational and therapeutic manager. In this capacity, the family will need to interact with a variety of professionals and service agencies during their child's life. This is especially true in the early years when the initial diagnosis is made and services are obtained. Interventionists are involved with the initial contact with families. This is where interventionists will help cast the die for further parent-professional interaction. We want the family to understand how to interact with professionals, be able to seek information they need, know how to communicate, be aware of the limits of professionals' opinions, and be able to seek the services that best fit their family. The family will be the most knowledgeable about the child and that child's place within the family system.

Although families possess their own resources, they differ in the extent and degree to which they use their resources. Those families with fewer resources will need more assistance and guidance in obtaining and using new resources. Families with more resources will need less support and guidance.

When joining with a family (Haley, 1976), the interventionist should perform an assessment of the type and quality of resources the family possesses. The family can develop a list of what they feel they have and need. The family can also complete a paper and pencil needs assessment form, such as the Family Needs Survey (Bailey, D. and Simeonsson, R., 1988). In addition to this tool, there are a variety of other scales available. These scales usually ask questions about whether the family perceives the need for specific services and information. These needs could be economic, transportation, medical, etc. The scales also ask about social needs such as emotional support, the availability of leisure time, intervention services, etc. These scales can be given to the family to complete, or interventionists can use them to stimulate thinking and use them as a general guideline for performing an informal assessment. The interventionist must remember that families have a variety of needs. Needs for medical supplies, special transportation, day care, therapies and clothing are just a few of these needs. In addition, families may need to develop the capacity to work with professionals and design services.

Families become empowered when they have the resources to address all of the identified needs and are not consumed by the process.

We want the families to have the best resources available. Following will be a few examples of goals for mobilization of resources that professionals can use.

- Mobilization of resources that exist
- Strengthen resources that exist (reinforce, encourage and model)
- Supplement resources that exist
- Add new information and knowledge
- Help define the problem
- Introduce new community resources
- Explain the workings of agencies
- Explain the procedures to obtain services
- Explain the limitations of modern science and therapies
- Provide assistance in utilization of resources
- Encourage assertiveness and participation
- Support families' feeling states
- Provide accountability
- Provide feedback and opinions, not as truth but as opinion
- Share the professional's own resource utilization and challenges
- Encourage partnership with professionals
- Encourage leadership and confidence
- Encourage individualization
- Help create and foster the development of new goals and dreams

Perhaps some of the success of home intervention is attitudinal, in believing that we are assisting the family rather than resisting the family. CHIP interventionists strive to interact with the family in positive accepting ways, not viewing them as a case to be managed, but rather as a family to be assisted. Perhaps part of the success of this model lies in the family making the best use of their resources rather than following directions from professionals. Professionals should foster families' independence, rather than encourage their dependence upon professionals to make their decisions for them.

VII. CASE MANAGEMENT

As professionals shift from child-centered therapy to family-focused intervention, there is a necessary and logical shift in what constitutes case management. The logical extension of family empowerment is to allow the parents a voice in the selection of who will be the case manager for their family. In some instances, the parents may choose to be their own case manager. In other situations, the family may choose a professional to be their case manager. This concept is the embodiment of allowing families to make their own choices and to utilize their own resources in order to play a meaningful role in the services for their child. In many cases, families want to view themselves as, at the least, in partnership with professionals, and at best, in charge of the services their child will receive. They are a family in charge of the choices to be made about their child and their family. It must be acknowledged that some families will count on professionals to make all of their decisions, and in this sense they may approximate the concept of traditional case management. But other families will elect to be an active partner in the design of services for their child and family, and there will be more participative management. Current case management includes an informal network of parents, friends, and professionals who help the family select and evaluate services for their child with disabilities and their family.

Family-centered case management is the system that assists families in locating, accessing and utilizing services within a community. This concept of family-centered case management recognizes the possibility that a family may in fact choose to be their own case manager with assistance and back-up support. It could also be considered a participative case management system.

Interventionists working with the Colorado Home Intervention Program have been doing participative informal case management for some time. It seems to be inherent in the job since the facilitator becomes involved with the family on an intimate level due to the nature of making home visits. Given the family-focused nature of the approach and philosophy of home intervention, the natural course of events places the facilitator in a position to assist the family in a variety of ways. This is informal participative case management. Participative case management requires the professional to determine how involved to become in the mobilization of a family. Participative case management is an allowing process, where we allow a family to make choices with which we may not always agree. It is a process whereby we must be flexible enough to allow other agencies to participate, whether or not we always agree with their approach. Perhaps the best case managers are facilitators by nature, in which they attempt to negotiate among all of the involved agencies and professionals. They attempt to coordinate professionals with differing philosophies and treatment strategies. Flexible case managers are facilitators who help the family sift through the multitude of decisions regarding their family and child with disabilities, and assist them without taking ownership or having the desire to control the decision making process. Informal case managers take the multitude of recommendations and assist the family in making sense of them, rendering the process less overwhelming. The facilitator's role is that of a true partner. If facilitators are not the identified case manager, they can still facilitate by being a team member.

Resources: Two excellent videotapes are distributed by the Colorado Department of Education.

- **Taking Charge: Family-Centered Case Management**

- **Creating a Vision: The Individualized Family Service Plan**

Copies can be obtained by contacting:

Colorado Interagency Coordinating Council
Colorado Department of Education
201 East Colfax Avenue
Denver, CO 80203

VIII. FAMILY INVOLVEMENT CRITERIA – FAMILY MATURITY LEVELS

The issue of how to get involved with families often perplexes interventionists who are beginning to work with families. If our observations are correct and families differ in their ability to utilize resources, how does the interventionist decide how much direction and assistance to provide? If the goal is to assist, but not monopolize the decision making process of a family, how much assistance is too much? One ingredient in the empowerment process is to help the family utilize resources, but only enough to encourage them to take steps toward greater independence. Families represent a wide spectrum of abilities, motivations and resources. It isn't easy for interventionists to gage how involved to become with a family. Families who enter into the partnership at a high level of functioning and utilization, will most likely need some encouragement and emotional support but not a great deal of assistance or direct instruction. A family who enters into the partnership with less readiness and fewer resources will most likely need a great deal of assistance. The question becomes, is there an optimal way to approach different families?

First, we must think about where to start with a family. We most likely have some information about the family, whether this came from an interactive assessment or from a standardized instrument completed by the family. This assessment data will help the interventionist make some preliminary decisions as to how involved he or she needs to be with the family. For example, if interview and/or written assessment data reflects that this is a family with excellent resources and resource utilization, then the interventionist and family may identify this family as their own case manager. In this situation, the interventionist needs to respect the family. If the interventionist chooses to be too demanding or offers too much assistance to this family, it may injure the partnership between family and professional. The opposite may be true for a family who has few resources and limited readiness. Such a family may be very loving and supportive, but may have no idea how to work with agencies. This family may need a great deal more assistance and direct involvement by the interventionist. As the family acquires more resources and the ability to utilize them, the interventionist will become less involved with the family. The choices made about the degree of professional involvement can influence the growth of the family and the strength of the partnership between families and professionals.

Hersey and Blanchard (1977) have a management model called situational leadership that may help shed some light on how involved to become with a family. In general, their model suggests that different levels of resource utilization will require interventionists to choose different styles of interaction with families. An interventionist should have at his or her command a variety of ways to interact with families and a variety of interaction styles. The concept suggests that the interventionist should adjust his or her interaction style to match the situation.

Hersey and Blanchard's model may help the interventionist to choose where and how to become involved. Professionals wish to interact on an optimal level with families, while not wishing to offend or disrupt their forward progress. It would be ideal to start our partnership with families offering the right amount of assistance they need.

The continuum of family resource utilization is divided into four general levels. The criteria that will be used to assess all four levels are RESOURCES and READINESS. The two dimensions of resources and readiness interact in four matrix possibilities.

- **Level One:** The lowest on the continuum of resource utilization. These families are LOW in resources and LOW in readiness.
- **Level Two:** These families are LOW in resources and HIGH in readiness.
- **Level Three:** Families are HIGH in resources and LOW in readiness.
- **Level Four:** These families are HIGH in resources and HIGH in readiness.

This model suggests that the interventionist needs at least four styles of interaction in order to effectively match the different needs of different families. These interaction styles are: **(1) Directing, (2) Coaching, (3) Encouraging and (4) Delegating**. These four interaction styles can be placed on a continuum of professional involvement. The first style, directing, has the interventionist actively involved in empowering the family and helping them to mobilize resources. Directing is a style in which the interventionist provides a lot of education. Style Two, coaching, is one in which less support is needed. The third style is supporting and involves less active assistance than Style One or Two. The fourth style is delegating, in which the family requires little assistance. It is important to note here that little assistance does not mean there is no relationship between the family and interventionist. Families at Level Four often want interaction with professionals, but it tends to be more emotional in nature and predicated on validation rather than direct assistance.

The following descriptions are the four combinations of style of interaction and level of resource utilization.

