Early Intervention Colorado
for Infants, Toddlers & Families

An Academy for Developmental Intervention Assistants

Working With Families

Instructor's Guide & Handouts

Module A: Understanding the Evolving Concept of Family through a Cultural Lens

Module B: The Impact of Illness and Identified Disability on Family Life: Cross Cultural Perspectives

Module C: Cultural Responsiveness: Supporting Each and Every Family

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Working With Families

This manual is accompanied by a PowerPoint document titled, "Working With Families Slides**" that the instructor may project or prints slides and convert them into transparencies to project them using a traditional overhead projector.*

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Technical Support for CO-TOP*EIS Academies

The following technology information is to assist with using the video clips within the slides of the CO-TOP*EIS Instructors' Manuals.

You must have Media Player for viewing (Windows & Mac versions available). We also recommend using external speakers for your computer.

To view a video, you must have Media Play installed on your computer. Media Play operates on Windows and Mac systems and is available FREE. To obtain Media Player visit:

http://www.microsoft.com/windows/windowsmedia/player/10/default.aspx

We also highly recommend using external speakers connected to the computer when playing the video clips for increased amplification of sound.

Academy Introduction

This academy is designed to assist the Developmental Intervention Assistants (DI Assistants) consider the concepts of family, culture, cultural and linguistic differences and the issues and concerns that can arise when one attempts to build relationships with families from cultures different from one's own. Issues of stereotyping, the danger of assumptions and misunderstandings or lack of appropriate communication can interfere with the positive outcomes for both children and families involved in early intervention services at home, in childcare or in other settings.

The instructor's role in this academy is to share information and promote in-depth reflection and discussion about what it means to build relationships with each and every family you serve. Explorations of differing perspectives of the participants about their own specific beliefs about life ways, child rearing practices, and other factors that influence family's lives and decision-making will enhance understanding of the need for "unconditional regard", and developing the listening skills necessary to support families. A series of videos/DVDs are suggested and provide the foundation for many discussions and self-reflections. Because of the nature of this academy, it is strongly recommended that the instructor reads through the entire academy and views DVDs and reviews prepared scenarios and handouts for facilitated discussion.

It is important for the instructor to be mindful that the role of the DI Assistant is limited. They are not prepared to counsel, refer, or provide information to the families they are working with independent of their supervisor and team members. Although they will be working with families in their homes, potentially working with children in child care situations or in group programs with toddlers, DI Assistants need to be continually reminded they cannot make independent decisions about what the family needs or provide information without first consulting with their supervisor and other team members. Given the DI Assistant's role to extend services and supports provided by the EI Team, they must be constantly reminded of their need to use their knowledge and strengths as a "team member" and not an independent support for the family. They might be considered to be another pair of "eyes and ears" with their team as they interact with children and families in implementing the goals of the IFSP. In this regard, it is critical that they learn "to read family member cues", to understand how the life ways, values, beliefs, and other influencing factors impact a families ability to thrive. With this information, DI Assistants can better understand how they can communicate with their team to improve services and supports for both children and families they work with.

While many of the activities in the academy assume that the participants are in DI Assistant positions, your audience may consist of in-service DI Assistants as well as those who haven't been in DI Assistant positions. You may advise the latter group to reflect on their previous work experience or any related experience with infants, toddlers, and families with children with special needs.

This manual is accompanied by a PowerPoint document titled, **"Working With Families Slides"** that the instructor may project or print slides and converts them into transparencies to project them using a traditional overhead projector. The Power Point document also provides information and resources to enhance participant understanding of key materials.

Note to Instructor:

At the beginning of the training, advise participants to procure a three-ring binder to keep handouts, personal notes and materials used in the class. It is recommended that the instructor brings a three-hole punch to class for participants' use or make sure that all handouts are run on three-hole paper.

In this academy the participants will be required to write their reactions and reflections to the materials presented. It is therefore, recommended that they create a separate section as a journal in their notebooks for this purpose.

A. Discussion: Logistics & Norms (Slide 2)

At the beginning of the training:

- Welcome participants and introduce yourself as the instructor(s).
- Give them a brief overview of which you are, where you are from, and information about your background that is relevant to this teaching this academy.
- Have participants at each table introduce themselves (who they are, where they work, and what they do)
- Explain the concept of establishing group norms with regards to what participant behavior is considered acceptable and valued by the class (e.g. respects others, increases productivity, reduces annoying disruptions) and encourage participants to contribute one norm they consider important (e.g. no side conversations, stick to the schedule etc.).
- Address logistical issues (e.g., breaks, bathrooms, lunch plans).
- Encourage participants to ask questions throughout or to post them in a specially marked place (parking lot).

B. Academy Goals

Using **Slides 3-5** and Handout **H1**, review the modules with the DI Assistants at the beginning of class.

Module A: Understanding the Evolving Concept of Family through a Cultural Lens (5 hrs)

The DI Assistant will:

1. Describe what makes a family and the different family constellations.
2. Explore and strengthen the understanding of the concept of Family-Centered Practices.
3. Describe cultural differences, the danger of stereotypes as a barrier to individual consideration.
4. Identify challenges and barriers to building relationships given linguistic diversity among families.
5. Identify socioeconomic factors that frame a family picture.

Module B: The Impact of Illness and Identified Disability on Family Life: Cross Cultural Perspectives (5 hrs)

The DI Assistant will

1. Recognize the family as a system that changes over time.
2. Identify stages and characteristics of the grieving process and how it might apply to families with infants with developmental disabilities.
3. Identify factors of strength and resilience in families that DI Assistants can support.

Module C: Cultural Responsiveness: Supporting Each and Every Family (5 hrs)

The DI Assistant will

1. Explore the vision of supporting infants and toddlers with identified challenges and their families in inclusive settings.
2. Develop an understanding of the importance of listening to family perspectives and stories.

3. Examine the strengths and limitations of DI Assistant role in connecting families with team resources and community supports.
4. Develop an understanding of the concept of family leadership and its impact on the family.

Module A: Understanding the Evolving Concept Of Family through a Cultural Lens

Instructor's Guide

Working With Families

Module A: Understanding the Evolving Concept of Family through a Cultural Lens

A. Energizer: What is Meaningful to You?

DI Assistants will participate in an activity that provides an opportunity to share something about them and sets the stage for discussing differences as valued aspects of themselves.

A.1 Steps

- Show **What is Meaningful to You?** slide **(Slide 6)**
- Have participants take something out of their purse or backpack that is a symbol or representative of an aspect of their life.
- Ask them to reflect on the item they have chosen and why it is meaningful or what it represents.
- Share the items with a person sitting close to them.
- Ask for a few participants to share their "story" of the item with the larger group.
- Ask what they learned from this activity. Possible responses could include:
    - Everyone has meaning and substance in their lives
    - Some value similar items or representations about themselves
    - Some items chosen were unique and important to that individual
    - If someone showed a picture or gift from a family member, it speaks to the importance of family and relationships. (If they did not choose anything of this nature, then model by choosing something of your own, as the instructor that will illustrate this.

B. Module Goals:

Using the **Module a: Understanding the Evolving Concept of Family through a Cultural Lens** handout and **(H1, page 55 /Slide 7)**, review the goals of the module. Describe what makes a family and the different family constellations.

The DI Assistant will:

1. Describe what makes a family and the different family constellations.
2. Explore and strengthen the understanding of the concept of Family-Centered Practices.
3. Describe cultural differences, the danger of stereotypes as a barrier to individual consideration.
4. Identify challenges and barriers to building relationships given linguistic diversity among families.
5. Identify socioeconomic factors that frame a family picture.

Goal 1: Describe what makes a family and the different family constellations.

The purpose of this section it to help participant develop an understanding that there are two parent families, single parent families, blended families, some with multiple generations living together or apart, some with children and some without. It is important to learn more about the same or differing constellations of families and how the concept of family may change over time if one is to work with children in the context of their family.

1.1 Activity: Who Is In My Family?

The DI Assistants will participate in an activity to identify and define "Who is in my family?"

1.1.1 Steps.

- Show **Families** slide **(Slide 8)** with pictures of families and present that families come in all shapes and sizes.
- Show **Who is in your family?** slide (**Slide 9**) and distribute plain white sheets of papers and markers, pencils and/or pens and give the following directions for the activity.
- All participants draw who is in their family.
- The drawing is meant to depict who is in their current constellations as family members and can of course include whomever they consider to be part of their family.
- They can use diagrams, stick figures, shapes and/or other symbols to represent "who are the members of your family."
- Allow time and encourage all participants to complete the task.

