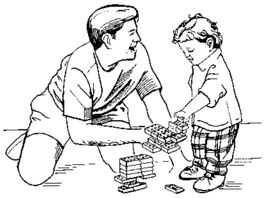
Including Families Who Have Children with Disabilities into Parent & Family Education



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disabilities (working with children & families), grief*, coping*, resiliency*, special education, inclusion (*when child has a disability)

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Objectives:

As a participant in this guided self-study, practitioners will be able to:

- increase our understanding of what it's like to parent a child with disabilities.
- understand the cyclical nature of grieving that represents the emotional reactions parents experience.
- be familiar with major coping strategies and our role in supporting parents.
- utilize a family systems and family-centered approach when working with families.
- be aware of strategies that help develop a trusting relationship and appropriate interactions with parents.
- be aware of the resilience of families and our role in promoting it.
- incorporate the fifteen guidelines for working effectively with families.

Introduction

An increasing number of parents of children with disabilities are participating in parent and family education with a number of programs being very successful in their efforts to include these families. To ensure that integration into programs is a successful experience for families, parent and family educators need an understanding of what it's like to parent a child with special needs and clarification of their role in supporting families.

Similar Needs — Unique Needs

Parents of children with disabilities have many of the same needs that any other parent has, such as the need to understand the development of their child, or issues related to discipline or childcare. In addition, most of these families have unique needs related in some way to the disability. For example, the childcare issue might be that the parent can't find anyone willing to take a child with special needs. The behavioral concern might be related to the child having an oppositional disorder with the child needing a specialized behavior plan. Depending on the severity or involvement of the disability, some families have few unique needs while other families face multiple challenges.

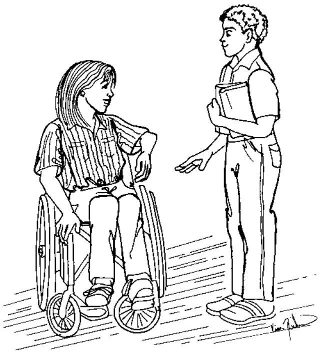
Because of this variability, the needs of some parents may be met through parent education, while needs of other parents may not. Be aware of resources in your community and know how to make appropriate referrals for parents whose needs can best be met elsewhere. Programs have different procedures for making referrals. Be familiar with the procedures that are used in your program and community, remembering that sharing information or making a referral are only done when requested by parents and with their permission.

All parents want the best and the most for their children. Parents who have children with disabilities are no different. It's a big challenge to rear a child with a disability because few of us have been trained to be parents and fewer yet have been trained to be parents of children with disabilities. Remember, disability doesn't happen only at birth. On any given day, one of us could have a child who becomes a person with a disability because of an accident or illness. Would we know how to parent without help? Would we know where to go for help? Sometimes parents aren't sure where to turn for help, either.

Special Education

Special education laws have been passed by the federal government to protect the rights of families of children with disabilities. Because of these laws, every school district has trained personnel to work with these families. Find out who coordinates the early childhood special education program as well as other special programs in your community. In many cases, the families participating in parent education will already be involved in special education services. With parent permission, you can talk to the special educator for insights into programming. Special educators are valuable resources.

The field of disabilities has undergone many changes during the last two decades. An understanding of what is available to persons with disabilities will be helpful because parents may come to you with questions and be fearful of the future. You will be able to reassure them that there are programs and trained professionals to support their future needs. Federal laws ensure that children with identified disabilities have the right to be educated from birth to age 21 in the public schools. This must be a free, appropriate education that takes place as much as possible in integrated settings. Upon completion of high school, students can get jobs through their state's rehabilitation services. Today, many of these jobs are in the public sector where the clients are employed independently or through supported employment where a job coach is available for training and supervision. Young adults with disabilities can live in group homes, supervised apartments or independently, depending on their capabilities. Community social workers help parents locate these types of services.



Prejudice and Stereotypes

Prejudices about persons with disabilities still exist today. Many of these beliefs have been handed down through the generations. You may find that at times parents become somewhat defensive because of what they have had to cope with in their schools or neighborhoods *(e.g., exclusion, looks and comments)*. Hopefully, as people with disabilities are integrated more and more into our communities, stereotypes will diminish. As families are integrated into parent education programs it's important that we do not perpetuate any of these stereotypes *(e.g., people with Down syndrome drool and aren't able to learn to read)*. Because of early intervention, technology and the many other programs that exist today, children are developing skills and capabilities that far exceed earlier beliefs. It's impossible to generalize about their abilities. View each person as an individual with his or her own strengths and limitations.

As a parent educator working with these families, it's important that you examine how you feel about persons with disabilities. Be aware of any prejudices you may have toward this group of people. Ask yourself:

- Are you quick to judge?
- Do you make first impressions on looks or behavior only?
- Are your opinions about people with disabilities your own or based only on what you've heard?
- Have you generalized what you've heard to include everyone with a disability?
- Have you actually interacted with people who have disabilities?

It's not uncommon to have fears or feel uncomfortable about the unknown. If you are unfamiliar with children with disabilities, several visits to their programs or better yet, some volunteer hours, will help you grow in your understanding. In this way you will learn about them as people and become aware of their capabilities as well as their disabilities.

"Person First" Language

"A disability is defined as a condition of the person, whereas a handicap is the result of barriers imposed by society and come between the person and the environment."

The words we use when talking or writing about persons with disabilities, and the order in which the words are used, greatly influences the images that are formed and the negative or positive impressions that result. The philosophy of using "person first" language demonstrates respect for people with disabilities by referring to them first as individuals, and then referring to their disability when it is needed *(e.g., child with Down syndrome rather than Down syndrome child)*. Using the phrase, *"The blind child"* makes the disability the most important attribute about the child. While saying, *"The child who is blind"* takes the focus away from the disability, making the disability but one descriptor. While this order is more awkward, it is more respectful. Many advocacy organizations are promoting this "person first" philosophy. Within this philosophy, we are also cautioned about the choice of words we use. "Disability" is preferred over the term "handicapped" which originated from a begging term meaning "cap-in-hand." A disability is defined as a condition of the person, whereas a handicap is the result of barriers imposed by society and come between the person and the environment *(e.g., curbs but no ramps for wheelchairs)*. Words such as "crippled," "victim," and "afflicted" that have a negative connotation should be avoided.