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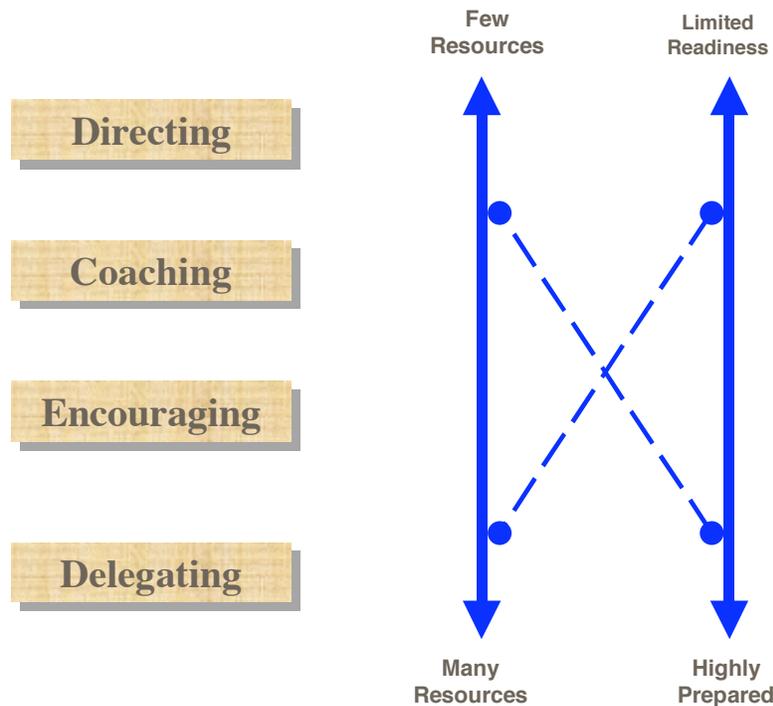
Now that we have described the different levels of resource utilization and style of interaction, it is important to describe how to place a family into this model. The following information lists some of the characteristics of resources and readiness that can be used to determine which style of interaction the interventionist can use.

Characteristics of few resources:

- Family may feel distant and confused
- Family members take a limited amount of initiative
- There is limited follow-through
- Family members have difficulty understanding
- Family members do not ask questions
- There is limited change in the child and/or the family
- Family members may be oppositional

Characteristics of high resources:

- Family is open and direct
- Family members take the initiative
- Family members have a clear understanding of special needs
- Family members request more information
- There is consistent follow-through
- There are identifiable gains in skill acquisition for the child and/or the family

Characteristics of limited readiness:

- Family members forget information
- There are economic challenges
- There are many children in the family
- The family has a limited support system
- Family members may have low self-confidence
- Family members are passive
- Family members may be stuck in the grief cycle
- Family members have limited experience with agencies
- Family members may be rigid and controlling

Characteristics of sufficient readiness:

- Family members understand concepts
- Family members implement objectives in novel ways
- Family members are open & flexible
- There is evidence of consistent follow-through
- There are minimal family demands
- The family has an external support system
- Family members may be confident and assertive
- Family members accept the diagnosis
- Family members are familiar with agencies & their function

Let us use an example to illustrate this process. A family functioning at the highest level, Level Four, would most likely be capable of contacting the professional

themselves. The professional interacting with this family would adopt the delegating style of interaction and trust that the family will accomplish their goals without assistance. The interventionist is there to reinforce the need, complement the process, listen to the feelings involved in the task, and assist the family when needed. With a Level Three family, the interventionist may need to find the name of the agency and assist the family as they make plans to contact the agency. An encouraging style of interaction is appropriate for this family. With a Level Two family, the interventionist may need to find a name, phone number, and assist the family in making the contact. The contact may be made when the interventionist is with the family. This family benefits from a coaching style of interaction in which the interventionist takes a more active role. The family operating at Level One will most likely need much assistance, provided by an interventionist who directs the family. This family may need the interventionist to make the referral and handle all the necessary issues. Although the interventionist is taking a more active role, the hope is that he or she will be thinking of how to shift more responsibility to the family.

   A successful collaboration exists when the interventionist creates a context in which the family is able to use their own resources. Matching style to family utilization of resources is one of the many tools professionals can use as part of the collaboration process.

IX. RESOURCES OF THE CHIP FACILITATOR

Professionals are well-trained in their disciplines. They are all a product of university training programs, internships and professional experience. They are good at what we have defined as secondary processes. But not all professionals are trained by their university training programs to be comfortable with families and the demands of working with families. Their training programs do not always instruct them in what we have previously defined as primary processes.

This part of the manual will focus on specific clinical issues that facilitators have found to be of concern as they provide family-focused intervention. A number of specific clinical topics will be discussed to demonstrate how to better understand the demands of family involvement. These topics are intended to be resources for the interventionist.

Ten basic topics will be discussed:

1. Joining a family (Jay Haley)
2. A model of functional families (Olson & McCubbin)
3. Structural family issues (Minuchin)
4. The feeling states of grief, conflict and allowing (Moses)
5. Enmeshment and detachment with families
6. Parenting ideas (Garber)
7. Guilt, expectations and cognitive therapy (Burns)
8. Being a guru (Koop)
9. Communications (Carkhuff)
10. How to consult

TOPIC ONE: Joining a Family (Haley, 1987)

The first contact with a family is critical. The initial interview with a family sets the tone for subsequent contacts and can influence families' attitudes about professionals in general. The initial impressions that a family forms about professionals and the intervention process may have long-term effects.

The interventionist should be careful to give the impression of desiring a partnership with a family from the first moments of contact. The attitude of the interventionist and how the interventionist relates to the family will influence the family's first impressions. The interventionist should approach the family as an equal. The interventionist should attempt to interact with the family in a respectful manner and listen to what the family has to say about their needs, hopes and dreams. He or she can express concern, acknowledge that there are no magical cures, and be sure not to use technical language when communicating with the family. A true partnership starts with listening and questioning. If the interventionist keeps these principles in mind during the initial contact, the likelihood for a successful interaction increases.

Virginia Satir (1987) stated that professional interactions with families depend on trust, trust that is built through initial interactions and communications. This trust can be developed if interventionists are aware of how they talk to families.

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Jay Haley (1976) writes about conducting the first interview with families. It is here that the partnership is initially formed. He suggests that the joining process is critical for two reasons. First, it is the foundation for further contact. Second, the initial interview allows the interventionist to obtain information about the family and their needs. This information will be obtained through the verbal reports of family members as the interventionist makes observations.

Haley conceptualizes four distinct stages in the joining process: (1) Social Stage, (2) Problem Stage, (3) Interaction Stage and (4) Goal-Setting Stage.

Stage One: The Social Stage

In this stage, the interventionist meets and talks to *every* family member. Haley suggests it is valuable to communicate with all family members in order to draw everyone into the process. Therefore, introductions and communications with all family members should occur before problems and issues are discussed. The goal is to obtain a social response from all family members by listening and attempting to have a light and informal introduction. The interventionist notices how the family members interact. In this social stage, communication helps to build trust. It is not the time to act as a professional who has all the answers, or to use language that may intimidate families.

Stage Two: The Problem Stage

In this stage, the family members talk about the problems they are having, their dreams for their child, and their needs. The interventionist listens and offers very little feedback to the family, except to let them know that they were heard and understood. This is the stage in which the seeds of intimacy are planted. If the family feels heard and understood, intimacy can grow. The interventionist learns how the family perceives problems and the language the family uses to describe events. The interventionist may ask the family to elaborate. This is also the initial step toward empowerment. The family is talking about their problems and concerns instead of having the interventionist tell them what they need.

In Stage Two, the more open and ambiguous the interventionist is, the more the family will put forth their own ideas. Haley states that the professional should speak first to the family member who is not very involved in the process. This will encourage participation and communicate interest in the ideas of the uninvolved family members, thereby pulling uninvolved members into the process. Another idea is to treat the family member who will encourage therapy with the most respect. It is important that the interventionist does not appear to side with the ideas of any particular family member. Interventionists working with families for the first time may be surprised by the disagreement among family members. The interventionist should refrain from offering advice in this stage. In order to keep the interaction positive and fruitful, the focus of the questions and discussion should be directed toward facts, not feelings.

Stage Three: The Interaction Stage

In this stage, the interventionist asks the family to discuss all of the problems and concerns that were noted. It may be the first time that the family has discussed the problems or given feedback to other family members. It is a time to distill the concerns and needs of the family into a list that would identify goals. Again, the interventionist attempts to facilitate the conversation, but does not offer advice or suggestions. The role

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of the professional is to clarify the offerings of the various family members. This stage is critical to empowerment because the interventionist encourages family members to talk to each other rather than talk to the professional. The family is asked to discuss their own problems instead of looking to the interventionist for the answers. They begin to take ownership of their problems and needs, and hopefully see the problems as something with which they can cope. The family is in charge of the discussion, working together, telling the interventionist what they need. Communication and partnership issues take shape in this stage. We want the family to see that they have the ability to work together, to work with professionals, to solve some problems, and have control of their lives.

Stage Four: The Goal-Setting Stage

  This is the stage in which the family mutually identifies their goals for intervention. During this stage the family will clarify relevant issues and develop goals. The interventionist takes the goals and assists the family by stating them in a solvable way. The interventionist, as a team member, then begins to brainstorm with the family about how these goals can be attained.

   This process of joining a family initiates the partnership between the professional and the family. It creates an interaction that empowers the family to utilize their own resources. It also creates the foundation in which the family will allow a professional to teach them how to attain additional resources. It is this mutually respectful interaction that we wish to foster throughout the intervention process.

TOPIC TWO: A Model of Functional Families (Olson & McCubbin, 1983)

   In this manual, we will focus on two approaches that help the interventionist to identify characteristics of a healthy and functional family. The first is Olson and McCubbin's (1983) orientation to functional families. The second approach is Minuchin's (1979) structural approach. The intent is not for a interventionist to act as a family therapist. The goal is to help all of those participating in the family/professional partnership to have some basic awareness about families and what makes them functional and healthy. The models of Olson and McCubbin and Minuchin offer some basic information about the family unit. This information is provided as a way to understand what is happening within a family.

   Olson and McCubbin write about their Circumplex Model. In the creation of the Circumplex Model, they attempted to find some unification in the literature on families. The Circumplex Model is a summary of much of the research concerning families and how they operate across the lifecycle. It offers a clear view of what constitutes a healthy and functional family.