1.2. Discussion: Similarities and Differences of the Concept of "Family"

- Show **Similarities and Differences** slide (**Slide 10**) and ask each participant to share their picture with the person next to them.
- Ask them to identify similarities and differences among their family constellations:
  - Race
  - Culture
  - Family constellation (single parent, nuclear, extended, foster families, families with adopted children etc)
  - Heritage
  - Other considerations
- Debrief with larger group examples of similarities and differences and if cultural and/or linguistic differences apply. Use "stories" or examples shared by participants to make points about families.
- Show **Take Away Message** slide (**Slide 11**) and discuss implications in terms of the key message:

All families are unique but many have similar or different family constellations that are impacted by various cultural, linguistic and other factors.

- Encourage them to add other key messages.

1.2 Lecture: Consideration of Definitions of Family

- Use **Definitions of Family** handout and slides (**H2, page 57 /Slide 12- 13**) and review definitions of families

> "big, extended, nuclear, multigenerational, with one parent, two parents, grandparents. We live under one roof or many. A family can be temporary as a few weeks, or as permanent as forever, we become part of a family by birth, adoption, marriage, or from a desire for mutual support…
>
> ….A family is a creature unto itself, with different values and unique ways of realizing its dreams; together our families become the source of our rich cultural heritage and spiritual diversity…our families create neighborhoods, communities, states, and nations"
>
> (Report from the House Memorial 5 Task Force on Young Children and Families, New Mexico, 1990)

- Debrief how definitions fit in with participants' perception of families.
- Show **Parents' Quotes** slide (**Slide 14**) and refer to **Definitions of Family** handout (**H2, page 57)**

> "To make progress and have a family go in a positive direction, the family has to feel valued… that the information they are sharing is just as important as is the information the professionals are sharing…for the family to feel this is critical to success" Linda Roan Yager ~ Parent
>
> "What they need… they need to know about our culture… how we raise our kids… what we do when they are sick… when they are with adults… when they eat, and when they go to school. They need to learn how we think and feel as a family about our kids." Maria Sandoval ~ Parent

- Discuss the following points based on the quotes in the above slide*:*
    - Understanding of family perspectives is very important.
    - How different individuals from different cultures can share some common beliefs, characteristics and/or life ways but are not defined by them.
    - How individuals from different cultures might perceive a certain situation like "disability" or "illness" but assumptions about individual families can be dangerous unless we share information that helps us understand families' own perceptions.

1.3 Activity: Reflections

DI Assistants will participate in an activity reflecting what most families have in common and different ways families express their values.

1.3.1 Steps

- Ask participants to reflect and write down what values all or most families have in common regardless of specific cultural life ways or orientations?
- Have the participants share what they wrote.
- Show **Family Values: Vision for Future** slide **(Slide 15)** and compare the list with their answers
  - Love?
  - Health?
  - Friends?
  - Success as they would define success?
  - Happiness?
- Ask if there are different ways of expressing or playing out the importance of key values.
- Ask them to list and describe what this might look like from varying perspectives?
- Discuss answers as a whole group.

Goal 2: Revisit and strengthen the understanding of the concept of Family-Centered Practices

2.1 Activity: What does Family-Centered Practice mean?

The DI Assistants will participate in an activity to recapitulate what they learned about Family-Centered Practices in Early Intervention Teamwork Academy

2.2.1 Steps

- Show **What does Family-Centered Practice mean?** slide **(Slide 16)**
- Ask participant to discuss in pairs what they have previously learned about Family-Centered Practices in Early Intervention Teamwork Academy and take notes on:
  - What does family-centered practice mean?
  - Why is it important to use family-centered practices?
- Have them share their discussion notes with the large group.

2.2. Lecture: Family-Centered Practices

- Use **Family-Centered Practices: Why?** slide (**Slide 17**) and **Family-Centered Practices** handout (**H3, page 58)**, highlight the importance of family-centered practice:

  > "The family is the constant in the child's life while the service systems and personnel within those systems may be involved only episodically" (Crais, 1990).
- Relate the above quote to some of the responses the group provided in the preceding activity.

- Use **Division for Early Childhood Education (DEC) Recommended Family-Based Practices Definition** slide (**Slide 18**) and remind participants that they learned about these in the Early Intervention Teamwork**:**
  "a philosophy or way of thinking that leads to a set of practice in which families or parent are considered central and the most important decision maker in a child's life and that service systems and personnel must support, respects, encourage and enhance the strengths and competence of the family."
- Highlight that the ultimate goal is to become family-centered even though it might seem an elusive goal when families are coming from diverse perspectives.
- Use **Factors That Enhance Family-Centered Practice** slide **(Slide 19)** and **Family Centered Practices** handout (**H3, page 58):**

Professor Dorothy Scott has written extensively about family-centered practice. She recently outlined the factors that can enhance family centered approaches. These include:

  - A genuine commitment to working with the whole family;
  - A conceptual framework which allows us to understand the ecological or natural contexts of children, families and communities, in the wider society;
  - A recognition of the skills in engaging families, nurturing their hopes and aspirations for their children, building on their strengths; and
  - A focus on inter-agency, inter-professional cooperation.

2.3. Discussion: Challenges for Early Intervention Providers

- Mention Family-Centered Practice poses some challenges for early intervention service providers.
- Ask participants to think of some issues that may be considered as challenges while delivering services that are family-centered.
- Sum up their responses using **Challenges for Early Intervention Providers** slide **(Slide 20):**
  - Family constellations e.g. lone parent families, children living with grandparents etc.
  - Marital status of parents (Divorce and separation)
  - Family size
  - Variety of cultures in the community
  - Religious beliefs
  - Poverty
  - Drug and alcohol addiction in families
- Allow participants time to take notes on **Family-Centered Practices** handout (**H3, page 58).**
- Explain that as families have become more complex, and their family and working lives more intricately connected, family services and family policies have had to adapt to meet these new realities.
- Emphasize that each child needs to be recognized as an individual with unique characteristics, strengths and needs and each family needs to be recognized as having unique concerns, priorities and resources. To work effectively with families providers

are required to adjust and adapt strategies continuously with families that may adhere to individualized values beliefs and practices.

- Clarify the above by pointing out that it really is about "individual consideration" of each child and family as unique, without prior assumptions or stereotypes.
- Show **Take Away Message** slide **(Slide 21)** and highlight that working with families from different cultures than yours involves challenges as well as opportunities:

> Working with families from cultures different from your own can sometimes be frustrating and require further study and information gathering….
>
> AND
>
> Can be an opportunity to be exposed to a richness of human experiences, to learn new information, and to grow as an individual

- Emphasize that actually, the opportunities often outweigh the challenges

Goal 3: Describe cultural differences, the danger of stereotypes as a barrier to individual consideration.

3.1 Discussion: What is Culture?

- Use **What is Culture** slide **(Slide 22)** and ask participants to think of words or activities that describe or represent a culture.
- Record on board or flip chart.
- Use **Culture** handout **(H4, pages 59-60)** and **Definitions of Culture** slides **(Slides 23-25)** to affirm ideas and provide examples of definitions and statements about culture.

Cultures are systems of behaviors and customs passed from one generation to the next. The rules, language, religion, family systems, recreation, and education that a group of people share provide predictability and safety in their daily lives. When people are bound together by common beliefs and practices, they understand each other and the world around them has meaning. *Everyone has a culture, but often individuals are not aware of the behaviors, habits, and customs that are culturally based*" Hall, 1976

"Culture is the way of life of a group of people, including shared views of the world and social reality, values, beliefs roles and relationships and patterns or standards of behavior (such as communication style). Cultural features are linked to a sense of shared ancestry and continuity with the past and can be based upon race, ethnicity, nationality, geographic locations, as well as other dimensions of diversity (Chen et al, 1998)

A culture is a complex and evolving pattern of life, rooted in tradition as well as place. Culture is indelibly a part of each person's identity, but individuals also influence culture. It defines how we see ourselves and how we perceive others (Ina Corinne Brown, 2009).