In addition, there is difficulty with using the term "normal" to refer to a person without a disability as the inference is that a person with a disability is "abnormal." A person with a disability may have some abnormal development, but is not an "abnormal" person. When referring to what is "normal" or inferring to what is "abnormal" be careful to clearly indicate that you are talking or writing about development and not a person or program. For example, use *"normal development"* instead of *"normal child;"* use *"mainstream classroom"* instead of *"normal classroom;"* use *"children without disabilities"* instead of *"normal children."* Usually a form of the verb "to have" is the most effective way of expressing the link between a person and a disability (*"has autism"* rather than *"is autistic"* or *"has epilepsy"* rather than *"is an epileptic"*). Remember that a person is a human being and should not be confused with a condition. The words we use have the potential of positively impacting society! Refer to the handout, *"Person First" Language (FI-P/CD p. 49)* for additional examples of this philosophy.

Understanding Comes First

In order to work effectively as partners with parents, it's important for us to understand what it's like to be a parent of a child with a disability. If you have not "walked in their shoes" you will never really know what it's like. But, you can increase your understanding by becoming aware of what these families experience.

Shattered Dream

During pregnancy, all parents dream about the child they hope to have. When the child is born with a disability, the parents' dream is shattered and their loss is extreme. Most parents report that the experience of finding out about their child's disability is devastating. Parents are supposed to be able to "fix things" for their children. Having a disability is something they cannot fix; they can't make it go away!

Models of Grieving

Often you hear about the grief these families experience. Parents have reported feeling anger, denial, loneliness, and despair as well as other feelings after being told the diagnosis of their child. Parents do grieve the loss of their "hoped for" child. Grieving is a natural human response to a significant loss. It is not just the sadness that is associated with mourning, but is a range of emotions that humans experience as they try to accept the loss, change, death or disappointment which has happened in their lives. The emotions experienced during grief seem to be intrinsic and cross-cultural and are part of the natural healing process. Researchers have tried to describe what these parents experience according to grief theory.

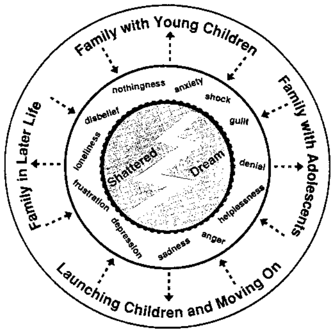
The stage model of grief developed by Kubler-Ross is often used to try to explain the experience of parents with children with disabilities. However, parents have indicated that working through a series of stages and reaching a final stage of acceptance does not accurately describe their pattern of grieving.

Olshansky used the term "chronic sorrow" to describe the psychological reactions of parents who have children with mental retardation. Olshansky (1966) contended that the intensity of the chronic sorrow changed over time, but was present throughout the life of the child. However, parents have reported that the feelings of grief do disappear for short and sometimes prolonged periods of time, thus challenging the theory of chronic sorrow as an accurate description of their grieving process.

The *Cyclical Grieving Model*, which has been developed more recently, represents a clearer picture of the grieving pattern that parents of children with disabilities have reported. *"Cyclical grieving is the intermittent reoccurrence of one or more emotions which are part of the grieving process and experience by parents who have children with disabilities."* A variety of events throughout the life cycle of the family may trigger grieving to reoccur. The duration and intensity of the reoccurring feelings diminish with the passage of time. When grieving is not occurring, parents have reported being free of the feelings associated with grief. During this time parents work toward understanding and accepting their child while reorganizing their lives to cope with whatever demands are placed on them.

Cyclical Grieving Model

The *Cyclical Grieving Model (FI-P/CD p. 50)* represents the cyclical nature of grieving reported by parents who have children with disabilities. The model is illustrated with three concentric circles which represent the following:



Shattered Dream

Inner Circle: The inner circle represents the parents' shattered dream. According to Moses, the severe loss experienced by these parents is the loss of their dream child. When parents are expecting a baby, they dream about the child they will have and dream what the child will look like, their hopes for the child's talents and capabilities and the child's future. When the child is born with a disability or when the disability is identified later in the child's life, these dreams are shattered and no longer are possible. Moses indicated that the parents grieve for the dream child and this grieving helps the parents let go of their dream and eventually become able to refocus and dream new dreams for the child they do have.

Emotions Experienced

Second Circle: The emotions depicted in the second circle are feelings parents have reported experiencing at the time of diagnosis and intermittently thereafter. The emotions included in this model are a representation of feelings that parents have reported. The words are placed randomly within the circle to illustrate that the emotions are not experienced in any predetermined order. The emotions may appear and reappear with a parent experiencing one, two or more simultaneously.

Family Life Cycle

Outer Circle: The third or outer circle depicts the life cycle of a family; namely family with young children, family with adolescents, family launching children, and family in later life. (McGoldrick & Carter, 1982) The family life cycle is one dimension of a family systems framework and views a family as it changes and moves through time. The change alters the family structure and its functioning priorities which in turn change the way the family interacts. The challenge for a family who has a child with a disability is that while they cope with the changes in the family system, they also have to deal with the chronicity of their child's disability.

Arrows: The dotted arrows away from and toward the emotions as well as away from and toward the developmental stages of the family life cycle represent the cyclical nature of grieving. Parents move toward the reoccurrence of the emotions, and further away, with this movement contingent on events in their lives. During the life cycle of a family, a number of events trigger the reoccurrence of one or more of the emotions which make up the grieving process. Parents have acknowledged the cyclical nature of their grieving. *"Even those who can tolerate their grief and depression proceed with the work of mourning slowly and unevenly to protect themselves from being overwhelmed, and to preserve their capacity to function in daily life."* Another comment from a parent describes the cyclical nature of their emotions. *"Perhaps disappointing would be a better word than sorrow. I firmly believe we did have many peaks and valleys. There is sadness, but many joyous and funny moments too."*

The occurrence of cyclical grieving does not preclude parents from deriving joy from their child's development and achievements. When a parent whose child has mild retardation was asked what was most rewarding about her daughter, she responded, *"The love she gives us. She has one foot in the adult world and the other in childhood so she looks at life in a joyful way…my other children are better people because of all of this too."* Many parents have reported while being a parent of a child with developmental disabilities is challenging, it has made them stronger.

It's important that professionals who work with parents of children with disabilities understand the cyclical nature of their grief and how a variety of events may trigger it to occur *(Cyclical Grieving, FI-P/CD p. 51)*. For example, a mother who had a daughter with Down syndrome was receiving home-based services. One day as the professional drove into their driveway, the mother happened to be looking out the window. The mother reported that as she watched the approaching car, she looked around the neighborhood and was reminded that no other neighbor needed home services; emphasizing to her that her daughter really did have significant problems. This particular event triggered grieving to reoccur. The mother reported that she became extremely sad, cried and was angry that it was her child who needed help and her house that had to be visited. As professionals, we may not anticipate that an event such as a home visit could cause this type of reaction. Yet, if we understand cyclical grieving, we will understand why it might happen. Often parents are equally surprised at their reactions. This is an example of a seemingly insignificant event that became significant because of this parent's perception of the event. In situations such as this, we can help parents understand what is happening and reassure them that they are experiencing feelings and reactions that are normal.