   The Circumplex Model attempts to identify why some families cope successfully with the stressors and problems that confront every family, while others do not. The Model is composed of three main components. Two elements that comprise the model are adaptability and cohesion. Communication is the third component and is said to facilitate adaptability and cohesion.

   The Circumplex Model uses four levels of adaptability and four levels of cohesion, forming a 4x4 matrix. This 4x4 matrix will generate sixteen possible family types. The sixteen family types will vary in the dimensions of adaptability and cohesion. The

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Circumplex Model states that families who are extreme on either or both dimensions of adaptability and cohesion are not functional families. The families who are moderate on the dimensions of adaptability and cohesion are balanced families and are the healthiest and most functional.

The four balanced family types are (1) flexibly separated family, (2) flexibly connected family, (3) structurally separated family and (4) structurally connected family. These four family types are balanced. By being in the mid-range of cohesion and adaptability, these families can move in either direction when confronted with problems and stress. The families who are in the mid-range of cohesion are not disengaged or enmeshed. Rather, they are connected or separated. If stress or problems confront the balanced family, they can become more connected or less connected in order to cope with the stress. This is not the case with less balanced families who have little flexibility in their response pattern due to their lack of balance and adaptability. The conclusion of the Circumplex Model is that balanced families have greater resources, are less vulnerable to stress, will cope more efficiently with stress, will use various coping strategies, and will have greater levels of family satisfaction.

The most important characteristic is the concept of balance. We can encourage our families to have a balanced approach to their family functioning. Families can be encouraged to be engaged, focused and flexible. The interventionist can model behaviors for the family, sharing stories about how we function in our own families. We can reinforce the family's use of a balanced approach. We can discuss how hard it is to change styles, yet how functional change may be. We can teach concepts of balance. But most of all, as a team, the interventionist can brainstorm new ways to cope with the stressors and problems that confront the family.

Communication is the key to families achieving a healthy balance. Without communication, the family would not be able to discuss options or demonstrate the needed love and approval for its members. Families with poor communication skills will not be balanced or able to achieve balance. Communication is what makes functional adaptability and cohesion possible.

TOPIC THREE: Structural Family Issues (Minuchin, 1974)

Minuchin (1974) describes the structural approach to families. This approach rests on a number of basic assumptions that are important to consider. The first assumption is that when the circumstances or structure of the family is modified, this modification will have an impact on the behavior of the family. The structural approach says that changes in the external world of the family or changes in any family member will bring about changes in the whole family. As interventionists working with families and their children with disabilities, we are working within the context of their lives. As interventionists partnering with families, we can influence the function of a family.

A second assumption of the structural approach is that context influences inner processes. The context will influence how the family members feel about their connection to the family and their belonging to a family.

The third assumption is that the interventionist working with a family becomes a part of the context of that family. As reviewed in earlier parts of this manual, this connection is why it is so important to join the family in positive and productive ways.

The structural approach views the family as a system. The structure of the family contains the rules regarding how the family members relate to one another. This structure is invisible and often unspoken. But, the structure underlies the interaction among family members and individuals outside of the family. The interventionist learns how the family works as he or she joins with them and begins to see who is in charge. What if the interventionist finds out that one parent is in charge of the family, at the exclusion of the other parent? What if the interventionist finds out that the parents do not communicate between themselves, but rather through the children? What if the interventionist finds out that the children are in charge of the family? The interventionist is learning about the rules and structure of the family. If the structure of the family is not healthy, what can the interventionist do? We do not want to be family therapists, but we do want to have some influence on the context and structure of the family with whom we are working. As was suggested earlier in this manual, implementing the secondary processes of intervention may not be possible until the primary processes are addressed. The structural rules of a family are primary processes that will affect intervention.

Another element in the structural approach is boundaries. Boundaries are the rules that govern how and when individuals interact. The two extremes on the continuum are disengaged and enmeshed families. The disengaged family operates with rules that do not promote a great deal of closeness between family members. The disengaged family has little connectedness and little contact. The sense of family unity is absent from the disengaged family. The support that a family can offer its members is limited. In the disengaged family, the needed love and support that is the basis for the healthy self-image of the children may be absent. The disconnected family has strong and impenetrable boundaries between family members.   Consequently, few emotions and little emotional support pass between members. The disengaged family has a lack of order, structure, and often does not have any one family member in charge. In this type of family, there may be a feeling of isolation and lack of support. The context of the disengaged family has a significant influence on the family members. As we, the interventionists, become a part of the context of a disengaged family, we can have an influence on their context. We can help clarify, assess, and reshape the rules that govern the interaction patterns of the family.

At the other end of the spectrum is the enmeshed family. The boundaries of the enmeshed family do not allow for separation. The family is bound together so tightly that there is little room for individualization and privacy. The rules that govern the interaction of family members allow for over-involvement in each others' lives. This sort of enmeshment often affects nuclear and extended family members. In a sense, enmeshment means that there are not adequate limits or rules to maintain healthy role definition and independence. The boundaries in the enmeshed family are not clear. The parents can be anxious when there is an indication that a member of the family will gain independence and reject the rules that maintain the interdependence and closeness.

Neither extreme is desirable. Much like the Circumplex Model of Olson and McCubbin, a healthy and functional family has a balance. This balance would allow enough

disengagement for family members to be individuals. This individualization is important. Yet there needs to be a sufficient amount of connectedness to give the family a sense of belonging. The balance is the critical component that allows a family to interact and be connected in appropriate ways. The boundaries of a family define how this balance will be achieved. Minuchin would define healthy boundaries as clear boundaries. Clear boundaries are the middle-ground between the extremes of disengagement and enmeshment, allowing the family to communicate a sense of belonging to its members. This sense of belonging, in combination with a sense of individuality, is critical to every family member's sense of identity.

   When working with a family, it is important to identify the rules and structure of the family. Our repeated interactions with the family give us clues about the family patterns and family structure. The patterns reflect the boundaries and the subsystems of the family. And, it is these patterns that will reflect change if the structure of the family is modified. It is also important to note that changes in the patterns and structure of a family are a normal process. A healthy functional family is not static. In order to meet the demands of life, a family must be in a constant state of change. This change allows for adjustment to the new incidents that confront the family as they move through their life cycle. Sometimes families need to be reminded that they need to be flexible as they adjust to the new demands that life presents. The family needs to be reminded that all families have the tendency to resist change and use old methods of coping. Families need to become comfortable with the idea that new responses will be needed to cope with new demands.

   Power hierarchy is another important structural issue in all families. A healthy family has an identifiable power hierarchy. There needs to be a power hierarchy in order for the family to be functional. A well balanced power hierarchy can be loving and supportive. Without this power hierarchy that delineates who is in charge, the family is not directed and moves toward chaos. Families and society function more efficiently when there is an established power hierarchy to govern their operation. This would be the same need that governments and corporations have; they all need someone to be in charge. The power structure may vary depending on the culture. In most Anglo cultures, the mother and father share the power by being a partnership in charge of the family. Of course, there are times when a family cannot be democratic because some decisions do not lend themselves to a joint decision process. For example, decisions in crisis situations must be made quickly. This is not true for all cultures. In some cultures, the power is shared with an external source, such as the medicine man. Regardless, it is critical that the cultural context of power is considered when working with families.

   What constitutes a healthy power hierarchy for a family? In most cases, the mother and father are jointly in charge of the family. While the children would not be in charge of the family, they would have some access to the parents. Interactions that display these types of boundaries would be the parents setting limits, the children following the rules of the family, and there being some give and take across the boundary of authority. The power hierarchy would not be rigid, but flexible and accessible. The mother and father are in the leadership role of the family. They are nurturing disciplinarians, allowing communication between kids and parents, allowing individualization, and being connected in loving ways. As professionals, we want to encourage this balanced family structure.

We often work with families who do not have this structure and demonstrate weak boundaries. We may join a family and it becomes obvious that the children do not listen to the requests of the parents. It isn't that the children are being destructive or rude intentionally, but they have little sense of boundaries. They have little sense of the rules of interaction within the family. What is the interventionist to do? If our assumption about primary processes is correct, we may not get any therapy accomplished until the family establishes boundaries. The boundaries would include establishing rules in which the children follow the structure that the parents wish to establish. When visiting with the family for an intervention session, there is a need for orderly turn-taking, being quiet at times, and allowing adults time to talk without interruption.

How do the parents begin to establish boundaries? Many families do not know how to do this. They do not know which boundaries are too rigid and which boundaries are unclear. As a result, they do not know what boundaries are appropriate for their child with disabilities. They may not understand that boundaries are healthy and necessary for a functional family and that if they are overprotecting their child, this will have an impact on his or her social-emotional development. They may not understand that boundaries are not synonymous with authoritarianism. Indeed, having boundaries can reduce stress, making for a more loving family. Children need limits, rules, and boundaries that are fair and consistent. This consistency provides comfort and security for children and adults.

An example of a family with boundary and power hierarchy problems is when the children are running about the house not doing what is asked of them. The parents make empty threats in attempts to control the behavior of the children, yet the children pay little heed. The child with disabilities is catered to, having about as much authority as the parents. The other siblings may demand attention and want to have their own therapy sessions.

If the interventionist has joined with the family, he or she can have an influence on the structure of the family. Techniques the interventionist can use with a family with unclear boundaries are to suggest ideas about limits and boundaries, complement attempts by the family to define and enforce boundaries, suggest improvements to the boundaries that currently exist within the family, model appropriate boundaries for the family, and help the parents and family become comfortable with the need for boundaries. Many parents need to be supported in the establishment of boundaries. The parents need to know that boundaries are needed and that they are not bad parents because they make and enforce these boundaries. They are not bad parents because they establish a power hierarchy in which the children are not always in control.