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3.2. Lecture: The Nature of Culture

- Use **The Nature of Culture** slide **(Slide 26)** and **Culture** handout (**H4, pages 59-60**) describe the key characteristics of culture:
  - Culture is not static: it is dynamic and ever- changing
  - Culture, language, ethnicity, and race are not the only determinants of one's values, beliefs, and behaviors
  - In describing any culture or cultural practice, within group differences are as great as across group differences ….sometimes greater.
  - Dimensions of culture and ethnicity are typically frames in terms of differences in relation to another group…the majority/mainstream culture
  - Everyone is the product of one or more cultures and everyone has a culture (Lynch & Hanson, 2004)
- Discuss how individuals can build relationships with families from cultures different from their own, when they take differences into consideration, without letting bias interfere with their actions, and provide different supports based upon individual differences of families.
- Use **Danger of Assumptions** slide **(Slide 27)** and **Culture** handout (**H4, pages 59-60**):
  - Cultural assumptions are beliefs which are so completely accepted within the group that they do not need to be stated, questioned, or defended (Chen, et al, 1998)
  - CAVEAT ! However, there is danger in assuming that because a family has certain cultural beliefs in common that they can be stereotyped in terms of adhering to all beliefs and patterns associated with their culture
- Explain that stereotypes about cultural differences are often misleading in terms what a family believes. Assumptions that just because a family is Native American or identifies as from the Hmong culture or any other, that they are like all others from their backgrounds can cause cultural clashes and conflicts. Many families come from a background or have had prior experiences of prejudice and discrimination based upon the language spoken or evens their name.
- Use **Additive Attitudes** slide (**Slide 28)** and **Culture** handout (**H4, pages 59-60):**
  - Each and every child and family comes with a rich cultural legacy that can be understood, respected, and celebrated.
  - Impact: The Perez-Mendez family from Mexico celebrates and lives "la familia" which translates into family traditions, speaking their native language in their home, while learning English as a second language, and maintaining connections with family that respect the "elders" and four generations of living relatives.
- Encourage participants to understand different cultural backgrounds and build their knowledge base of other cultures but be cautious about applying this knowledge until they know the family and have simply asked about their priorities or life ways. Doing this in practice speaks to an additive value/attitude towards cultural differences or multicultural perspectives and does not require that you believe the same things, but that you recognize and can understand and respect differences and celebrate families that are rich in traditions different from your own.

- Show **Subtractive Attitude** slide **(Slide 29) and Culture** handout (**H4, pages 59-60)**
  - Preserving your home language and culture is not a choice given subtractive attitudes towards those who do not speak English fluently or adopt the life ways of the majority of English speaking families in the community.
  - Impact: The Sanchez family gives up its heritage language and traditions in order to avoid discrimination visited upon the parents while they were growing up. These parents were punished for speaking their language of heritage in public schools and do not want the same experience for their children...
- Describe what happens when a cultural difference is not respected and a subtractive attitude results in that the cultural life way or language or difference is considered "less than" when compared to a mainstream culture. Long histories of subtractive attitudes towards differences and diversity pervade our country and have often set families different from the mainstream in conflict.
- Show **Family's Cultural Diversity** slide **(Slide 30):**
- "There exists no generic entity which may be dubbed the Southeast Asian family, the Native American family…each of these categories encompasses numerous cultures, their individual members may share tendencies in some areas and not in others. Individuals and families will be found to lie along different points of their cultural continuum (from traditional, for example to fully bicultural). These are valid cultural distinctions only in the very broadest sense of the term." Anderson & Fenichel, 1989, Zero to Three
- Discuss the above quote and inform the participants that during the Academy we will be discussing the issue of "moving beyond stereotypes" regardless of identified cultural background, through the concept of "individual consideration".

3.3 Activity: Where are you on a cultural continuum?

DI Assistants will participate in an activity to identify their placement on a cultural continuum.

3.3.1 Steps

- Discuss with participants that we all come from a culture.
- Discuss how different factors can influence actions and perspectives.
- Show **Cultural Continuum** slide **(Slide 31)** and ask individual participants about where they fall on the continuum in terms of their orientation and perspectives in respect to values of:
  - Extended Family ………….. Nuclear Family
  - Inter-dependence …………..Individuality
  - Nurturance …………………Independence
  - Traditional ……………….. .. Technology
  - Broad Ownership…………Individual & Specific
  - Differentiated rights…………Equality
  - Harmony……………………..Control

- Show slide **Similarities and Differences** slide **(Slide 32)** and discuss what do they know about cross cultural perspectives? (***Note to Instructor:*** *Emphasize the ethnic makeup of the region the DI Assistants and the CCB are located*).
    - African American
    - Anglo European American
    - Asian
    - Hmong
    - Indian
    - Indigenous American Nations
    - Korean
    - Latino
    - Somalia
- Transition into the next activity that picks up on dynamic nature of culture.

3.4. Activity: Think Pair Share

DI Assistants will participate in an activity to identify the influencing factors that determine their values, beliefs and life ways.

3.4.1 Steps:

- Use **Life Ways: Dynamic Nature of Culture** handout **(H5**, **page 61/ Slide 33)** and ask participants to turn to the person next to them and think about key messages they heard in their family of origin about:
    - ✓ babies crying
    - ✓ children and food
    - ✓ discipline
    - ✓ children with disabilities
- Show **Did Your Family Feel This Way?** slide **(Slide 34).**
- Read each message and ask participants to raise their hands if the message resonates with what they heard from their family of origin.
- Seek additional key messages the pairs came up with in their discussion.
- Ask participants to then think about if they still believe these key messages and what they learned from experiences that were part of their family's belief system
- Then ask participants to share a "story" about their belief system and how it has changed or not changed over time. Use these examples and stories to make the point that belief systems change…culture is dynamic in nature…
- Introduce **Change over time…** slide **(Slide 35):**
- "The context, [of a family story], is not a stagnant environment or a set of experiences frozen in time. Changes in environment and increased knowledge of how systems work are two Factors that cause sociohistorical context as well as the person living within that context to change". (Leistgna & Woodrum, 1996 quoted in Sanchez, 1999).
- Reemphasize the above point that we all change our life ways as we are influenced by many factors over the course of our lives. Just because a family

shares a belief or values with you, it does not necessarily mean they won’t change their perspective over time.

- Show **Take Away Message** slide **(Slide 36):**
  If you hear a story from a parent at any given time, consider that it is a story about a situation or perspective at that point in time and perspectives may change over time given new information, experiences, or other influencing factors**.**
- Lead them into the following discussion about how families’ decisions depend on where they are on the continuum of cultural identification.

3.5. Discussion: Continuum of Cultural Identification

- Use **Continuum of Cultural Identification** handout **(H6, page 62 / Slide 37)** and inform the participants that you will be discussing the definitions and patterns of assimilation, acculturation and marginalization on the continuum of cultural identification.
- Show **Assimilation** slide **(Slide 38)**
  - Assimilation is when identified groups give up their culture and adopt the mainstream values and beliefs of the mainstream culture “mainstreamers”…Assimilation can be forced (e.g. American government & American Indians) or a reaction to fear of discrimination and prejudice for many immigrant populations or a choice by those wanting to adopt the life ways of the majority culture.
  - (instructor to share examples and seek examples)
- Show **Acculturation** slide **(Slide 39)**
  - Acculturation is described as a process from those who hold fast to their traditional life ways and beliefs to those who not only operate primarily with the dominant culture, but adopt the standard values of the mainstream culture…Families may move about on this continuum ….often associated with choice (bicultural) to maintain aspects of cultural identity while adopting aspects of the mainstream or dominant culture.
  - (instructor to share examples and seek examples)
- Show **Marginalization** slide **(Slide 40)**
  - Culturally marginal individuals are those individuals who essentially follow their own way and do not identify with any particular cultural group. In some instances they reject their own culture of heritage and also do not accept the values and life ways of the mainstream, and thus are considered marginalized from society.
  - (instructor to share examples and seek examples)
- Highlight that it is important to realize that there are many different circumstances that impact how families make decisions about preservation of their culture, or potentially completely assimilating to the new culture or life ways of the “mainstream”. If families feel they need to make an absolute choice to assimilate or do not feel comfortable that they can make choices, they may become alienated or marginalized from both cultures and lose the vital supports they need.

3.6: Activity: Moving Beyond Stereotypes

DI Assistants will participate in this activity to reflect on the importance of moving beyond stereotypes and its implications for relationship building with each and family.