It is very difficult, if not impossible, to predict which events or developmental changes will act as catalysts to grieving. The reoccurrence is unique to each parent and is influenced by his or her perception of the event. As professionals we should not be diagnosing or judging, rather supporting parents when they struggle with events in their lives. Because the reoccurrence of grieving is based on the perceptions of the parent, some families grieve very little while others grieve a lot. Professionals need the knowledge to understand what parents experience and the skills to help them refocus from their shattered dream so they can begin dreaming new dreams while remaining positive and optimistic.

Understanding How Parents Cope and How We Support

The term coping refers to the things people do *(either by thinking or acting)* to increase a sense of well-being in their lives and avoid being harmed by stressful events. The actions we take to reduce our feelings of stress are our coping strategies. Five major coping categories that we all tend to use have been identified by Goldfarb, Brotherson, Summers & Turnbull.

Passive Appraisal

Passive appraisal refers to ignoring the problem. This might happen at first when parents are trying to cushion themselves against the shock of what has happened; or later when they "take a break" from the problem and read a book, go shopping or fishing. It's almost as though they are pretending the problem doesn't exist for a period of time. This is a healthy coping strategy when used appropriately. Obviously, if a person pretends the problem doesn't exist at all and fails to address the issue it would not be a healthy response. Professionals can suggest to parents to "take a break." Often parents need encouragement to take these much needed breaks!

Reframing

Reframing sometimes called cognitive coping is another very important coping strategy. Reframing is when the person looks at the problem or stressful event in a new or different way. This in turn can make the problem seem more manageable or gives parents more control which in turn reduces the stress level. For example, when a parent is overwhelmed with the many tasks that have to be done, a list can be made with priorities and timelines. This helps put the parent back in control with a course of action that seems possible to follow. Parents might reframe by observing another child with a disability that in their perception is even more challenging than their own. Following this observation, parents often are thankful for their own child. It's important that professionals do not make these comparisons. Professionals may provide the opportunity for parents to observe other children, but the parents themselves must make the observation and draw this conclusion. When parents become overwhelmed because their child is unable to do a number of things, the professional can help the parent by looking back several months and identifying what the child has learned. This is reframing by looking at what the child can and cannot do in a new way that is much more positive. These are a few examples of the many ways professionals can help parents reframe by looking at things in a new way.

Spiritual and Social Support

Spiritual support is very important to some families and can be very stress reducing. Parents may not be church goers, but still may have a belief in a greater power which helps provide answers to why this has happened and gives them someone to turn to for support. We can encourage parents to utilize spiritual support when parents have identified this as one of their coping strategies. Social support is the practical *(e.g., bringing food or doing childcare)* and moral support from family, friends and neighbors. The families that seem most resilient are those with strong social support networks. It's important that families are encouraged to use their existing network. In the last few years, parent-to-parent support groups have proven successful for parents who have children with disabilities. In these groups, a family who has recently learned that their child has a disability is matched to an "older" family with a child with the same disability. In this way, a family that "has been there" is available to support the new family. Parents have reported this to be one of the best kinds of support. It is important to remember that parents with a strong social support network may not feel the need for a structured support group. It's important to know these groups are available but the family makes the decision to join based on its needs.

Formal Support

Formal support is the help obtained from professionals. While this support is important, the social network is more important and the kind of support where most families turn for help. It is important that formal support is available to families but it should not be assumed that all parents want to access this support. In years past, it was assumed that if a family had a child with a disability, the entire family needed help. This kind of thinking came from a deficit model mentality. Today, we recognize the strengths of each family and build upon these strengths. We don't assume all families need counseling!

Each family copes differently. By recognizing our own coping strategies and those of our family, we become more understanding of the many ways people cope. Do the *Stress-Coping Activity (FI-P/CD p. 52)* at this time to identify your coping strategies.

In order to utilize any of these coping strategies you'll recognize that it's necessary to take time for yourself. Often parents who have children with disabilities fail to take this time because of the many demands placed on them. Encourage parents to take time for themselves — time to recharge their battery so they have the energy to continue the many daily demands. Taking time is important for all parents, but is particularly important for parents of children with disabilities. Support families by giving them permission to "take a break" and by providing them with resources in the communities that they can access as needed.

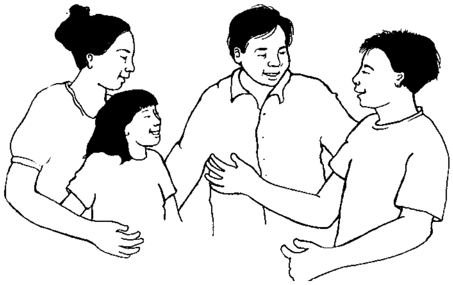
Understanding Cultural Diversity

As professionals, its impossible to know everything there is to know about the many cultures represented in our society. However, professionals must develop cultural sensitivity. This means, *"…having knowledge that cultural differences as well as similarities exist…being aware of the cultures represented in one's state or region, learning about some of the general parameters of those cultures, and realizing that cultural diversity will affect families' participation…"*

Cultural differences may have an impact on the following issues that are of interest to professionals working with families who have children with disabilities: the meaning of a disability, childrearing practices, views of medicine and health care, willingness to seek help, views of intervention, communication style, amount, type of participation, and family member involvement. It's important not to make assumptions about a family's beliefs, concerns, priorities or resources. Meet with families, discuss issues with them and let them provide the information that is needed in order for you to work effectively with their family.

Strategies for Working With Families Who Have Children With Disabilities

It is helpful to recognize that all families have likenesses, but it's also important to understand that families have differences too. Families who have children with disabilities have some unique, challenging needs that are very different from other families. Sometimes in our efforts to include all parents by recognizing likenesses, we underestimate the challenges these families must face. Families want to be included; they want their children to be part of the group. They do not want to be known only as *"the Xiong family who has a child with Cerebral Palsy."* Each family has many attributes and should be recognized by many of them, not just one. They also want to be understood. Families who have children with disabilities report feeling alone and isolated. This comes from people avoiding them because they do not know what to say or do. It comes from the family not knowing to whom to turn for help or support. Families could gain important information in parent and family education which would support them in both of these situations.