There are a number of ways in which the interventionist can influence the family. For example, the interventionist working with a family with unclear boundaries can restate what the parents say and expand upon it. For example, "Jim, your parents just asked you to sit down. Please come over here and sit next to me." The interventionist can also ask permission to create a boundary. "If it's okay with you, I'd like Jim to sit over here with me. Jim, I need for you to sit over here and listen while I talk with your parents." Another approach would be, "If it's okay with you, I need Jim to go and watch some television in the other room so that we can talk." In each case, the interventionist can stop the conversation if the child interrupts thereby enforcing the boundary. A conversation can follow where the interventionist is sympathetic regarding how difficult it is to be

consistent, how badly one can feel while enforcing boundaries, and how much work it involves. The discussion can include praise for the parents for the limits they set.

Some families need even more direction. In this case, the interventionist may take a more active role. For example, the interventionist might say, "We really need to have the other children do something else while we work with each other. Is there somewhere else the other kids can be while we are doing this activity?"

In these examples, the goal of the interventionist is to demonstrate to the family how to set boundaries and be consistent. This is done in a positive way. If the interventionist joins the family properly, actions that enforce boundaries are often welcomed by the family. Families often know that something is needed and the interventionist can supply the structure and demonstrate what is acceptable and necessary. Early interventionists who work with families, especially in their homes, can be uncomfortable with the family structure. And, they are often surprised when families are willing to learn about structural issues. It is important to become comfortable with facilitating boundaries and helping to create a positive family structure.

Examples of Family Structures:

Healthy Family:
The mother and father are in charge of the family. They are at the top of the power hierarchy and the children are below. In the following diagram, the boundary between parents and children is represented as a dotted line to indicate that the boundary is permeable, allowing communication between parents and children. The mother and father are drawn close, but not so close that it creates a boundary between the two parents. They are close enough to have the connectedness needed to provide healthy care to the children. The nuclear family is separate from extended family. This structure and these boundaries represent an ideal family structure.

(**M** – Mother) (**D** – Dad) (**C** – Children)

A healthy structure would be: M D
                                          - - - - - -
                                             C

Unhealthy Families:
Examples of unbalance hierarchies are:
- **Model A:** Families in which the children are in charge of the family

- **Model B:** Families in which the child with disabilities is inserted into the power hierarchy with the parents

- **Model C:** Families in which the parents are not connected in a partnership

- **Model D:** Families in which a parent is over-involved with the child with disabilities to the exclusion of the other parent

(**H** – Child with Disabilities) (**M** – Mother) (**D** – Dad) (**C** – Children)	
Model A: Families in which the children are in charge of the family	$\dfrac{C}{M\ D}$
Model B: Families in which the child with disabilities is inserted into the power hierarchy with the parents	$\dfrac{MHD}{C}$
Model C: Families in which the parents are not connected in a partnership	$\dfrac{M\,/\,D}{C}$
Model D: Families in which a parent is over-involved with the child with disabilities to the exclusion of the other parent	$\dfrac{M\,/\,D\ H}{C}$

Working with Families to Create a New Structure

   If a family structure is unhealthy, the interventionist can work with them to create a healthier structure.

Model A: $\dfrac{C}{M\ D}$

   In Model A, the interventionist helps the parents to take charge of their relationship with their children. The parents may need to learn that it is acceptable to be in charge of the children. In addition, they may need information about how to identify and set fair boundaries. The interventionist can model appropriate interactions. The parents may also need to create appropriate expectations about how much energy it takes to be in charge. The interventionist can point out situations in which the parents are not being consistent and how rules are being violated. Many parents do not see these violations of the boundaries and benefit from an outsider who shows them when they are occurring. The parents need to develop a reputation for being in charge, and this will take time and energy. Finally, the parents need to think about the types of rules and consequences that they will use in response to their child's behavior.

Model B: $\dfrac{MHD}{C}$

   In families who have a child with disabilities, the child can sometimes have about as much power as the parents. Other children in the family do not have this type of control

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or power. In this situation, the goal for family structure is for all children to be equal. The child with disabilities may demand additional time and energy, but he or she should follow the same rules as the other children in the family. If the other children see the child with disabilities as being equal with the parents in terms of power, the child with disabilities will not be accepted by his siblings as easily. The parents may not understand the difference between the child's need for additional services and the need for normal placement in the family structure. The goal is to move the child with disabilities to the same level as the other children in the family.

Model C:
$$\frac{M / D}{C}$$

In Model C, the goal is to help the parents connect with each other to a greater degree. The interventionist can ask questions in such a way as to encourage an equal ownership of problems. Instead of allowing one parent to answer all questions, the interventionist can ask for input from both parents. The goal is to increase communication between the parents. Tasks can be designed that require both parents to cooperate and share responsibilities. The interventionist can provide suggestions for how the parents could work together more closely. They can be taught that working together is possible and more productive. The interventionist can assure the family that there are a number of ways to accomplish a goal and that each parent can do it in a different way.

Model D:
$$\frac{M / D\,H}{C}$$

In Model D, we are doing what we attempted to do in both Model B and Model C. The parents need to unite and move the child with disabilities to a more appropriate position in the family structure. The interventionist addresses issues regarding structure and boundaries because these issues will dictate how the family reacts to the demands of the child with disabilities.

TOPIC FOUR: THE Feeling States of Grief and Conflict (Moses, 1983)

When an interventionist becomes involved with families, he or she will become involved with the family's feelings. There are a number of ways that the interventionist will come fact-to-face with the feelings and emotions of a family who has a child with disabilities. He or she will be involved in the grief process of the family members. Grieving is a natural process and a natural reaction to a loss (Moses, 1983). The birth of a child with disabilities prompts a family to adjust the dreams they had regarding the birth of their child. From the time of conception, the family likely began to formulate dreams and plans for how they will live with the addition of that child to their family. A child with disabilities creates circumstances in which many dreams will be adjusted. There will most likely be additional responsibilities.

The process of grieving involves feeling states, loss of old dreams, adjustments, fairness issues, and the formulation of new dreams. A family who understands the grieving

process will be better equipped to face losses in the future. If the family and interventionist understand the feelings that are involved in a grief reaction, they will cope better with their own needs and those of the family.

Along with the grief, family members experience many feelings and emotions. They may experience frustration as they learn to cope with the demands of having a child with disabilities. Dealing with all the service providers and agencies that become involved in the life of a child can be a considerable source of stress for a family. In addition to offering empathy for the feelings and emotions that the family is experiencing, the professional will have their own reactions to and feelings for the events occurring within the family and with the child.

Perhaps the most important concept to remember when interacting with the family is for the interventionist to know that he or she is not in a position to fix the family's feelings and emotions. When we are depressed or angry, we do not need advice such as, "It will be okay in the morning," or "It could have been worse." Advice like this does little to help make us feel better. In fact, it can make us feel worse since it seems to imply that our feelings are not important or valid. On some basic level, what most people need when they are challenged is companionship and someone to listen. Helpful comments may include statements like, "That really hurts", "You were really disappointed", and "It's hard adjusting to that change." These statements are reflective and not intended to "fix" the problem. The interventionist should listen to and reflect back to the speaker. This indicates that they heard the feelings. To become comfortable with feeling states requires the interventionist to become comfortable hearing a family's emotions. They do not need to do anything beyond listening to and supporting the family.

What should an interventionist do when a family member starts to cry? On a simple level, hand the family member some tissues. But, there is a judgment call that needs to be made by the interventionist. If this is the first time that these specific feelings have been expressed, the intervention should stop and the family member should be allowed to express his or her feelings. The interventionist's role is to listen and support, and acknowledge the feelings. He or she should provide comfort and acceptance. The family member may need to know that having these feelings and expressing these feelings is acceptable. If the interventionist appears comfortable, the family member will realize that expressing their feelings is acceptable. If the interventionist is not allowing the family to express their feelings, or if the interventionist is trying to fix the emotions, he or she may be inadvertently communicating to the family member that the feelings they have are not acceptable.

In a different situation, the family member may express feelings and emotions that have been discussed several times in previous interactions. Their present expression may be less intense. In this situation, the feelings should be acknowledged and tissues dispensed, but intervention should continue. The judgment the interventionist must make is how much attention should be given to the feelings. At some point the interventionist must direct the conversation back to the current task. When the family and the interventionist have a good partnership, and when a family member needs to talk or slow down the pace of intervention, he or she will communicate this to the interventionist.

Another difficult issue for a professional is when a family expresses anger toward services, agencies and professionals. The interventionist can use the same tools as outlined above. He or she can make comments such as, "You sure seem angry." This type of comment reflects the emotion back on the family. Another type of reflection that communicates awareness and facilitates interaction may be, "Agencies are frustrating to deal with." The angry family is not looking for a quick fix, they are merely needing to express their emotions. The interventionist does not need to try to repair the situation or show them that agencies are good organizations. The interventionist does not need to defend or criticize service providers. He or she can make comments such as, "I don't blame you for being angry. Sometimes the system can be difficult for those of us who are familiar with it." The interventionist needs to allow feelings without personalizing them. The interventionist needs to expect anger from families and to know that this anger is not directed at them. Most of the anger that an interventionist will experience from a family is anger with the system or frustration with a specific issue. When family members experience hurt feelings or feel disappointed, this will often be expressed as anger. The interventionist needs to listen to and allow this anger. Perhaps he or she can suggest that the anger is a normal reaction to frustration and disappointment. The interventionist needs to avoid becoming angry, remembering that the anger is not a personal attack. Like the expression of other feelings, the exhibition of anger helps the family cope and move forward with their life.