Note to Instructor: this is a summary of the conflicts and stereotypes presented in the book, The *Spirit Catches You and You Fall Down* by Anne Fadiman. In this story the Hmong parents are considered to be "less than" and are ultimately accused of hurting their daughter by not giving her correct dosages of medication for a seizure disorders. Conflicts arise between physicians and the family as they cannot communicate with the family given language differences as well as differences about the superiority of western medicine over spiritual beliefs. It isn't until a cultural mediator and appropriate supports are provided that the family is trusted to care for their child.

3.6.1 Steps

- Use **Activity: Story of Lia**" slide and handout (**H7, page 63/ Slide 41).**
- Ask participants to form groups of four.
- Request each group to pick a recorder who will take notes during their discussion.
- Ask participants to:
  - Discuss why it is important to build relationships with Lia's family?
  - Brainstorm and develop a set of guidelines or principles that they would use with their team when working with families like Lia's family that are from cultures different from their own.
- Ask the group recorders to share the guidelines they considered to be important for teams building relationships with each and every family with the large group.
- Use **Guidelines for Building Relationships With Families** handout **(H8, page 64/ Slide 42)** and connect the listed key messages with participant responses:
  - Listen to the whole story before reacting.
  - Don't operate on assumptions.
  - Affirm or repeat to be sure you are hearing the story correctly.
  - Ask permission before acting.
  - Respect differences in spiritual beliefs and child rearing practices, even when different from your own.
  - Be careful of stereotypes based on others opinions.
  - Avoid judgments as they can cause harm.
  - Immediately seek appropriate resources and supports when there are linguistic differences that are barriers to communication.
- Sum up the discussion with **Moving Beyond Stereotypes** slide (**Slide 43**):

  "All families, in fact, vary greatly in the degree in which their beliefs and practices are representative of a particular culture, language group, religious group, or country of origin."

3.7. Lecture: Your Cultural Journey to Family-Centered Practice

- Distribute **Stages of Cultural Competence** handout **(H9, page 65 / Slide 44):**

  - ✓ Cultural Awareness involves a provider's sensitivity to his or her personal beliefs, values and biases and how they might influence perceptions of a family.
  - ✓ Cultural knowledge involves provider's seeking information and knowledge of a family's cultural world view and expectations.
  - ✓ Cultural skills involve the provider's ability to intervene in a manner that is culturally sensitive and relevant (Sue, Ivey & Peterson, 1996)
- Emphasize that as DI Assistants they need to follow their own cultural journey - knowing their own biases, expanding their knowledge base about various cultures, and ultimately building upon skills they have to not only respond to families with sensitivity but also providing relevant information with support from other team members.
- Show **Your Cultural Lens** slide **(Slide 45)** and refer to **Stages of Cultural Competence** handout (**H9, page 65)** to reinforce the above point**:**
- Each of us brings our own culture, values beliefs and experiences to each relationship we build with families…our background and experiences affect everything we do…they provide us a "cultural lens" through which we view how we ourselves raise our children, how we organize our household, how we talk and use language, how we view disability…we need to enlarge our cultural lens to "wide angle" to understand other's experiences, values, and beliefs and how these influence each and every family. (Hall, 1976).
- Address any questions/comments that the participants might have about the quote.

3.8. Activity: Reflection on worldview of families from different cultures

The DI Assistant will reflect on their own worldview to life ways and compare it to others and discuss implications for working with different families.

3.8.1 Steps

- Use **Reflection: Worldview of Families From a Different Culture** handout and slide **(H10, page 66 / Slide 46)**.
- Ask the participants to think of a family from a different culture than theirs that they work with or know in their community.
- Ask them to reflect on the following questions:
  - What is their (the family's) worldview and adherence to traditional life ways?
  - How is their worldview different than yours (the DI Assistant's)?
  - What aspects of child rearing and beliefs about this family will impact your work as a DI Assistant?
- Have a few participants volunteer to share their reflections.
- Ask them to save their reflection in their journal.

Goal 4: Identify challenges and barriers to building relationships given linguistic diversity among families.

4.1 Activity: Marta's Story

DI Assistants will participate in an activity to identify helping indicators for working with families that speak a different language that theirs

Note to the instructor: The video may take some time to load, please wait a few minutes. It is a long video; therefore play only the first 5 minutes. The story is about Marta, a mom who moved to the USA from Mexico. She does not speak English on the video. Any participants who speak Spanish may understand her but the others will not. Listening to this mom speaking in Spanish and watch the reaction of the participants who do not understand her. Only to this for the first five minutes and then review the following steps.

4.1.1 Steps

- Play the first 5 minutes of the video clip on **Marta's Story (video clip)** slide **(Slide 47**) and ask the participants to listen carefully.
- Explain to the participants that they will be listening to a mom, Marta who moved here from Mexico.
- Ask participants how many were able to understand the content of the video.
- Distribute **Marta's Story** handout **(H11, pages 67-68)** and give participants another 5 minutes to read it
- Show **Marta's Story: Considerations** slide **(Slide 48)** and ask participants to answer the following questions:
  - What worked for Marta?
  - What was troubling or concerning?
  - How does the knowledge that you gained through this video impact your practice in early intervention?
- Have participants share their answers to the above questions.

4.2 Lecture: The Power of Language: Valuing Linguistic Differences

- Present **The Power of Language** slide **(Slide 49)** and distribute **Power of Language: Valuing Linguistic Differences** handout **(H12, pages 69).** Explain that the power of language is great because language and culture are so interdependent, communicating with families from different cultural and linguistically different backgrounds can be very complex.
- Present **Communication** slide **(Slide 50)** and state that when language of the family and the provider are different it is clear that communication may be severely compromised. However, speaking the same language does not guarantee communication. In addition, researchers state that communication is both verbal and non-verbal which is critical to cross cultural competence. Tell them that we will be

discussion communication in detail in Module C of the Academy while in this module we are focusing mainly on linguistic differences

- Present **Valuing Linguistic Differences** slide **(Slide 51)** explain that there are over 114 different languages represented in the homes of children in Colorado. Highlight that providers cannot learn 114 different languages but they can value the diversity and power of languages and seek ways to communicate with families as they build relationships.

Note to Instructor: See Module C for more information

Goal 5: Identify socioeconomic factors that frame a family picture.

- Show **Socio-Economic Factors** slide **(Slide 52)** with the group and set the stage for the activity that follows.

Nearly 13 million American children live in families with incomes below the federal poverty level, which are 20,650 a year for a family of four. The number of children living in poverty increased by 11% between 2000-2006. There are 1.2 million children living in poverty today more than in 2000. NCCP, 2007

5.1 Activity: Unequal Childhood Scenarios

DI Assistants will participate in an activity demonstrating how socioeconomic factors contribute to family life ways and may pose challenges for families.

Note for the Instructor: Scenarios for this activity are adapted taken from the book, *Unequal Childhoods,* Lareau, 2003. The scenarios compare the experiences of children from middle class families that frequently intentionally expose their children to many activities and learning opportunities (soccer, baseball, dance, music classes etc) outside of school to enhance their success with those of children from working class families or families in poverty, wherein different priorities for maintaining health, food , and other consideration leave children to play and develop on their own in more naturally occurring situations. Expectations and opportunities are different and according to the author counteract stereotypes of differences based on race and ethnicity.)

5.1.1 Steps

- Distribute **Unequal Childhood Scenarios** handout (**H13, page 70)**
- Ask small groups to read each scenario, discuss and fill in the columns in terms of
    - daily routines,
    - priorities
    - values
- In large group debriefing, ask participants to discuss how similarities and differences might impact their work with families across settings

- Show **Scenario One** slide **(Slide 53) :**

Laughing and yelling, a white toddler named GT splashes around in the swimming pool with his nanny in the backyard of his 4 bedroom house in the suburbs. As on most evenings, after a quick dinner his father drives him to Gymboree at the local rec center. His brother has a baseball game as a different location…as they rush out of their works clothes and get the children ready for activities; the boy's parents are harried…

- Have participants review daily routines, priorities and values that they discussed for Scenario One.