Family Systems

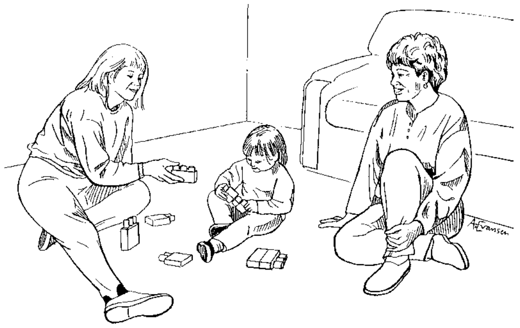
It's helpful to view families who have children with disabilities from a family systems perspective. This theory views the family as an interacting and reacting system which is balanced and strives to maintain its balance. When there is a change or problem with one of the members of the system, this change affects the entire system. (Linder, 1983) Having a child with a disability affects all of the family members in the system in ways that may be positive or negative. The roles that are defined within a family system often must be changed when a child with a disability comes into the system. For example, Joey may need therapy three times a week; who is going to do it? Joey may need considerable help with eating, bathing, dressing, etc. How will they find time? Parents need to add these and other tasks to their roles and fit them into their schedules or designate other family members to help. Parents have reported that one of the biggest stressors they have are the daily caretaking demands which often do not diminish for years. One mother, stressed from the overload of daily demands, said to a professional, *"…there is no time in my life that hasn't been spoken for, and for every 15-minute activity that is added, one has to be taken away."* One solution is for professionals to help find ways for parents to work with their child during routines that need to be done anyway *(e.g., language during bath time, therapy during diaper changes).*

Brothers and Sisters

As members of the system, brother and sisters are also affected. They are asked to help in a number of ways in order for the family to get everything done so it can maintain balance. While all members of a family system can be expected to help, it's important that the amount of help isn't excessive. Studies have indicated that in families who have a child with a disability, the oldest female sibling is generally expected to help with caretaking and is often overburdened with responsibility. Parents may not recognize that they are expecting too much or that their other children's needs are not being met. For families, these changes in expectations evolve slowly over time and may become excessive without anyone intending for this to happen. Siblings need time of their own, time to be with their parent or parents and have their own needs met. When there are other children, encourage parents to regularly take time for them either individually or together. Give the parents permission to leave their child with a disability in order to give quality time to their other children. Encourage using respite care if it's available. Training sitters to care for their child may be necessary. While this is time consuming, the benefits are enormous. Professionals may play a role in this training. The child with the disability also gains by making new friendships and having special attention for a period of time.

Family-Centered Approach

When we work with families the preferred approach is family-centered. This means that the family is recognized as the constant in the child's life and drives any decision-making. It means that professionals recognize family strengths and honor their choices. In other words, the professional does not judge what a family needs; rather the family indicates what it needs and what is realistic for their system. For example, when using a family-centered approach, the professional would tell the family about a number of resources that are available in the community and the parents would indicate if they wanted to access any of them. In comparison, a professionally-centered approach is where the professional gives the parents the schedule of the support group and expects them to be there because they have a child with a disability! The parents are partners in a family-centered approach and they are in the "driver's seat" when it comes to deciding what supports and services they need. While professionals have expertise in their areas of training, parents are recognized as the experts with their child and with what goes on in their home and in their community.



Training in the past was professional-centered. The professional was seen as the expert and the most qualified to define any problems, and parents were pretty much told what should be done. Over the years, parents became more involved, but at first the families were only permitted to take part in fundraisers and be on advisory boards! As professionals began to recognize the importance of family participation, we became more family-focused, meaning the family's needs related to the child's development were recognized and professional services were provided to meet these needs (e.g., respite care, transportation). The family-centered approach recognizes parents' strengths and the importance of working as a team. To help determine if your program is family-centered, do the activity, *Is Your Program Family-Centered? (FI-P/CD p. 53)*. Give yourself a "pat on the back" for all of the family-centered practices that you are using and continue to strive for a family-centered approach.

Developing Interpersonal Trust

An important step in forming a partnership, with the parents with whom we work, is developing a trust relationship. This relationship provides the condition for change and growth. Trust is a belief that the other person will act honestly and can be depended upon. Three basic components are involved in developing this trust relationship:

- **Creating conditions of safety.** This refers to both the professional's behavior and the environment. The professional must be comfortable with him/herself and not put on a façade. Rather a warm and positive demeanor is important. In regard to the environment, it has to be a safe place to share information. A place where others will not interrupt by walking into the room, or where others won't overhear the conversation.
- **Providing a model for self-disclosure.** Self-disclosure is sharing personal information with the parent with whom you are communicating. It's important that professionals be willing to share. By modeling this sharing, it increases the probability that the parent will also share. It's extremely important that the professional does not share too much as this takes the focus away from the parent and defeats the purpose of the self-disclosure.
- **Providing reinforcement when risk-taking does occur.** When a parent takes the risk to share, it's imperative that the professional reinforce that risk. This reinforces the probability that the parent will share again. For example, a professional might say, *"I know that was difficult for you to share with me, but now I will have a better understanding of your child and I'll be able to work more effectively with him."* When parents hear comments such as this, they feel good that they shared the information, even if it was difficult, and will be willing to share again.

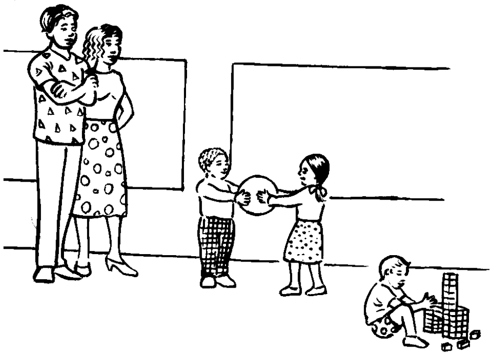
Validation of Feelings

When parents take the risk to share how they feel, it's important for professionals to validate their feelings. You might say, *"I can see why that made you angry,"* or *"Those are tough behaviors to live with; I can see why you're frustrated."* Parents report that it offends them when professionals indicate that they know or understand what they are feeling when the professionals in fact, have never had to live with their particular situation. Remember not to say, *"I know how you feel,"* unless you have actually "been there." Our ability to communicate with parents is very important in developing a trust relationship and a partnership. As a reminder of the skills you need in order to communicate well, do the *Excellent Communicator Exercise (FI-P/CD p. 54).*

Integrating Parents Into the Group

Adaptations

Parent educators need to be flexible and willing to adapt the content or the processes utilized during classes. For example, a parenting strategy is being discussed *(e.g., toilet training)* that may or may not be appropriate for the parent whose child has a specific disability. If the strategy is not appropriate, brainstorm with parents other possible strategies that might be helpful to this parent. If you are unsure of an appropriate strategy, check with your special education resource so you can have additional information for this parent at the next class.



Another example involves the many parent education classes that ask parents to observe their children noting the child's development, skills and interactions. Parents who have children with disabilities can participate in this observation. However, even though parents know their child is delayed, keep in mind how difficult it is to observe your child in activities with others when he or she is behind everyone else and has difficulty doing many of the activities. This can be very depressing with a parent benefiting little from this activity. Adapting this observation task so a staff person is available to support this parent and others throughout the observation would increase its effectiveness. The staff person could point out what the child can do and how his skill level fits into the total developmental sequence. In this way, the parents can see some progress or success even if their child is delayed from the rest of the group. The parents would gain insights into the child's developmental pattern through this activity.