Moses (1983) writes about the process of grieving. He does not classify grief into fixed stages. His first point is that successful grieving is based on the expression of feelings and emotions. His second point states that successful grieving includes the formulation of new dreams based on the reality of the situation. It is normal for issues to surface at pivotal times in the child's life cycle. The family members will need to express their feelings about these changes, frustrations and lost dreams.

Moses states that an individual will not successfully grieve a loss until he or she can express his or her feelings and emotions. The family who has a child with disabilities is similar to any family that has a loss. They will experience a variety feelings and emotions at different times. These feelings are somewhat random and not fixed in stage progression. The interventionist can expect the family to experience anger, depression, sorrow, denial and guilt. Denial can serve a positive function in that it allows a family some time to come to grips with the issues they face. Normal denial allows the family time to cope. Interventionists should allow the family members time to experience this denial. However, a family that is in denial for a protracted amount of time may need to be referred to other professionals for counseling.

Guilt is a common feeling that families express. The families of children with disabilities often feel responsible for that disability. In addition, the interventionist can feel guilty that they cannot fix the family's problems. Both types of guilt, while not rational, represent the feelings of grief. The interventionist can reassure parents that they are good people and that they may be assigning responsibility to themselves for a condition in which there is no liable party.

Depression is also a common emotion. Often, the process of expressing the feelings of depression will help the depression decrease. The interventionist can make a referral for

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counseling if the depression is excessive and inhibits normal functioning. For the vast majority of families, the level of depression and anger will not be excessive.

The grieving process is ongoing and can be reinstated by new events and new issues, so the interventionist should expect to encounter various forms of grieving throughout the intervention process. The grieving process does not erase issues from the family's memory, but it helps to decrease the intensity of their emotions.

The second issue that Moses discusses is the formulation of new dreams. The grieving process is created because dreams are lost. A family holds dreams and expectations around the birth of a child into the family. When the child with disabilities is diagnosed, the old dreams and expectations have to be modified. Successful grieving fosters development of new dreams and new expectations to replace those that are lost.

Decision-making can also facilitate the grieving process. It is suggested, therefore, that interventionists allow families to make their own decisions. It benefits families when they can chart their own course for intervention and services. The interventionist must have a solid understanding that in the partnership with the family, he or she is only a single vote. The family will make decisions with which the professional may not agree. The process of being family-focused rests on the ability of the professional to allow a family to make their own decisions.

TOPIC FIVE: Enmeshed and Detached Families

Many people who go into the helping professions have a tendency to want to take care of families and the individuals they serve. While interventionists are in a caring profession, we are not required to become caretakers. As interventionists, we want to facilitate growth and provide needed services to families, but we do not want to become the caretakers of those families that we serve. There is no question that we will empathize with the pain and struggles that the families experience. Our goal is to maintain appropriate distances with the family. Appropriate distances promote healthy functioning for the family and for us as interventionists. Maintaining a healthy distance does not preclude having feelings and emotions. A healthy distance only stipulates a relationship in which we are involved in appropriate and healthy ways with a family.

The goal in dealing with families is to maintain a healthy balance. To achieve this balance, the interventionist needs to feel focused, be able to communicate with the family, listen to the needs and emotions of the family, and remember that the feelings and emotions of families need to be expressed. The interventionist helps the family learn to take care of issues on their own.

Minuchin (1981) suggests that a balanced family has clear boundaries in place that fall on a continuum between the extremes of detachment and enmeshment. The family involvement criteria of Hersey and Blanchard (1988) suggest that professionals need to assist families to help them to grow and develop their own resources. The interventionist is not a caretaker nor will the interventionist always be there to fix the family's problems. Many families are so confused and overwhelmed by the demands of having a child with disabilities that they are willing to allow an interventionist to take a caretaking role. There are families who have low resource utilization and limited confidence that lets them allow an interventionist to be a caretaker. But, interventionists provide a disservice

to a family if they take care of them.   Does the interventionist need to be a caretaker because it fills a need of her own? If the interventionist does not act as a caretaker, does s/he feel guilty? Does the interventionist have a basic belief that to be a good professional, she must be a caretaker? Is the interventionist a controlling individual? Many helping professions attract individuals who have a need to control and be in charge. Many professionals are such soft and caring individuals that they allow their own beliefs to influence what they feel others may need. The interventionist needs to evaluate his or her own needs to be sure that interactions with families promote a healthy partnership.

In contrast to being a caretaker, interventionists also want to avoid being detached. Families often complain that doctors tend to give diagnosis in a brief form, then disappear. These individuals are so detached from the family that few feelings are communicated and little comfort is provided. The families who comment on this style of interaction often report that they are left with an empty feeling. A more balanced approach would be for the doctor to deliver the diagnosis and schedule an additional few minutes to discuss the impact of the diagnosis with the family. For the medial doctor to do this, he or she must be comfortable with feeling states, realize that there is no ability to fix the problem, have an awareness of other's needs, and have some sense of boundaries. In this example, the doctor does not need to take on the role of caretaker, nor does he need to be so detached that he does not give the family some support and comfort.

Families need encouragement and they need to hear that their feelings and frustrations do not make them bad individuals. A family who has a child with a disability can feel very lonely and overwhelmed. The interventionist needs to disclose and share on a healthy level. It is not healthy for families to work with interventionists who are detached or enmeshed.

Examples of situations in which boundaries are unclear are excessive phone calls, solving problems the family should take care of, or being drawn into marital problems. The interventionist will have to make a judgment regarding the degree of their involvement and the type of response he or she will have toward the family. For example, it is common for some families to telephone the interventionist too often and talk for extended periods of time. What should the interventionist do to maintain boundaries? He or she should ask a question about the nature of the calls, such as whether the calls are necessary, and what purpose they serve. The interventionist must realize that there are few real emergencies. When emergencies arise, there are a number of agencies and sources that can help. The interventionist can help the family to realize the resources that are available. If the family takes charge of the situation, the interventionist can praise them later for making good choices. The interventionist needs to maintain boundaries in order to accomplish a balance with his or her personal life. It may be good to model this balance for families. In contrast, the interventionist does not want to be so isolated and detached that phone calls are never received or returned. The interventionist should merely select which phone calls to return, when to return them, and the length of the calls. The goal is to have enough involvement to support the family and not so much involvement as to be enmeshed with the family. After support has been given and feelings listened to, the interventionist can say something such as, "I'll see you Monday and we'll see how you're doing." or "You know there are not any answers to that and you're doing the best you can. I'll see you Monday."

It is also appropriate for the interventionist to refuse to do things for some families. He or she does not want to foster situations in which the family looks to someone else to handle their problems. The interventionist can maintain a balance by helping the family learn how to use their resources. An example may be a situation in which a family asks the interventionist to make a call for them. This call may be to another professional or agency. The interventionist can say, "I think you should be able to do that. We'll talk Monday about how it went." At times, a statement directing the family to take action may be necessary. For example, "I think that you need to make the contact. Here is how you do it."

A co-dependent relationship is not desirable, and we can discourage families and individuals within a family from being co-dependent. This can be done by encouraging independence, pointing out their co-dependency, and encouraging healthy interactions. One of the main characteristics of co-dependency is the process of looking to others for strength and caretaking. Individual family members can be so weak that they have no confidence in themselves. They will look to other family members or the interventionist to make decisions for them. Families may look toward agencies and professionals to take care of them. In addition, therapists can also have a need to be caretakers and develop co-dependency with families. In general, co-dependency is based on a lack of confidence. They have not individualized to the degree that they can be alone or be themselves without fear of rejection by others. They want to be liked and they choose caretaking as their way of being accepted.

Co-dependents may have little internal sense of what is acceptable behavior, so they conform to those around them. Interventionists want to maintain a healthy, non-caretaking relationship with all individuals with whom we work. We want to promote growth and a healthy balance with families. We can do this by establishing and maintaining boundaries. At times these boundaries may make us uncomfortable, but they are necessary. Part of being a helping professional is to be in control of our own feelings, while still being able to work toward healthy outcomes.

TOPIC SIX: Parenting Ideas (Garber, 1987)

Parents with typically developing children have questions and concerns about proper parenting. So, when a child with disabilities enters the families, the situation can become overwhelming. Today's parents have been exposed to a variety of parenting styles and may be unsure which techniques are most effective. As a result, parenting is an issue with which families need guidance in order to learn new techniques and approaches. The family will also need to be allowed to adopt the parenting style they feel will be productive for their family.

Parenting is highly dependent upon many issues. Good parenting is based on the healthy structure of a family. If the family does not have clear boundaries and rules, the parenting will reflect this confusion and lack of structure. An enmeshed family will most likely have a very permissive style toward the children. The children may be indulged to excess and develop negative behaviors. Conversely, a family who is detached may appear unstructured and this may impact the development of a child's confidence. The family who is balanced and has a well-defined structure will most likely have the best atmosphere for good parenting. Successful parenting provides a balance of love,

consistency, encouragement and consequences that children need. Good parents will structure their family in ways that encourage and model the behaviors they deem necessary. Children will learn a great deal about values, beliefs, motivation and opinions from their family.

Children need to be given choices, but rather than choosing from a wide variety of possibilities, it may be more manageable to provide two acceptable options. There are times when it is acceptable to not offer children any choices at all. Children do not always have the cognitive development or the experience to make decisions.

Another issue in parenting is related to promoting a child's self-concept. It is important for parents to be aware of how they treat and talk to their child. This will have a great impact on how the child values him or herself. Children with poor self-concepts often come from families who are quiet. Families who do not communicate may leave the child with the assumption that he or she is not accepted.