- Show **Scenario Two** slide (**Slide 54**)

Only 10 minutes away, a Black 2 year old AW, is riding home from child care with his mother in their beige, leather upholstered Lexus. A's mother is tired but talks with her son about school…She has a long Thursday ahead of her. She will get up at 4:45 to go out of town on business and arrive home at 9:00 that evening. The next day she will chauffeur A to a private Suzuki violin lesson, followed by a visit to his Nanna and then a soccer game for her older child…Discussions between parents and children are a hallmark of middle-class child rearing…

- Have participants review daily routines, priorities and values that they discussed for Scenario Two.

- Show **Scenario Three** slide (**Slide 55**):

Farther away a Black two and a half year old boy, HM, plays outdoors in the housing project in which he lives, with his two male cousins. After giving up searching for a basketball, they come in to watch sports on TV and then go back outside for a water balloon fight. People sit in white plastic chairs outside the apartments and music and TV can be heard.

- Have participants review daily routines, priorities and values that they discussed for Scenario Three.

- Show **Scenario Four** slide (**Slide 56**):

Only 20 minutes away in a "blue-colored neighborhood and slightly farther away in a public housing project, childhood looks different. Mt Y, a white working class father picks up his son, Billy, from his Head Start child care program. He has a beer while his son watches some TV, then rides his "trike' and plays on the sidewalk outside of their apartment. Other nights he and his Dad might sit on the sidewalk and with cars and trucks. At 5:30, B's mother arrives home after work as a house cleaner and makes dinner. They all sit down together as a family and await the visit from an uncle who typically stops by to talk.

- Have participants review daily routines, priorities and values that they discussed for Scenario four.

- Show **Similarities and Differences** slide (**Slide 57)** and review the similarities and differences and be sure to add that both sets of families want the best for their children major life task :
  - to put food on the table,

    - ✓ arrange for housing,
    - ✓ negotiate unsafe neighborhoods,
    - ✓ take children to the doctors,
    - ✓ provide clean clothes and
    - ✓ get children to bed and ready for school the next morning…
- Highlight that unlike middle class parents, concerted development of children through organized activities is not an essential priority or aspect of good parenting.

5.2 Discussion: How does the 'culture of poverty' apply?

- Show **How does the 'culture of poverty' apply?** slide (**Slide 58)** and discuss the following questions with the participants:
    - Is there a difference in the concerns, priorities and resources of these parents and families?
    - Is there a difference in daily routines, activities, places, and relationships between middle class families and those in working class or in impoverished situations? How will this impact your building relationships with families?
- At the end of the discussion, wrap up Module A and address any questions that the participants might have.

MODULE B:

The Impact of Illness and Identified Disability on Family Life: Cross Cultural Perspectives

Working With Families Academy

Module B: Impact of Illness and Identified Disability on Family Life: Cross Cultural Perspectives

A. Module Goals

Using the **Module B: Impact of Illness and Identified Disability on Family Life: Cross Cultural Perspectives** handout **(H1, page 55/ Slides 59 & 60)** review the goals of the module:

The DI Assistant will:
1. Recognize the family as a system that changes over time.
2. Identifying emotions, stages, and recycling characteristics of the grieving process and how it might apply to families with infants with developmental disabilities.
3. Identify factors of strength and resilience in families that DI Assistants can support.

Goal 1: Recognize the family as a system that changes over time.

Note to the instructor: In this section, we focus on changes in a family when a child is identified with a disability by first applying Bronfenbrenner's circles of support to the participants using diagrams for them to use to fill in based upon their own relationships with others. They will then complete the circles activity based upon a family with a child with disability as one way of introducing the feelings and concerns of families whose children are being identified and how this often creates imbalance in a family. A video of families receiving services in a neonatal intensive care unit can illustrate the feelings and grief states families move through when their child is identified with medical challenges and how the impacts of one family member changes the life of others in the family, that families are unique in how they deal with the grieving process regardless of their socio-cultural backgrounds, and although they are strongly influenced by basic cultural beliefs and values, they are not defined by them.

1.1 Lecture: Families as Systems: The Balancing Act

- Present **Family as a System: The Balancing Act** slide **(Slide 61)** to explain the family as a system:
  - Is constantly developing and changing.
  - Consists of interrelated members.
- Highlight that:
  - You cannot view one member apart from the others… the child cannot be viewed separately from the family.
  - Change in one part (member) affects lives of others. Andrews & Andrews (2000)
- Point out that recognizing the family as a system that changes over time demands we look at how interactions impact all family members as well as the child involved in intervention.
- Explain that in fact each family can be viewed as a series of concentric circles or systems depicting relationships of child and primary caregivers in the inner circle (micro system), surrounded by others in concentric circles reaching outward to the macro system of societal supports based upon proximity of relationships.

1.2 Activity: Who is in Your Circle?

DI Assistants will participate in an activity to identify significant family members and what would change in the family if there was a child with disabilities.

1.2.1Steps:

- Provide each participant with **Who is in Your Circle?** handout **(H14, page 72),** a series of concentric circles on both sides of the paper.

- Ask each participant to put themselves and whoever is most important to them in terms of relationships in the center circle.
- Then ask, in terms of relationships with those that are closest to them, who they would put in each of the series of circles. Emphasize they fill in the circles from "micro system" outward to "macro system" with social agents that are present but not necessarily in relationship to the family such as police, firemen, politicians etc in the outer circles.
- Show them **Circles of Support in Human Development** slide **(Slide 62)** and ask if their "co-centric circles" look like the example on the slide - with the individual and the family at the center, extended family and close friends in the next circle, extended friendships of activity groups in the next circle. The last circle would include teachers, doctors, dentists (those providers or agents seen on an infrequent basis; extending outward to others who are part of community or society in terms of "macro system supports".
- Then, ask participants to turn over the page and see whether the members of each circle would change if a child with a disability was in the inner circle.
- Show **Does it look different?** slide **(Slide 63)**
- Discuss:
    - Who would be in their world then based upon relationships and contacts?
    - How might this impact their daily life and routines?
    - What changes may result?

Goal 2: Identifying emotions, stages, and recycling characteristics of the grieving process and how it might apply to families with infants with developmental disabilities.

2.1 Activity: You are not Alone

DI Assistants will participate in an activity to identify common reactions of family members faced with their child being identified with medical challenge or a developmental disability.

2.1.1 Steps

- Distribute the **You Are not Alone** handout **(H15, pages 73-78 / Slide 64).**
- Ask participants to read about the common reactions of family members faced with their child being identified with medical challenge or a developmental disability.
- Discuss with participants the constellation of emotions that can occur as typical reactions.
- Encourage participants to share personal experiences or stories.
- Show **Child's Medical or Disability Diagnosis: Parents' Typical Emotions** slide (**Slide 65**) to sum up the discussion :
    - Parents' typical emotions/reaction on their child's first diagnosis of a medical condition or developmental disability include:
    - Initial feelings of shock and numbness,
    - Feelings of grief, an "inexplicable loss", disappointment, isolation

    - Denial “ this is not happening to me”,
    - Potential anger at those that are trying to help.
    - Anxiety about and Fear of the unknown or anticipated change
    - Feelings of guilt and self-blame, “What did I do wrong?”
    - Overwhelming confusion and feelings of powerlessness
    - Rejection
- Point out that these recognizable feeling states are based on many resources including the stages proposed historically by Kubler Ross (1969) and others who have refined her model.

Note to the Instructor: Back in 1969, Elisabeth Kubler-Ross identified five stages of grieving.

i. Denial: The initial stage: "It can't be happening."
ii. Anger: "How dare you do this to me?!" (Either referring to God, oneself, or anybody perceived, rightly or wrongly, as "responsible.")
iii. Bargaining: "Just let me live to see my son graduate."
iv. Depression: "I'm so sad, why bother with anything?"
v. Acceptance: '"I know that I will be in a better place."

- Highlight that although these feelings may be observed in a parent’s behavior they are not static nor necessarily occur in a definitive sequence as often described. In fact, most parents report these feeling can reoccur and recycle as life changes and their children go through periods of transition.
- Point out that it is important to note that not all parents go through these stages or feeling states and in fact they may accept the inevitability of the situation as part of their cultural belief system. Thus, it is important to understand that feeling states may differ based upon cultural life ways and spiritual beliefs.

2.3 Activity: Influence of Belief Systems

The DI Assistants will participate in an activity to develop an understanding of how families’ belief system can influence their grieving process stages or feeling states when faced with the challenge of having a child with disability.