Appropriate Expectations

Parent educators often encourage parents to take materials home with them to use with their children before the class meets again. While we recognize that all parents have busy home schedules, parents of children with disabilities may have even busier schedules because of their child's unique needs or excessive caretaking demands. We must strive to have appropriate expectations for all families. It's important that parents be given choices whether or not they want to take materials home. Be sure to recognize the pressure parents might be receiving from other parents. For example, you may be giving the choice of taking materials, however, if almost all parents are taking them, a parent who does not want materials might feel pressure to participate. Instill in parents the need for them to do what is appropriate for their family. Be sure to periodically give parents a break from "homework." Instead, encourage parents to read to their child every day or take nature walks.

Keep Reality-Based

It is very easy for parents of children with disabilities to assume that many of their family difficulties or challenges are because they have a child with a disability. As a parent educator, it's important that you help parents understand which behaviors occur because of typical development. For example, a parent might think all of the sibling fighting is because of Suzy, who has Down syndrome; another parent might think her infant cries because she has spina bifida. When in reality, all siblings fight; parents need us to show their children more appropriate ways to vent feelings and frustrations. And babies cry; some more than others! Often, brothers and sisters become so familiar with the child with the disability that they treat the child like they would any other sibling without a disability. Consequently, they fight with them! This shows a wonderful level of acceptance and should be encouraged unless the child has specific health or developmental problems that require special treatment.

Group Discussion

During the parent discussions, issues of concern to all parents should be discussed. The parents of the child with the disability will ask questions that address their child's unique needs. If the information would benefit the group, or if it only requires a short reply, you should answer the question. Remember this is also a time for parents of children without disabilities to learn! On the other hand, if the question is very specific, if you don't know the answer or it isn't appropriate to take the time away from the group, you should acknowledge the importance of the question, validate the parent's feelings and indicate how the question will be answered at a later time. If you are able to answer the question, indicate to the parents that you would be happy to spend some minutes after the general discussion to answer their question. If you are unable to answer their question, give the parents the name of a resource person they can call, or you contact your resource person and have the answer for them at the next session.

Resilience of Families Who Have Children With Disabilities

Garmezy defines resilience as *"the tendency for a child, or family to rebound from stressful circumstances or events and resume usual activity, accord, and success. Resilience is the power of recovery."* Resilient families are able to balance the demands of having a child with special needs with the other needs of the family. They tend to be realistic and flexible and find ways to incorporate the special needs of their child into their daily routines.

According to Patterson, resilient families are able to establish priorities and protect their sense of identity by maintaining normal family routine. They are able to protect themselves from too much outside intrusion. They learn about the disability, find the needed services, and balance the other needs of the family. However, families experiencing stress can get out of sync. When the marriage and the family is provided enough time, is nurtured and supported, it is better able to adapt. Developing a positive view of the child's condition or acknowledging positive contributions that the child has made to the family also promotes adaptation. It's important that families maintain their social network, discovering and utilizing sources of support from within and outside the family.

What can professionals do to promote resilience? They can:

- ➠ Provide support to families by making parents aware of available resources.
- ➠ Encourage families to take time for themselves.
- ➠ Help parents gain a positive view of their child; help them see positive contributions the child has made.
- ➠ Encourage parents to utilize their social network *(i.e., friends and relatives)*.

Often parents get overloaded with the demands of having a child with a disability and need someone to remind, encourage and support in these ways. Share the handout, *Reminders for Resilience (FI-P/CD p. 55-56)* with your parents for additional reminders. The worksheet, *Planning for Resilience (FI-P/CD p. 57)* can also be used when time allows.

In order for parent and family educators to include families who have children with disabilities successfully, there has to be a commitment to understand the families' unique needs and a willingness to adapt current programming. It's also important to develop an awareness of services in your community that can provide support to families. Staff needs to be respectful, treat families individually and recognize the challenges they face each and every day. The handout, *Guidelines for Working Effectively with Families (FI-P/CD p. 58)* provides important reminders for staff. In addition to the references below which provide the research-based foundation for the issues discussed in this *Focus Issue*, there is a list of *Recommended Resources (FI-P/CD p. 59-60)* for professionals and parents who have children with disabilities.

Note: See also the August 2005 interview with Peggy O'Toole-Martin, *Supporting Families of Children With Special Needs* and the March 2005 interview with Ted Bowman, *Finding Hope and Healing When Dreams Are Lost*, in the **FIS 2005 Online Collection** (**www.familyinfoserv.com**).

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Moses, K.L. (1983). *The impact and initial diagnosis: Mobilizing family resources.* In J.A. Mulick and S.M. Pueschel (Eds.) **Parent-Professional Partnerships in Developmental Disability Services** (pp. 11-34). Cambridge: The Academic Guild Publishers.

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Editor's Note: See also *Supporting Families of Children With Disabilities,* an interview with Peggy O'Toole-Martin in **Family Information Services 2005 Online Collection**. *(People & Programs* section interview, transcript and handout materials.)

“Person First” Language

The philosophy of using “person first” language demonstrates respect for people with disabilities by referring to them first as individuals and then referring to their disability when it is needed. In addition, words that conjure up stereotypes or pity are eliminated *(e.g., afflicted, cripple, victim)*.

Examples of “person first” language:

Use this:	**Instead of this:**
“Child has a disability”	*“Disabled child”*
“Man who is blind”	*“Blind man”*
“Child has Down syndrome”	*“Down syndrome child”*
“Baby addicted to crack”	*“Crack baby”*
“Child with retardation”	*“Retarded child”*
“Boy with a physical disability”	*“Crippled boy”*

Usually a form of the verb “to have” is the most effective way of expressing the link between a person and a disability. Such as: *“has autism”* instead of *“is autistic,” “has spastic muscles”* instead of *“is spastic,” “has epilepsy”* instead of *“is an epileptic.”*

Disability vs. Handicapped

A disability is defined as a condition of the person, either emotional or physical. A handicap is the result of barriers imposed by society which come between the individual and the environment *(e.g., a curb but no ramp for a wheelchair)*. It’s possible that a disability does not have to be a handicap! Rather, a person may do something a little bit differently than a person without a disability, but with equal participation and equal results.

Use this:	**Instead of this:**
“The boy with a disability”	*“The handicapped boy”*
“Children with disabilities”	*“Handicapped children”*
“Peers without disabilities”	*“Non-handicapped peers”*

Normal Child or Person

The difficulty with using the term “normal” to refer to a person without a disability is the inference that a person with a disability is “abnormal” or “not normal.” When using these terms be careful to indicate that you are talking or writing about development and not a person or program.