Another negative communication pattern is when the child is told that he or she could have done better. This may leave the child feeling inferior. These early experiences have a great deal to do with the confidence that child will have as an adult. Yet, the parents are not always aware of these critical interactions. For example, deaf and hard of hearing children often receive far less information, feedback and communication from their parents. They have received less input due to the hearing loss. This may significantly impact the child's self-concept.

Discipline is another area in which parents may need guidance. It is best to use a normal tone of voice. The unacceptable actions can be discussed, the hurt feelings shared and the consequences given. If the parent enforces the rules, there is often less or no anger. The parent who allows something to go on until they reach a breaking point can expect to get angry.

Another tip parents should remember is that children seldom do things to hurt their parents on purpose. Parents often take things personally, as if there was premeditation to their child's actions. For the most part, children act based on self-centered desires. Most often they have not considered the parents' feelings at all. If parents can remember this, they may be less hurt by the actions of their children. If they are less hurt, there is more of a chance that they will parent in rational ways.

A parent quickly gains a reputation with his or her children. If the parent is an easy mark, the children will know and will act accordingly. If the parent is loving, the child will come to him or her for comfort. The parent who is fair will be respected by the children. The parent who is soft will be pushed by the children. Parents can look at how their children treat them, for this reflects the reputation they have with the children. The child who pushes one parent but not another is telling these parents something about how they relate to the children.

Parents can use the "less than a thousand times" rule when communicating with children. This rule states that if a parent has told a child something less than a thousand times, most likely the child has not leaned it yet. Such an expectation will greatly reduce the anger and distress of the parent. Many parents believe in the myth of single trial learning. Another rule parents can use is the 'less than ten words' rule. This states that

parents should try to say things to their children in less than ten words. This is especially true when children are upset and not getting their way. Anything over ten words is perceived as a mini-lecture and the child may stop listening.

Short-term consequences are often the best behavior management tool. Children should always be reminded that they will never have to experience another consequence if they follow the structure of the family. However, if the need for consequences should arise, use short ones. Parents who ground a child for the rest of their life are only punishing themselves. Perhaps a punishment should start with the loss of something for a day. Then the next day can be a fresh start. This gives the child another chance to improve his or her behavior in a short time period. The goal of discipline is to teach, not to punish. So parents should choose a method of discipline that catches the attention of the child.

Another issue that challenges families is determining the difference between spoiling and indulging a child. A spoiled child will not develop a sense of community or a sense of others. A spoiled child is produced by overindulgence and the absence of limits and rules. To indulge children is acceptable, and at times great fun for the parents, as long as the rules and limits of the family are enforced. The child needs to be respectful and not manipulate in order to gain what he wants. While indulgence is okay, spoiling a child provides him or her a great disservice. A parent must be strong enough to know which is which, and have the fortitude to say 'no' when necessary.

Parenting is a complex process, but extremely important and very gratifying.

TOPIC SEVEN: Guilt, Expectations, and Cognitive Therapy (Burns, 1980)

Some families who have a child with disabilities experience guilt. Additional feelings associated with guilt can be feeling bad, not doing well enough, and depression.

Families who are going through the grief process almost always experience these feelings to one degree or another. The frustrations of dealing with professionals and agencies may stimulate some of these feelings. If the family members are sensitive individuals, they may find the daily routines of coping with a child with disabilities demanding.

The professional may also have feelings of guilt. A professional may take responsibility for complications and personalize statements the family makes. They may wish to fix the problems of those with whom they are working and feel bad for the pain and disappointments of the family.

While feelings of guilt are somewhat universal, they don't need to control our behavior and preoccupy our thoughts. We are about to review the principles written by Beck (1976), Maultsby (1986), and Ellis' (1975), all cognitive psychologists.

A basic premise of cognitive psychology states that we all have internal dialogues with ourselves, whether we are aware of it or not. We think and reflect and process as we deal with our world. Therefore, an individual has to be aware of his or her internal thinking.

Another premise of cognitive psychology is that this inner dialogue is a habit that we learn in our early years. However, our thinking is a habit that we can modify with practice and time. Our internal thinking occurs rapidly and without effort, but its content

is based on learned beliefs. If we can change and adjust the beliefs, we can change the automatic thoughts.

Our internal thoughts are based on our beliefs, and our beliefs may have been formulated long before we had the cognitive ability to evaluate them. If we are feeing guilty or if we have feelings of dislike for ourselves, our beliefs will not be realistic or rational. For example, some people have an expectation of themselves that they should be perfect or "superhuman," and when they are unable to attain perfection, they feel negative about themselves.

Another basic premise is that thinking creates feelings. If we are depressed, it is most likely that we are thinking negative thoughts. If we were thinking positive or neutral thoughts, we would not be depressed. To gain better control of our thoughts, we need to acquire productive habits of thinking.

For example, an interventionist walks into a family's home and the family is angry about the appointment time and the content of the previous week's session. This display of anger by the family could be an activating event. The critical next event is the thought process and self-talk that occurs. If the interventionist uses self-talk such as, "They are really angry at me. I must have had a terrible session last time. This family doesn't want to work with me anymore," the interventionist could be classified as having feelings of fear and guilt. Another interventionist experienced the same activating event yet had self-talk such as, "I wonder what made them so upset. Perhaps they had a bad day with their child. Maybe this is symptomatic of a grief reaction. I'll ask them when they calm down if I've really done something wrong. I'll respond to their anger with a reflective statement and see what happens,". This interventionist exhibits neutral feelings. If yet another interventionist experienced the same activating event and had self-talk such as, "They have a lot of nerve saying that to me. I work hard for that family," then that interventionist could experience feelings of anger and frustration. In this example, the same activating event had three different feeling outcomes based on three different processes of self-talk. The first and third interventionists in the example were negative in their thinking and personalized the activating event. However, the second interventionist expected distress to come with grief and had thoughts that were neutral.

Sensitive and stressed individuals often have thought processes that are negative, irrational, catastrophic and presumption-based. We want to develop habits of thinking in which we respond rationally to an event without making assumptions about what will occur in the future. We are dealing with complex issues and many emotions and feelings. If we are not careful, we will begin to think negatively about our skills. We need to make the best use of our limited time with a family and not spend a lot of energy worrying.

The interventionist can teach families cognitive skills that can help them to create more rational beliefs. Although a family may believe a number of irrational beliefs about the cause of their child's condition or their parenting abilities, they can acquire more rational expectations for their behavior. They can accomplish this shift by exploring their self-statements to see how these create their feelings.

TOPIC EIGHT: Being a Coach (Kopp, 1972)

Nichols (1984) suggests that family therapy is based on two main ideas, action and insight. Action and insight can contribute to an individual's growth and the growth of a family. Changing one's habits is an outcome of a change in one's insight and action. While many people have the insight to understand what they need to do to change, they may not take action. An example is when a person has the insight to understand that they should lose weight. But, if they do not take action, the insight is less meaningful. Change is obtained only when both action and insight are present.

Kopp (1972) supports the belief that action and insight are related. He thinks that individuals need teachers and helpers who can assist them to utilize their resources. He views the individual as having all that is needed to function as a healthy and productive person. But, that individual needs to know how to listen to him/herself and to understand how to trust his/her abilities. The same would be true for a family. Having the insight to know how to utilize resources and having the discipline and confidence to act on this insight is the basis of change. Kopp suggests that growth is based on people learning to use and trust their own resources. He views the professional as a coach. The coach helps the family members to address and manage their concerns. The coach introduces new ideas to the family. The coach guides others toward a more realistic understanding of themselves and of the world in which they live. The coach is a teacher who provides new information and new perspectives while allowing the learner to formulate his or her own conclusions. The coach offers guidance.

The attitude of the interventionist is critical. From the initial contact with a family, the interventionist acts as a coach and a cheerleader. The interventionist coaches and encourages from the sideline. It is important to understand our boundaries as professionals. We join in partnership *with* the family. We coach them and celebrate the progress they make. When the interventionist needs additional resources, s/he can find someone to mentor him/her. This mentor will assist the interventionist to obtain the insight s/he needs. Like the families with whom they work, interventionists need to have insights and take action.

Professionals are not always comfortable saying, "I don't know." There is a vast amount of information available related to hearing loss. Much of what we know is based on theory. There are many dynamics that make it impossible to predict outcomes. The interventionist may not know the answers. The partnership between the family and the interventionist is based on good communication and honesty. This honesty creates trust, which is the basis for change.

The family who has a child with disabilities will learn many new skills. The family may need a great deal of support in order to meet the needs of their child. They will need to learn how to work with agencies and learn to cope with their feelings. The interventionist will also learn from the families.

As interventionists, we want to encourage the individualization of family members and promote the development of a balanced family. We hope family members will identify their own boundaries and rules. We want to encourage independence.

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TOPIC NINE: Communication (Carkhuff, 1967)

Virginia Satir (1975) suggested that the progress she made with clients occurred because of the development of trust. Trust is a product of communication between individuals. If interventionists are to build trust, they must be honest with families about what they observe and how they observe the family members communicating with one another. Satir stresses the importance of congruent communication. When we are talking with others, our words need to match our feelings. If the listener perceives congruence between our words and feelings, the listener will trust the interventionist.

It is equally important to be diplomatic in delivering one's words and feelings. Diplomatic communication promotes trust. If the interventionist has properly joined with the family, the relationship will be the foundation for establishing trust. Trust is built on the honest sharing of opinions and ideas.

Communication is reciprocal. The speaker says something and the listener indicates that the message was received. This has nothing to do with agreement with the message, but only acknowledging what the speaker said. This simple feedback loop is often missing from daily communication. It is important to listen to the family and acknowledge that they were heard.