2.3.1 Steps

- Use **Examples of Influence from Belief Systems** handout **(H16, page 79 /Slide 66).**
- Have participants go over the following cultural religious beliefs:
    - Cultural: “If only I had worn the keys during the full moon as my mother told me, my baby would not have been born with a cleft palate”
    - Cultural: “This child is sacred and must be sheltered and protected as a child with special powers”
    - Cultural: “If Lia’s sister had not slammed the door, her soul would not have left her body”
    - Religious: “It is God’s will”
    - Religious: “It is punishment from God”

    - Religious: " It is a blessing from above"
- Ask participants to list additional examples from their own experience.
- Have participants share the additional examples.
- Show **Take Away Message** slide **(Slide 67)** and reemphasize the following points:
    - Not all parents experience all of these feeling states although many parents and family members have.
    - Feelings experienced can be highly influenced by personal cultural, religious, and spiritual values and beliefs.
    - Feeling states may re-emerge or re-cycle as parents face new experiences and transitions during different points in their child's life.
    - Parents are to be respected and supported as they travel this journey.

2.4 Activity: An Unexpected Journey

The DI Assistants will participate in an activity to view a video that details the reactions of four different families to the birth of a premature child.

Note to Instructor: This activity you may use the video An **Unexpected Journey or** a website to Neonatal Intensive Care Unit (NICU) website or vignettes from parents experiences in the NICU NICU youtube

2.4.1 Steps

- Distribute **An Unexpected Journey** handout **(H17, page 80/ Slide 68)**
- View the video An Unexpected Journey.
- Ask participants to work in pairs and identify:
    - Key reactions of the families to their child's situation…emotions and feelings of guilt, pride, fear, frustration, sadness, etc
    - The impact on the lives of all family members
    - Specific strategies used by the hospital "team of providers" to support families given different situations and concerns as they traveled this journey
- Share the key points of your discussion with large group.
- Distribute **Welcome to Holland** handout **(H18, page 81 / Slide 69)** for participants to again hear another parent's perspective on an unexpected journey.
- Have them read the poem and ask them: What did you learn from this poem?
- Discuss responses and address any questions.

2.5 Activity: What You Should Know About My Child

DI Assistants will read another poem from a parent of a child with special needs and identify key messages that will help them in their work with families**.**

2.5.1 Steps

- Use **What You Should Know About My Child** handout **(H19, page 82 / Slide 70)** for participants to again hear another parent's perspective on an unexpected journey.
- Have them read the poem and ask them: What key messages did you learn that will help your work with families of children with disabilities?
- Discuss responses and address any questions.

2.6 Activity: Supporting Transitions to Home

DI Assistants will participate in an activity to identify and reflect on supports for families when they leave the Neonatal Intensive Care Unit (NICU) to go home.

2.6.1 Steps:

- Ask participants to identify and discuss in small groups what supports were available as families featured in the **An Unexpected Journey** video or on the website transitioned to home after their experience in the NICU.
- After about three-five minutes of small group discussion request expanded discussion about if there are differences in how parents' beliefs, supports, and/or perspectives influenced this process.
- Ask participants to reflect in their journals about what is important to remember about "transitions to home" and how they might specifically support families with children identified for Part C services as they transition to home.
- Debrief ideas as a large group.
- Show **Supporting Transitions to Home** handout **(H20, page 83 / Slide 71)** with key ideas for supporting transitions:
    - Recognize that some families need to have time to absorb what has happened and adjust to it.
    - Some families may want to deal with the feelings of fear, confusion, helplessness, anger, guilt, and need more time to deal with these issues. Affirm that feelings are real, and respond with empathy.
    - Other families may need a "sounding board" or someone to just listen to their fears and other feelings associated with their circumstances.
    - Listen without judgment
    - Refer to service coordinator and other team members as appropriate
    - Provide information when asked.
- Ask participants to write additional ideas that resulted from their discussion. Let the participants know that they will be talking about supporting families further in Module C.

2.7 Activity: In her shoes…

DI Assistants will participate in an activity to identify how stages of the grieving process apply to families with infants with disabilities that may represent differing beliefs about disability.

Note for the Instructor – An optional activity related to this video was included as an optional activity in the Early Intervention Teamwork Academy **(Module C, Goal 3, Activity 3.1)**. The participants in your class may or may not have seen it before. If the participants have already seen this video, you can ask them to bring their journal entry on the video from the previous class and share it with the group.

This video tells the story of Elizabeth's birth, subsequent diagnosis of Down syndrome, how the family reacted and what and who provided support to Aracelly during the first years of her struggle to help her child. Have participants discuss what might have happened if the news of a diagnosis had been delivered differently, and how this mother and family could have been supported if Elizabeth was born today. Focus on specifics of family as integral to the team process.

2.7.1 Steps

- Show **Aracelly & Elizabeth** slide **(Slide 72)**
- Ask participants to consider:
- How do differing beliefs about disability impact the differing reactions by this family and address the following questions:
    - What culturally based factors apply to various responses to the news of Down Syndrome?
    - What was concerning about how the diagnosis was initially provided?
    - What supports did Aracelly appreciate and benefit from as she traveled her path with Elizabeth?
    - How did this family adapt in terms of their cultural life ways?

- Show **Arecelli and Elizabeth** video clip **(Special Quest) (Slide 73)**
- Debrief in large group and discuss the feelings described by Aracelly when faced with the diagnosis of Elizabeth and how feelings of shock, isolation, fear, anger and frustration were generated and dealt with.
- Discuss how the support from her gynecologist comforted her when the pediatrician had previously left her with a diagnosis that confused her and left her with a suggestion of institutionalization given his predictions that Elizabeth was "mentally retarded and would never walk".
- Discuss the varying family reactions of "Don't say anything to family", "God will fix it" and how this reflects differences in values.
- Ask the participants to note Aracelly's reaction to ongoing challenges and differing professional reactions to Elizabeth's troubles with feeding and subsequent need of heart surgery. Did she feel listened to by her pediatrician?
- Discuss how Aracelly gathered strength from various family members (her sister) and felt about various services provided, including her thoughts about how social service visitors doubted her ability to care for her child versus the very positive feelings she had toward early intervention and supports.

Goal 3: Identify factors of strength and resilience in families that DI Assistants can support.

3.1 Discussion: Tapping into the Family's Internal Resources

- Show **Tapping into the Family's Internal Resources** handout and slide **(H21, page 84 / Slide 74)** and go over the concept of unconditional positive regard as coined by humanist **Carl Rodgers**
  Unconditional positive regard:
  - Is blanket acceptance and support of a person regardless of what the person says?
  - Is essential to healthy development.
  - If not experienced by people (i.e. lack of unconditional positive regard), may result in seeing themselves in the negative ways that others have made them feel.
  - Can be facilitated by keeping in mind the belief that all people have the internal resources required for personal growth.
- Discuss the implications of unconditional positive regard in our work with families in early intervention. Encourage participants to share personal stories about situations where unconditional positive regard helped them overcome challenges.
- Show **Resilience** slide **(Slide 75)** and introduce the concept of resilience as a response to adversity is considered an innate capacity bolstered by environmental "protective factors" such as family cohesiveness and external supports... the same supports that nurture us all.
- Use **Protective Factors include …**slides **(Slide 76) a**nd describe the concept as follows:
- Protective factors include:
  - The supports and opportunities that buffer the effect of adversity, crisis, or challenges and enable development to proceed …
  - Family strengths, assets, as well as outside influences such as productive alliances with other families and positive family professional partnerships
  - All parents have following inner strengths or resources that can serve as a foundation and can be utilized to build their resilience:
    - ✓ faith, flexibility, humor, communication skills, problem-solving skills, mutually supportive caring relationships, the ability to identify and access outside resources and services when needed.
  - All of these strengthen the capacity to parent effectively, and they can be nurtured and developed through concrete skill-building activities or through supportive interactions with others.
  - Community services that help families in crisis include early intervention programs that focus on culturally competent, family-centered care.
  - Research suggests they appear to transcend ethnicity, social class, geographical locations and historical boundaries and predict positive outcomes for anywhere from 50-80% of a high risk population
- Show **Take Away Message** slide **(Slide 77)**: Resilience is based upon "protective factors" such as individual family strengths, family supports, and supports provided by early intervention and other services that can serve to "buffer" the adverse impacts of having a child identified with a disability.