Use this:	**Instead of this:**
“normal development”	*“normal child”*
“child without a disability”	*“normal child”*
“mainstream classroom”	*“normal classroom”*

“refer to specific development” (e.g., normal hearing, normal vision)

> *“We have a choice to continue to send negative messages which will be harmful to persons with and without disabilities, or we can accept the challenge and change our language which has the potential to positively impact society.”* (Dr. Joan K. Blaska)

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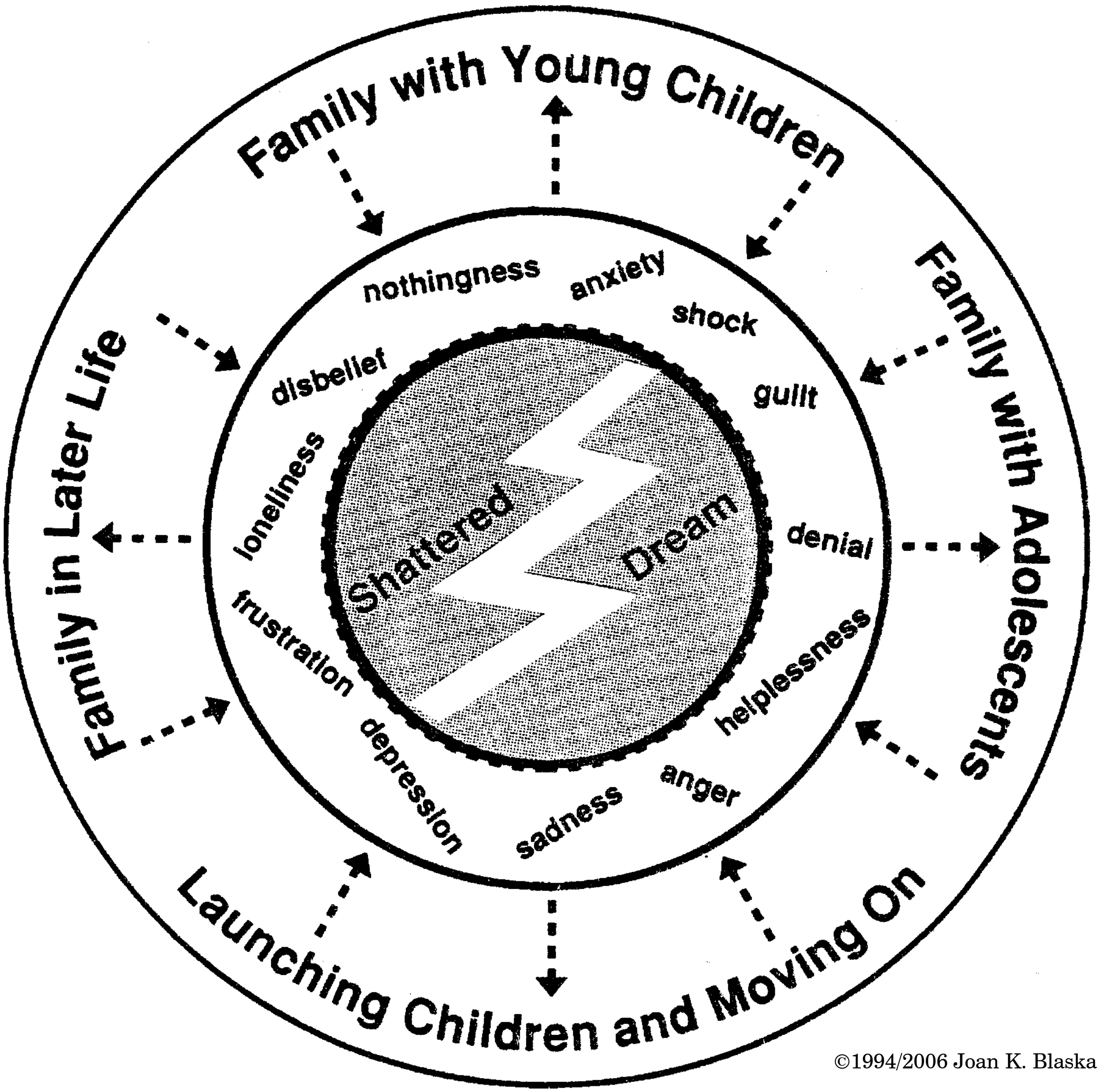
Cyclical Grieving Model



Inner circle — Shattered Dream

Middle circle — Reoccurring Emotions

Outer circle — Intermittent Grieving
Throughout the Life Cycle of Family

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Cyclical Grieving

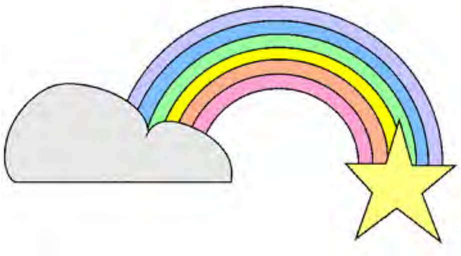
Parents who have children with disabilities experience the emotions of grief as they cope with the loss of the child they had dreamed about and anticipated. Their dream has been shattered. The severe loss they experience is the loss of their dream child. Grieving helps parents let go of their dream and eventually become able to refocus and dream new dreams for the child that they do have. Emotions appear with a parent experiencing one, two or more simultaneously.

Cyclical grieving is the intermittent reoccurrence of one or more emotions, which are part of the grieving process and experienced by parents who have children with disabilities. Cyclical grieving occurs throughout the life cycle of the family and is triggered by a variety of events. Parents have reported that significant events (such as a child needing surgery in order to walk) as well as seemingly insignificant events (seeing a child at the grocery store who is developing typically) as triggers for grieving. The seemingly insignificant events were significant to some parents based on their perception of the event. It is difficult if not impossible to predict which events or developmental changes will act as catalysts to grieving. The reoccurrence is unique to each parent and is influenced by his or her perception of the event.

The frequency of cyclical grieving and the intensity of the feelings diminish with the passage of time. During the days, weeks, and months when grieving is not occurring, parents are free of the feelings of grief. The occurrence of cyclical grieving does not preclude parents from loving their child and deriving joy from their child's development and achievements. Parents are busy working toward understanding and accepting their child who has the disability, reorganizing their lives to cope with whatever demands are placed on them, celebrating accomplishments and dreaming new dreams.

Grief is a human emotional reaction to severe loss.

Each of us can actively
work through
the grieving process
by being
aware of it,
understanding it,
and trusting it.