Active listening (Rogers, 1961) is a strategy that focuses on the interventionist's responses. For example, a family member makes a certain statement. The interventionist would not respond to the statement with new data or advice. Rather, the interventionist will repeat and reflect on what they heard the family member say. "What I heard you say was…" is a classic reflective statement. This type of reflective statement tends to improve the clarity of the message.

The communication among family members maintains intimacy within the family unit. Good communication shares information about attitudes, beliefs and actions. The same is true for the professional-family partnership. The more that is shared, the more connected the family members feel to the professional. The interventionist can encourage a family to communicate by demonstrating open communication. Interventionists need to operate with the belief that the sharing of feelings and observations are critical to maintaining an intimate and trusting partnership with the family.

Communication is a learned habit. Each person comes from a family that has rules about communication that are based on how the parents communicated within their families of origin. If the individuals within the family are to change their communication style, they will need practice. The interventionist may need to become comfortable with communication and disclosure as well.

Maintaining the current topic is another good communication tool. Sometimes a family member will jump from topic to topic. When this happens, issues will not get settled. The interventionist can interrupt the process and suggest that additional topics be discussed later.

The interventionist creates the communication environment by offering empathy, respect, and genuineness. The interventionist can reflect on the family's feelings.   Using this reflective technique, the interventionist communicates his or her depth of understanding of the family's feelings. The feelings of the family need to be treated with

respect. The professional must be careful to not tell the family that their feelings are incorrect. As a general rule, feelings are not right or wrong and should be listened to without critical evaluation. Families often report that no one asks them how they feel or listens to what they say. Listening shows respect, and interventionists are being genuine when they listen with interest and authenticity. While the interventionist may not agree with a statement, he or she can still listen in order to understand the feelings of the family. The interventionist should attempt to state responses in simple ways that do not steer the conversation too far from the original thought.

Carkhuff (1967) created a 1 to 5 scale to rate the responses of a professional to the communications of a family or individual. Rankings of 1 and 2 will limit communication. A level 3 response is reflective and facilitative. Rankings of 4 and 5 demonstrate understanding at a deeper level. At level 4, the feelings being expressed are being reflected back to the speaker at a deeper level than the speaker originally expressed. Comments at level 5 encourage ongoing exploration.

The following example exhibits Carkhuff's model. A family states, "We get so angry at the agency who services our child. We try to follow the rules but never seem to do it correctly."

- A level 1 response would be, "Agencies are a pain."
- A level 2 response might be, "Everyone has problems with agencies."
- A level 3 response would be, "It's frustrating dealing with agencies."
- A level 4 response might be, "It really makes you feel incompetent dealing with agencies."
- A level 5 response might be, "It's hard not to take the demands of the child with disabilities personally. With your child comes so many professionals and responsibilities."

Statements at level 1 and 2 may shut down communication. The level 3 statement is reflective and demonstrates that the respondent understands what was said. Statements at levels 4 and 5 will most likely elicit additional comments from the family. Our goal as interventionists is to encourage communication and help the family to be aware of their feelings.

Communication is not only the basis of a successful professional-family partnership, it is important to the family's ability to grow, change, develop intimacy, and promote self-esteem within its members.

TOPIC TEN: Consultation and Collaboration

When an interventionist becomes involved with a family, he or she will also interact with a variety of other professionals and agencies. The additional professionals involved with a family may be service providers, therapists providing child-centered therapy, medical personnel, service coordinators, case managers, school staff, social workers, etc. Families benefit from the ideas of many professionals from different disciplines. As professionals working with families in a family-focused model, we want to be an active participant with the professional team. The consultation process and the collaborative process allow for utilization of all available resources.

The interventionist needs to be flexible enough to work with the program the family designs. The interventionist needs to work with the different personalities that are present when a variety of professionals are involved with a family. The guiding force should always be what is in the best interest of the family. We should not coerce the family to make choices.

Steele (1975) sees the consultant as having a variety of roles. Nine common roles have been identified:
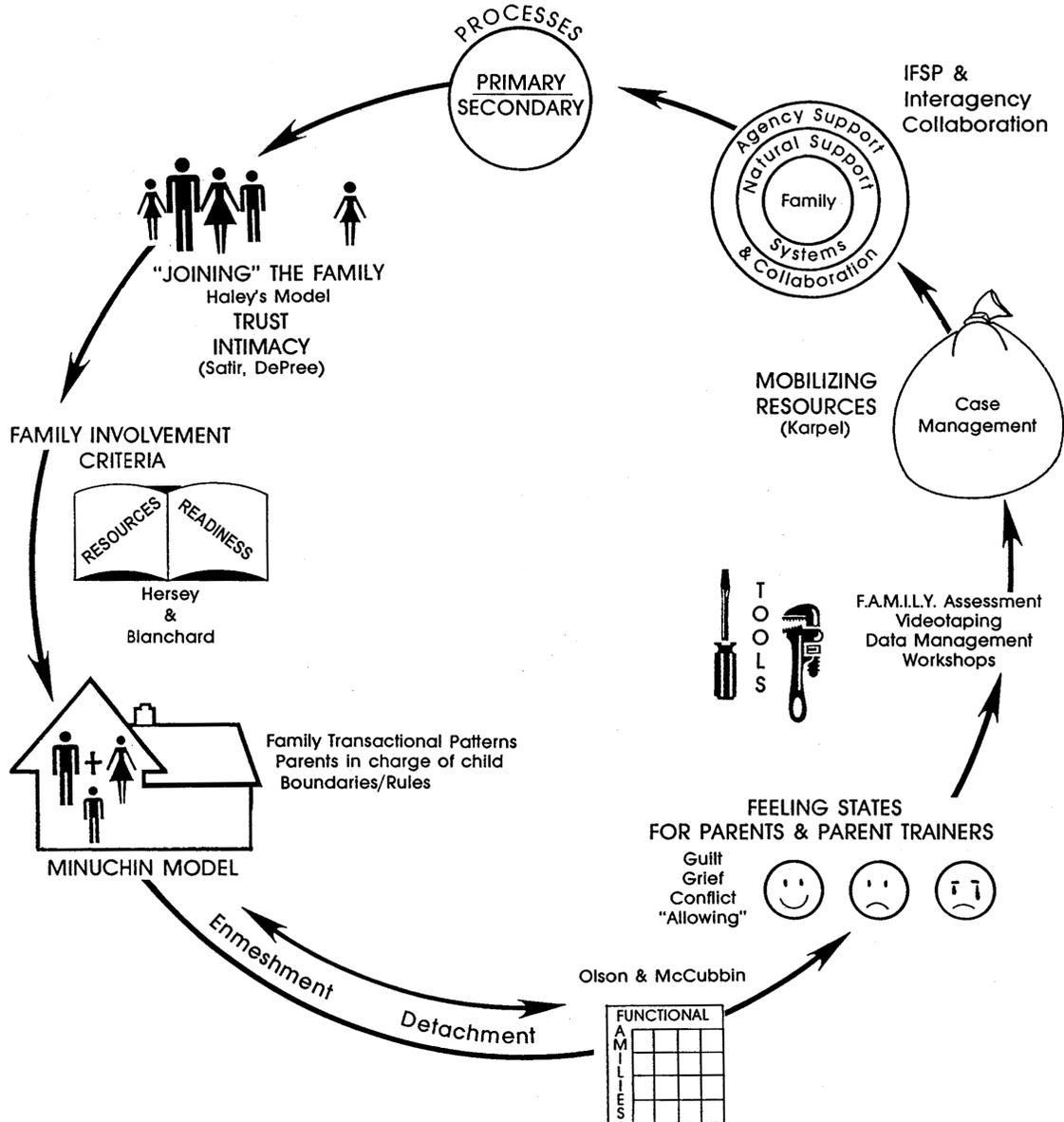
1. **Teacher:** The consultant teaches and shares information with the family and other professionals.

2. **Student:** This role reflects the dual nature of being a consultant. The family will teach the interventionist about the family and about their child with disabilities. The interventionist will be ready to ask questions for the family and other professionals to answer.

3. **Detective:** The consultant gathers data.

4. **Barbarian:** This metaphor suggests that, at times, the interventionist must be capable of interrupting the status-quo that may inhibit change. In this role, the interventionist makes statements and reflective comments that may challenge the family.

5. **Clock:** In this role, the interventionist stresses the need to complete goals within specific time limits. The consultant monitors the time and comments about progress and limitations.

6. **Monitor:** In this role, the interventionist keeps track of changes. Observations are made and feedback is offered that comment on progress.

7. **Talisman:** The talisman focuses on being supportive. The talisman tracks progress and reinforces the progress made by a family.

8. **Advocate:** The advocate supports issues on behalf of the family in a way that reflects the family's values and beliefs.

9. **Ritual Pig:** At times, a consultant may share unwanted information. Hopefully, the bond created by joining with the family is strong enough that the consultant will not lose contact with the family when this happens.

The goal of our interactions with families is open, honest communication. As interventionists, we will add our resources to a family's knowledge base. But, the interventionist should refrain from placing pressure or expectations on the family. This is important to consultation and collaboration.