3.2 Activity: Your Own Protective Factors

DI Assistants will participate in an activity affording them an opportunity to reflect on their own sources of support for handling stress and challenges in their lives.

3.2.1 Steps:

- Ask participants to list their own sources of support that lead to their own ability to handle stress and challenging situations in life
- Ask them to share their list with others in groups of four and discuss how knowing your own "protective factors" helps in working with other families.
- Ask them to share the gist of their small group discussion with the large group.

3.3 Activity: Resilience Factors of Families

DI Assistants will review "family stories" and identify strengths, assets and environmental factors that lead to resilience and positive functioning of a family

3.3.1 Steps:

- Use **Resilience Factors of Families** handout (**H22, page 85 / Slide 78).**
- Distribute **Beach Center Family Stories Anthony, Caleb, Charlie and Harper stories** handouts **(H23, pages 86-88/ H24, pages 89-91 / H25, pages 92-94 / H26, pages 95-97).**
- Divide class in groups of four or five and assign one story to each group
- Ask that one person in the group reads the story aloud to others.
- Ask the participants to discuss what strengths in family members, sources of information, supports and other factors led to resilience in the challenging situations described.
- Debrief in large group by comparing the identified factors of each family story that led to the family's success in handling challenges in a positive way.
- Show **Factors that Support Family Resilience** slide **(Slide 79)** which sums up the discussion:
    - Close –knit extended family
    - Role of "affirming" provider who supports family choices
    - Positive parental attitudes
    - Positive attitudes of providers
    - Service providers in EI that garner needed resources during times of crisis
    - Team –based services
    - Welcoming child care resources
    - Ongoing frequent communication and collaboration
    - Spousal understanding and support
    - Maintaining high expectations
    - Parent's that feel safe to ask questions
    - Family to family support Refocusing on strengths versus deficits …
    - Networking
    - Focus on advocacy and supporting parents as they grow in confidence, comfort level and capabilities to be the "voice for their child".

- Allow a few minutes to the participants to write down any points that they may have missed.

3.4. Discussion: Implications for Early Intervention Service

- Have participants discuss questions and implications of the concept of the family strengths and resilience for practices used by DI Assistants and the early intervention team.
- Write salient ideas shared by participants on a flip chart.
- Show **Implications for Early Intervention Services** slide (**Slide 80)** and sum up the discussion with the following points:
    - Early Intervention Services are respectful of and compatible with a family's cultural strengths and needs.
    - Culturally competent agencies and practitioners are able to view a family's strengths and needs within a cultural context and integrate culturally relevant information in helping the family develop a meaningful plan of action.
    - Cultural competence is a skill learned by the individual , team and the EI program, fostered by a commitment to provide services that are culturally appropriate and that make a positive difference for children and families

Module C:

Cultural Responsiveness: Supporting Each and Every Family

Module C: Cultural Responsiveness: Supporting Each and Every Family

A. Module Goals

Using **Module C: Cultural Responsiveness: Supporting Each and Every Family** handout (**H1, page 55 / Slide 81 & 82)** review the primary goals of this module.

The DI Assistant will:

1. Explore the vision of supporting infants and toddlers with identified challenges and their families in inclusive settings.
2. Develop an understanding of the importance of listening to family perspectives and stories.
3. Examine the strengths and limitations of DI Assistant role in connecting families with team resources and community supports.
4. Develop an understanding of the concept of family leadership and its impact on the family.

Goal 1: Explore the vision of supporting infants and toddlers with identified challenges and their families in inclusive settings.

1.1. Activity: Family's Vision of Inclusion

DI Assistants will participate in an activity to discuss the family's vision of inclusion after listening to a video clip Creating Bright Futures from Special Quest.

1.1.1 Steps:

- Use **Family's Vision of Inclusion** handout and slide **(H27, page 99/Slide 83)**
- View **Creating Bright Futures - Including Infants and Toddlers with Disabilities** video clip **(Special Quest) (Slide 84).**
- Explain to the participants in this video they will hear how parents and early intervention professionals feel about inclusion.
- Ask participants to work in pairs and discuss the questions on the handout:
  - What vision of inclusion is illustrated in the video clip?
  - What do you hear families and service providers say about their experiences?
- Ask them to share their answers with the whole group
- Discuss responses as participants share.
- Show **Take Away Messages: Vision of Inclusion** slide **(Slide 85)** and point out any of the following key points that were not mentioned by the group:
  - Childhood belongs to all children.
  - Children with disabilities can do things that no one thought they could do—others get to see that.
  - Seeing kids as kids first
  - Parent was unsure if she was giving her children what they needed. It helped to have someone to talk to - someone to say she was doing a good job.

1.2 Activity: Value Statements: Pass the Envelope Please …

DI Assistants will participate in an activity to discuss values statements and how they might apply to families in various cultures.

1.2.1 Steps

- Use **Values Statements**; **Pass the Envelope Please …**handout and slide **(H28, page 100 / Slide 86)**

"Children are likely to live up to what you believe of them" *Lady Bird Johnson,* Former First Lady of the United States.

"When I approach a child, he inspires in me two sentiments: tenderness for what he is and respect for what he will become" *Louis Pasteur,* Microbiologist

"Life affords no greater responsibility, no greater privilege, than the raising of the next generation" *C. Everett. Koop*, Former Surgeon General of the United States.

- Show **Discussion** slide **(Slide 87)** and ask participants to answer:
    - What do these quotations say to you about your work with young children and families?
    - What do they say about including infants and toddlers with disabilities and their families in community?
- Ask participants to discuss each values statement and how it might apply to families coming from cultures different from their own.
- Ask each group to come up with their own one value statement related to working with families:
- Ask them to share their statement with the large group.
- Show **Examples of Value Statements** slide **(Slide 88)** and relate it to groups' responses if possible:
    - We need to maintain positive expectations for each child.
    - We must recognize the uniqueness of each child and family.
    - It is important to honor cultural differences.
    - Cultural stereotypes that might be harmful to children and families must be avoided.
    - Children and families are more alike than different, yet differences need to be acknowledged and valued

1.2. Reflection: Journal Entry

- Ask each participant to choose a value statement.
- Request that they reflect upon it and make an entry in their journal about how the value statement will guide their work with each and every family.

Goal 2: Develop an understanding of the importance of listening to family perspectives and stories.

2.1 Discussion: Communication Skills with Families

- Introduce this section by reiterating how important it is to practicing listening to family perspectives and stories and use of key communication strategies that build trust with families.
- **Distribute Communication** handout **(H29, page 101).**
- Use **Communication Skills with Families** slide **(Slide 89)** and explain that there are techniques and important things to remember including:
    - Listening is key!
    - When the language of the family and the provider are different it is clear that communication may be severely compromised

    - However, speaking the same language does not guarantee communication
    - According to researchers “Communication, both verbal and non-verbal, is critical to cross cultural competence” Lynch & Hanson, 2004
- Show **Having a Conversation** slide **(Slide 90)** and explain that techniques and important things to remember include the skill to:
    - ✓ Create an atmosphere of exchange
    - ✓ Focus on parent engagement and participation
    - ✓ Recognize the specific needs of a particular parent
    - ✓ Refrain from using professional jargon
    - ✓ Provide information
    - ✓ Be sensitive to challenges
    - ✓ Recognize strengths and resilience of families
- Show **Verbal & Non-Verbal Communication** slide **(Slide 91)** and explain that techniques and important things to remember include the skill to:
    - ✓ Recognize strengths and resilience of families
    - ✓ Be present
    - ✓ Use silence as a tool
    - ✓ Follow the lead of your partner
    - ✓ Let them know you are listening by nodding, leaning forward, eye contact (if appropriate)
    - ✓ Ask open ended questions
    - ✓ Restate or paraphrase what you heard to affirm you are listening or to clarify intent of speaker
- Ask participants to react to strategies and skills and respond if these would be helpful when talking with their doctor, their child’ service provider.
- Solicit what would be important for them personally in these situations when they are sharing their story. They may identify additional skills as well as affirm already identified key skills.

2.2 Activity: Listening Without Judgment

DI Assistants will participate in an activity to develop an understanding about the importance of listening without judgment.