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Stress-Coping Activity

Think of a stressful event that has happened to you within the last month or two. What did you do to cope with this stress? Identify what you DID, which means your *actions,* not feelings.
List your actions in the first column.

Stressful Event: ____

List Your Actions:	**Identify the Coping Strategy:**

For each *action* in the first column, identify into which of the five coping categories it belongs. List the categories in the second column. For example, if the action you took to relieve your stress was, *"talked to a friend,"* this would be **social support**. If the action was, *"went jogging,"* this would be **passive appraisal.** If you *"said some prayers,"* this would be **spiritual support**. An action may fit into more than one category.

By doing this exercise, it's possible to gain a better understanding of how you tend to cope with stress. By analyzing your actions, you may also discover that there are other coping strategies that you could also be using.

The Five Coping Strategies

- **Passive Appraisal** — ignoring the problem
- **Reframing** — looking in a new or different way
- **Spiritural Support** — belief in a greater power
- **Social Support** — practical and moral support
- **Formal Support** — help obtained from professionals

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Is Your Program Family-Centered?

To determine if your program is family-centered, professionals and parents can respond to each statement by circling: **Always, Sometimes**, or **Never**.

1. Families in our program generate all (or most) of the topics discussed.

Always **Sometimes** **Never**

2. Our program is more than willing to deviate from the planned topic to discuss an unplanned topic of importance.

Always **Sometimes** **Never**

3. Our program provides support to families by providing sibling care.

Always **Sometimes** **Never**

4. Our program provides support to families by loaning materials and toys.

Always **Sometimes** **Never**

5. Our program stresses that families should decide if they want to take home activity kits. Families are supported if they do not want to take one home.

Always **Sometimes** **Never**

6. Our program encourages parents to take a break from activity kits and encourages walks, reading stories, etc.

Always **Sometimes** **Never**

7. Parents have input into the activities and materials available for their children.

Always **Sometimes** **Never**

8. Our program provides both home- and center-based programs.

Always **Sometimes** **Never**

9. Our program collaborates with other agencies in our community to provide comprehensive community-based services for families and their children.

Always **Sometimes** **Never**

10. Our program provides information to families, but the families make all decisions regarding their children.

Always **Sometimes** **Never**

Scoring: Give yourself **2 points** for each time you marked **Always**. Give yourself **1 point** for each time you marked **Sometimes**. Give yourself **0 points** for **Never**. If your score is:

Between **12** and **20**	*You are providing family-centered services.*
Between **8** and **11**	*You are well on your way to becoming family-centered. A plan to rethink your program philosophy and shape current practices will help you move toward more effective family-centered programming.*
Below **8**	*Talk with the families who use your services. Listen to their perspectives, needs and ideas. There is usually a way to become more family-centered in your practices.*

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Excellent Communicator Exercise

Think of a person whom you feel has excellent communication skills. First, take some time to think about how this person makes you feel. List these feelings in the first column. Next, think about the behaviors this person displays that make you have these positive feelings. List the behaviors in the second column. *After completing both columns, look over your lists.*

Feelings:	**Behaviors:**

What you have identified are the behaviors **you need to display** in order to make the people with whom you communicate have positive feelings similar to those you experienced.

Good communication skills can be learned and are essential
if we want to work effectively with parents and families.

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Reminders for Resilience

Resilience is "the tendency for a child, or family to rebound from stressful circumstances or events and resume usual activity, accord, and success. Resilience is the power of recovery." (Dr. Norman Garmezy)

Take Time for Yourself!

It's important to take time for yourself to recharge your battery. It's necessary as parents are the most important persons in a child's life and you want to continue to be there for your child. Recharge so you can continue to have energy and enthusiasm. Stress is a part of life. What are you doing to help relieve yours and recharge? Life is full of commitments and your child with the disability is a part of your life and one of your commitments. Take time to focus on other aspects of your life that are also important to you as a person, such as special people, events, and hobbies. Take time for you! This isn't a luxury — rather a necessity.

Understand Yourself!

Be honest about the cyclical feelings you have regarding your child. Be patient with yourself and your spouse or significant other. Employ coping strategies that work for you such as time alone, running, reading, a night out, or time with a friend. Taking time for you also helps reduce stress.

Be Sensitive to Family Members!

Be sensitive to grandparents and other family members and their reactions to your child. They need time to work through their feelings too. They also need information about the disability and time with your child in order to understand, feel comfortable, and develop a relationship. Invite them to go to a doctor's appointment or a team meeting. They will feel included and at the same time will be learning about your child's capabilities and needs. Try to remember that most often they don't know what to say or do but really want to help and support you.

Who Is Important?

While your child with the disability is very, very important, he or she is no more important than your other children. Plan quality time with each of your other children and with your spouse or significant other; do this frequently.

Enjoy!

Take time to enjoy your child. Work to see your child as a person first who happens to have a disability. Take frequent breaks from teaching and training your child. Remember, every encounter does not have to be a time for teaching. Play together. Laugh together. Rejoice in your child's accomplishments, however large or small.

Be Willing to Ask for Help!

None of us were trained to be parents, more importantly, to be parents of children with disabilities. Sometimes we need help in knowing what to do or how to do it. Other times, we need help by getting a break from the daily demands. Be willing to admit that you need help. This is not a sign of weakness, rather a sign of strength because you are aware of your needs and those of your family. Be willing to use respite care. See the value for you and your family as well as the value for your child, such as new places, new friends, and special attention.

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Respect Your Child!

Respect your child and his/her abilities. Work to have appropriate expectations which will help your child grow and develop to the best of his/her ability. Be proud and celebrate these gains, however small they may be. Demonstrate respect by having expectations, giving responsibility and promoting independence.

Advocate for Your Child!

Advocate by understanding your child's need, knowing what is available for services and how to access them. Be assertive, NOT aggressive! While life isn't perfect for any of us, we must continue to have hope for the future. Be optimistic yet realistic in your dreams. Dream new dreams!

Work as a Team With Professionals!

Strive to work as a team player with professionals. Be honest. Communicate openly. Be willing to say, *"Enough!"* or *"That won't work in our home."* On the other hand, be willing to try new ways and take some risks. At the same time, remember to thank the professionals with whom you work.
Let them know how much they have helped you and your child. Remember, professionals invest a lot of their energy too. Remember, a strong team gets the best service for your child.

"Your life should be made up of many people, places and events.
Let your child who has a disability, be an important part of that life;
but not the only part." (Dr. Joan K. Blaska)

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Planning for Resilience

Take time for yourself —

Identify *two things* you would like to do for yourself **as soon as possible**:

1. ____

2. ____

Identify *two things* you would like to do for yourself **sometime in the future**:

1. ____

2. ____

Take time for your children —

What are *two things* that you could plan to do with your other children?