X. FAMILY EMPOWERMENT TRAINING

CHIP FAMILY FOCUSED PHILOSOPHY
FAMILY EMPOWERMENT

E. Alan Jones, Ph.D.

PROCESSES

PRIMARY
SECONDARY

IFSP &
Interagency
Collaboration

Agency Support
Natural Support
Family
Systems
& Collaboration

"JOINING" THE FAMILY
Haley's Model
TRUST
INTIMACY
(Satir, DePree)

MOBILIZING
RESOURCES
(Karpel)

Case
Management

FAMILY INVOLVEMENT
CRITERIA

RESOURCES   READINESS

Hersey
&
Blanchard

TOOLS

F.A.M.I.L.Y. Assessment
Videotaping
Data Management
Workshops

Family Transactional Patterns
Parents in charge of child
Boundaries/Rules

FEELING STATES
FOR PARENTS & PARENT TRAINERS

Guilt
Grief
Conflict
"Allowing"

MINUCHIN MODEL

Enmeshment

Detachment

Olson & McCubbin

FUNCTIONAL
FAMILIES

XI. Bibliography

Ackerman, N.J. (1984). *A theory of family systems*. New York: Gardner Press.

Amon, C. Remediation within state and federal guidelines. Colorado Department of Education.

Baker, B. (1976). Parent involvement in programming for developmentally disabled children. In L. Lloyd (Ed.), *Communication assessment and intervention strategies*. Baltimore: University Park Press.

Baker, B., Heifetz, L., & Murphy, D. (1980). Behavioral training for parents of mentally retarded children: One year follow-up. *American Journal of Mental Deficiency*, 85, 31-38.

Baker, T. (1979). *Birth to three: Developmental learning of the handicapped child*. Boston: Teaching Resources.

Beck, A.T. (1976). *Cognitive therapy and the emotional disorders*. Madison, CT: International Universities Press.

Beck, A.T., Rush, A.J., Shaw, B.F., & Emery, G. (1979). *Cognitive theory of depression*. New York: Guilford Press.

Beck, A.T. & Emery, G. (1985). *Anxiety disorders and phobias: A cognitive perspective*. New York: Basic Books.

Beck, A.T. (1988). *Love is never enough*. New York: Harper & Row.

Bernard, M.E. & Foyce, M.R. (1989). *Rational-emotive therapy with children and adolescents*. New York: Wiley.

Berne, P.H. & Sayary, L.M. (1985). *Building self esteem in children*. New York: Continuum.

Bubolz, M.M. & Whirren, A.P. (1984). The family of the handicapped: An ecological model for policy and practice. *Family Relations*, (33), 5-12.

Burns, D.D. (1980). *Feeling good: The new mood therapy*. New York: Signet.

Carkhuff, R.R. & Berenson, B.G. (1967). *Beyond counseling and therapy*. New York: Hold, Rinehart and Winston.

Cartright, L. & Ruscello, D. (1979). A survey of parent involvement practices in the speech clinic. *ASHA*, (21), 275-279.

Colorado Department of Education. *The process of assessment and staffing*.

Constantine, L.L. (1986). *Family paradigms: The practice of theory in family therapy*. New York: The Guilford Press.

DePree, M. (1989). *Leadership is an art*. New York: Doubleday.

Elkin, M. (1984). *Families under the influence: Changing alcoholic patterns*. New York: W.W. Norton & Co.

Ellis,A. & Harper, R.D. (1975). *A new guide to rational living*. Hollywood, CA: Wilshire Book Company.

Espinosa, L. & Shearer, M. (1986). Family support in public school programs. In R.R. Fewell & P.F. Vadasy, *Families of handicapped children: Needs and supports across the life span*. Austin, TX: Pro-Ed.

Fewell, R.R. & Vadasy, P.F. (1986). *Families of handicapped children: Needs and supports across the lifespan*. Austin, TX: Pro. Ed.

Fitzgerald, M.T. & Bess, F.H. (1982). Parent/infant training for hearing-impaired children. *Monographs in Contemporary Audiology*, (3), 3.

Fitzgerald, M.T. & Fischer, R.M. (1987). A family involvement model for hearing impaired infants. *Topics in language disorders*, (3), 1-18.

Fredricks, H., Baldwin, D., & Grove, D. (1974). A home-centered based parent-training model. In J. Grim (Ed.), *Training parents to teach: Four models*. Chapel Hill, NC: Technical Assistance Development Systems.

Friedman, E.H. (1986). Resources for healing and survival in families. In Mark A. Karpel (Ed.), *Family resources: The hidden partner in family therapy*. New York: Guilford Press.

Garber, S.W., Garber, M.D., & Spizman, R.F. (1987). *Good behavior: Over 1200 sensible solutions to your child's problems from birth to age twelve*. New York: Villard Books.

Haley, J. (1976). *Problem solving therapy*. New York: Harper Colopmon Books.

Haley, J. (1987). *Problem solving therapy, (2nd ed.)*. San Francisco: Jossey-Bass. Harvey, M.A. (1989). *Psychotherapy with deaf and hearing impaired persons: A systemic model*. Hillsdale, NJ: Lawrence Erlbaum.

Hersey, P. & Blanchard, K.H. (1977). *Management of organizational behavior, (3rd ed.)*. New Jersey: Prentice Hill Inc.

Jampolsky, G.G. (1985). *Goodbye to guilt*. New York: Bantam Books.

Jones, S.L. (1980). *Family therapy: A comparison of approaches*. Bowie, MD: Robert Brady CO.

Karpel, M.A. (1986). *Family resources: The hidden partner in family therapy*. New York: Guildford Press.

Kempe, C.H. & Helfer, R.E. (1972). *Helping the battered child and his family*. Philadelphia, PA: J.B. Lippincott.

Knox, L.L. & McConnell, F. (1968). Helping parents to help deaf infants. *Children*, (15), 183-187.

Kopp, S.B. (1972). *If you meet the Buddha on the road, kill him*. Palo Alto, CA: Science and Behavior Books.

Kubler-Ross, E. (1969). *On death and dying*. New York, NY: MacMillan Publishing.

Luterman, D. (1979). *Counseling and parents of hearing-impaired children*. Boston, MA: Little, Brown & CO.

Maultsby, M.C. (1986). *Coping better…Anytime, anywhere*. New York, NY: Prentice Hall.

McDade, H.L. & Varnedoe, D.R. (1976). Training parents to be language facilitators. *Topics in Language Disorders*, 7(3), 19-30.

McGoldrick, M. & Gerson, R. (1985). *Genograms in family assessment*. New York, NY: W.W. Norton.

Minuchin, S. (1974). *Families and family therapy*. Cambridge, MA: Harvard Press.

Minuchin, S., Rosman, B.L., & Baker, L. (1978). *Psychosomatic families: Anorexia nervosa in context*. Cambridge, MA: Harvard Press.

Minuchin, S. & Fishman, H.C. (1981). *Family therapy techniques*. Cambridge, MA: Harvard Press.

Minuchin, S. (1984). *Family kaleidoscope*. Cambridge, MA: Harvard Press.

Moses, K. (1983). The impact of initial diagnosis: Mobilizing family resources. In J.A. Mulick & S.M. Pueschel (Eds.), *Parent-professional partnerships in developmental disability services* (pp. 11-34). Cambridge, MA: Academic Guild Publishers.

Milick, J.A. & Pueschel, S.M. (Eds.) (1983). *Parent-professional partnerships in developmental disability services*. Cambridge, MA: Academic Guild.

Nichols, M. (1984). *Family therapy: Concepts and methods*. New York, NY: Gardner Press.

Nichols, W.C. & Everett, C.A. (1986). *Systemic family therapy: An integrative approach*. New York, NY: The Guilford Press.

Olson, D.K. & McCubbin, H.I. (1989). *Families: What makes them work*. (Updated Edition). Beverly Hills: Sage Publications.

Pearson, J.B. (1989). *Cognitive therapy in practice: A case formulation approach*. New York, NY: Norton & CO.

Pushaw, D. (1976). *Teach your child to talk*. New York, NY: Dantree.

Rogers, C. (1961). *On becoming a person*. Boston: Houghton Mifflin Company.

Satir, V., Stachowiak, J. & Taschman, H. (1975). *Helping families to change*. New York, NY: Jason Aronson, Inc.

Schaef, A.W. (1986). *Co-dependence: Misunderstood-mistreated*. San Francisco, CA: Harper & Row.

Shearer, M. & Shearer, D. (1972). The Portage Project: A model for early childhood education. *Exceptional Children*, (36), 210-217.

Siegel, M.G. (1987). *Psychological testing from early childhood through adolescence*. Madison, CT: International Universities Press, Inc.

Steele, F. (1975). *Consultation for organizational change*. Amherst, MA: University of MA Press.

Stuart, I.R. & Abt, L.E. (Eds.) (1981). *Children of separation and divorce: Management and treatment*. New York, NY: Van Nostrand Reinhold.

Tizard, B. & Rees, J. (1974). A comparison of the effects of adoption, restoration to the natural mother and continued institutionalization on the cognitive development of four year old children. *Child Development*, (45), 92-99.

Trad, P.V. (1989). *The preschool child: Assessment, diagnosis and treatment*. New York, NY: Wiley and Sons.

Trout, M. & Foley, G. (1989). Working with families of handicapped infants and toddlers. *Topics in Language Disorders*, 10 (1), 57-67.

Visher, E.B. & Visher, J.S. (1979). *Step-families: A guide to working with step-parents and step-children*. New York, NY: Brunner-Mazel.

Weil, M. & Karls, J.M. (1985). *Case management in human service practice*. San Francisco, CA: Jossey-Bass.

Weissbourd, B. & Kagan, S. (1989). Family support programs: catalysts for change. *American Journal of Orthopsychiatry*, 59 (1), 20-31.

Wood, P. & Schwartz, B. (1977). *How to get your children to do what you want them to do*. Englewood Cliffs, NJ: Prentice-Hill.

Worden, J.W. (1982). *Grief counseling and grief therapy: A handbook for the mental health practitioner*. New York, NY: Springer.