1. ____

2. ____

Enjoy —

What are *two things* that you could do just for fun with your child who has the disability?

1. ____

2. ____

Ask for help —

Identify *two people* you can turn to for help:

1. ____

2. ____

Respite care —

Identify *two people* who can baby-sit or do respite care for your child with the disability?

1. ____

2. ____

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Guidelines for Working Effectively
with Families of Children with Disabilities

1. Understand how your **VALUES** and **ATTITUDES** affect the way you interact and work with families. Work to understand other's values but don't set out to change everybody.
2. Develop your own **COMMUNICATION SKILLS** so that you are skillful and effective at listening, interviewing, conveying sensitive information, and working with parents as team members and partners.
3. Demonstrate utmost **RESPECT** to the children and families with whom you work. *"Respect begets respect."*
4. **EMPOWER** the families with whom you work by providing them with information and helping them develop skills so they can act on their own behalf.
5. Be proactive. Help families see existing **STRENGTHS** and actions that can be taken. Avoid the deficit model mentality.
6. Remember that all families with children who have disabilities are not homogeneous, rather a heterogeneous group with individual strengths and needs. Remember to **INDIVIDUALIZE** not generalize.
7. When parents are willing to express how they feel, provide support by **VALIDATING** their feelings, but do not indicate that you know how they feel unless you have actually been there. Have you *"…walked in their shoes?"*
8. Be **NONJUDGMENTAL** in your actions when working with families. Most things in life can be done in more than one acceptable and effective way. It may be different than your way, but is it wrong?
9. Be **SENSITIVE** to the needs of all individuals within the family system. Be knowledgeable and prepared to provide resources and make referrals.
10. Understand the cyclical nature of grieving so you are able to appropriately **SUPPORT** the families with whom you work.
11. When working with families from a **RACE** or **CULTURE** different from your own, educate yourself so you understand their beliefs including their view of having a child with disabilities.
12. Utilize a family-centered approach. Recognize parents as the **DECISION MAKERS**. You provide information, parents make the decisions.
13. Understand the unique needs of each family which will enable you to have **APPROPRIATE EXPECTATIONS** regarding the children and families with whom you are working.
14. Help families identify and utilize **EXISTING SUPPORT SYSTEMS** and help develop new ones as needed.
15. Support children with disabilities and their families by **ADVOCATING** on their behalf.
16. Be supportive to families as this helps them to be **RESILIENT**. Resilience is the ability to bounce back from stress.

This list is NOT presented in order of priority, rather all guidelines are important when working with families and should be happening simultaneously.

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Recommended Resources

for Professionals and Parents Who Have Children With Disabilities

Baskin, A., & Fawcett, H. (2006). ***More than a mom: Living a full and balanced life when your child has special needs***. Bethesda, MD: Woodbine House.

Batshaw, M.L. (2001). ***When your child has a disability: The complete sourcebook of daily and medical care*** (rev. ed.). Baltimore, MD: Paul H. Brookes Publishing Co.

Blaska, J.K. (2003). ***Using children's literature to learn about disabilities and illness*** (2nd ed.). NY: Educator's International Press. (Book lists and methods.)

Brill, M. (1994). ***Keys to parenting the child with autism***.
Hauppauge, NY: Barron's Educational Series, Inc.

Bruey, C.T. (2004). ***Demystifying autism spectrum disorders: A guide to diagnosis for parents and professionals***. Bethesda, MD: Woodbine House.

Bruni, M. (2006). ***Fine motor skills for children with Down syndrome: A guide for parents and professionals*** (2nd ed.). Bethesda, MD: Woodbine House.

Deiner, P.L. (2005). ***Resources for educating children with diverse abilities: Birth through eight*** (4th ed.). NY: Thomson/Delmar Learning. (Curriculum ideas.)

Geralia, E. (1998). ***Children with cerebral palsy: A parent's guide*** (2nd ed.).
Bethesda, MD: Woodbine House.

Gill, B. (1997). ***Changed by a child: Companion notes for parents of a child with a disability***.
NY: Doubleday. (Helpful notes from parents.)

Haerle, T. (Ed.) (1992). ***Children with Tourette syndrome: A parent's guide***.
Bethesda, MD: Woodbine House.

Hanson, M.J. & Lynch, E.W. (2004). ***Understanding families: Approaches to diversity, disability and risk***. Baltimore, MD: Paul H. Brookes Publishing Co.

Harris, S.L. (2003). ***Siblings of children with autism: A guide for families*** (2nd ed.).
Bethesda, MD: Woodbine House.

Holbrook, M.C. (Ed.) (2003). ***Children with visual impairments: A parent's guide*** (2nd ed.).
Bethesda, MD: Woodbine House.

Klein, M.D.; Cook, R.E. & Richardson-Gibbs, A.M. (2001). ***Strategies for including children with special needs in early childhood settings***. NY: Thomson/Delmar. (Curriculum ideas and methods.)

Klein, S.D. & Schive, K. (2003). ***You will dream new dreams: Inspiring personal stories by parents of children with disabilities***. NY: Kensington Books.

Korn, D. (2001). ***Kids with celiac disease: A family guide to raising happy, healthy, gluten-free children***. Bethesda, MD: Woodbine House.

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Kumin, L. (2003). ***Early communication skills for children with Down syndrome: A guide for parents and professionals*** (2nd ed.). Bethesda, MD: Woodbine House.

Martin, S. (2006). ***Teaching motor skills to children with cerebral palsy and similar movement disorders***. Bethesda, MD: Woodbine House.

McAnaney, K. (1993). ***I wish...Dreams and realities of parenting a special needs child***. Sacramento, CA: United Cerebral Palsy Association of California. (UPSC 916-442-3573).

McDonnell, P. (1997). ***News from the border***. Northfield, MN: Black Willow Press.
(Mother raising son with autism.)

McHugh, M. (2003). ***Special siblings: Growing up with someone with a disability***. Baltimore, MD: Paul H. Brookes Publishing Co.

Meyer, D.J. (Ed.). (1995). ***Uncommon fathers: Reflections on raising a child with a disability***. Bethesda, MD: Woodbine House. *(Fathers tell their stories.)*

Miller, N.B. (1994). ***Nobody's perfect: Living and growing with children who have special needs***. Baltimore, MD: Paul H. Brookes Publishing Co.

Naseef, R.A. (2001). ***Special children: Challenged parents: The struggles and rewards of raising a child with a disability*** (rev. ed.). Baltimore, MD: Paul H. Brookes Publishing Co.

Powell, T.H. & Gallagher, P.S. (1993). ***Brothers and sisters: A special part of exceptional families*** (2nd ed.). Baltimore, MD: Paul H. Brookes Publishing Co.

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