2.2.1 Steps

- Highlight that a big part of being responsive to families is being a good listener particularly with families whose culture is different from one’s own.
- Distribute **Listening Without Judgment** handout **(H30, page 102).**
- Ask participants to reflect upon the questions in pairs:
    - “What does it mean to listen without judgment when building relationships with families when their beliefs about disability, illness, death and dying are different from your own?”
    - “What would it look like in practice with families?”
- Have them write their ideas on the handout.

- Debrief ideas generated by the pairs in the large group.
- Show **Listening Without Judgment** slide (**Slide 92)** and sum up the ideas as follows:
    - Just listen and do not react negatively when a parent shares their feelings that might seem unacceptable to you
    - Listen and respond with affirmations like "I can see why you might feel that way", even when you disagree.
    - Offer suggestions only when asked;
    - Communicate with your team members and supervisor, especially if you are concerned about the feeling state, responses or reactions of parents you are working with."
    - "Be there" for families in terms of attending to their messages both verbally and non-verbally
    - Follow their lead if there is a pressing need to digress from your own agenda;
    - Respect family member privacy and confidential information.
    - Allow participants a few minutes to write down any additional ideas that they may not have included during the discussion.

2.3 Activity: Role Play - The Power of Listening

DI Assistants will participate in a role-playing activity to demonstrate the power of listening.

2.3.1 Steps

- Ask participants to pair up and share a story about their family or children or a situation they are or did struggle with.
- Ask them to take turns - have one person share as the other person listens for approximately five minutes.
- Have them debrief about each others' skills and reaction.
- Show T**he Power of Listening: Self Assessment with Feedback** slide **(Slide 93)** and ask them to reflect on their conversations:
    - How do I listen and respond to my partner?
    - Did I "hear" the information?
    - Did I ask open-ended questions and allow my partner to ask me questions?
    - Do I think I listened well? (Use of non-verbal as well as verbal) Examples
    - Did I share relevant information?
    - Was a mutual trust established?
    - What specific strategies were used and effective in allowing the "story teller" to share in a comfortable and confident way?
- Debrief outcomes and use of strategies with examples from group.

2.4 Discussion: Family Voices

- Show **Family Voices from Special Quest** slide **(Slide 94)**

- Ask participants to discuss the following questions:
  - ✓ What did you hear as families' priorities for their children?
  - ✓ What are these families telling us is important as we listen to their stories?
  - ✓ How does this help us build relationships with families?
- Present video clip: **Family Voices from Special Quest** slide **(Slide 95)**
- Add any of the following examples from the family quotes not mentioned by the group:

> *"I know my wish for Christopher is to be as independent as possible, to do the things that he wants to do as he sees other kids do it, and to be able to, whether it's public transportation or whatever it may be, I want him to have the ability and not to have any fear of trying to do that on his own. I just want him to be as independent as he can be."*—Penny Purser
>
> *"What we've learned [is] to deal with the things that we have because of Early Head Start. Because I know that there's that support here, and I know that I can do it.*"—Jennifer Merwick
>
> *"What I try to encourage parents to do is to go at the pace that's most comfortable for them, but not ever to lose sight of the fact that at some point, decision making really should rest with them. It is their child. This is their life".*—Ellie Valdez Honeyman
>
> *"You are not alone. We are part of this together, and we're going to work at a solution together.*"—Marcia Callendar
>
> *"Before I came here, it was like, whatever was happening, it just happened. I never said anything about it. Just let it go on. But since I've been here, I know that I can make a change. Just by being the mom, I can make a change."* —Eurika Grady
>
> "*It's not a matter of getting services. It's a way of life. They're not professionals, they are my family. I don't think of them that way, because they've become a part of us. They are all special. We understand that the program has changed the way we are, because, in the process of teaching the baby, they have taught us, too. How to be, to learn how to do, almost like the baby does, because they have trained me to be able to deal with people you come across."*—Jesus Gomez

- Discuss questions that participants may have in large group setting.
- Highlight the **Take Away Message** slide **(Slide 96)**

  Listening to families enables service providers to provide services that are designed with individual families and that meet their priorities and needs.

2.5 Reflection

- Use **Reflection** handout and slide (**H31, page 103 / Slide 97)**
- Ask each participant to list in their journal the strategies that they feel are important to remember as they build relationships with families.

- Reflect how or if they will change their strategies depending upon the culture and life ways of the family.

Goal 3: Examine the strengths and limitations of DI Assistant role in connecting families with team resources and community supports.

3.1 Activity: What Is Wrong With This Picture?

DI Assistants will participate in an activity to develop an understanding of the scope of their role in creating community connections for the family.

3.1.1 Steps

- Distribute the **Developmental Intervention Assistant Roles and Responsibilities** handout **(H32, pages 104-105).** Remind them that this handout was given to them in the Early Intervention Academy.
- Distribute **What is Wrong With This Picture?** handout **(H33, page 106)** with the following scenario:

> Sue, a DI Assistant, arrives for her appointment on time to work with an infant recently identified with overall developmental delays to find the child's mother, Maria, the mother, is close to tears, looking exhausted, as she "was up all night." Maria explains that her husband left last night after an argument. She says that they have been having problems for some time and he wants a divorce. Maria also shares that she has tried to make her marriage work but now realizes that it is beyond repair. She is really worried as has no source of income and doesn't know what to do or where to get legal advice. Sue tries to calm the mom down and tells Maria that her cousin, Kim is an attorney who volunteers at a nonprofit organization that provides pro bono legal services to low-economic families. Sue assures Maria that she will have Kim call her and talk to her. As she is leaving the home, Sue says, "if you don't hear from Kim in a day or two, let me know; I will follow up with her?" Next day, Sue doesn't mention anything to her supervisor about the situation and how she handled it.

- Show **What is Wrong With This Picture?** slide (**Slide 98**).
- Ask the participants to read the scenario as well as review the D I Assistant roles and responsibilities.
- Ask them answer the following
  - Did the DI Assistant act appropriately within the boundaries of the role?
  - What would have been the appropriate way of handling this situation?
- Acknowledge answers and lead them into the next discussion.

3.2 Discussion: Creating Connections to Community: What is the DI Assistant role?

- State that DI Assistants often live within the same community as the families they serve while their supervisors may commute and live greater distances away from communities they serve. Thus, in certain ways DI Assistants are representatives of the community at the early intervention program and can be an effective, knowledgeable, and much needed link between early intervention program and community. They may often share cultural and linguistic similarities with the community as well as have knowledge of community resources that the families might need to access.
- Show **Creating Connections to Community: What is the DI Assistant role?** slide **(Slide 99).**
- Ask participants to brainstorm as a large group:
    - What community resources families might want to build connections with (Possible examples that the group might come up with are - church, library, parent groups, parent to parent connections, clinics, community colleges etc) based upon their cultural life ways, interests, or other factors?
    - How you can facilitate the process of building these connections keeping in mind the boundaries of your role?
    - How might you contribute to the team knowledge of community resources and supports for each and every family?
- Show **Limitations of the DI Assistant Role** slide **(Slide 100)** and acknowledge the participant responses and emphasize that any questions/situation that they encounter in their work with families is best addressed through consultations and discussion with their supervisor and team members, especially the service coordinator. While they might have more knowledge about the community resources, they are actually limited by the scope of their role to establish connections without the direction and approval of their supervisor and other team members, especially the service coordinator**.**

3.3 Lecture: Cultural Mediators, Interpreters & Translators

- Point out that as more culturally and linguistically different families' participation in early intervention services increase; parents need supports to understand of these services and supports. As a DI Assistants, if they have linguistic and or cultural similarity with the parents, they have an important role on the team. They may be called upon to serve as an interpreter, translator and/or cultural mediator or broker under the supervision of their team.
- Distribute **Cultural Mediators, Interpreters & Translators** handout **(H34, pages 107-108)**
- Show **Who is a Cultural Mediator**? slide **(Slide 101)** and explain the term and how it is different than being an only an interpreter or a translator:

> When an interpreter/translator goes beyond translation of language and helps "translate" between the culture of the school environment and the child's family in order to enhance understanding, share information, and create a relationship that supports families as full participants in the process, this individual becomes a cultural **mediator.**

- Show **What Does The Cultural Mediator Do?** slide (**Slide 102)** and highlight that the cultural mediator is always trained and works under the direction of the supervisor and may become:
  - a referral source for community
  - a liaison with parent
  - a communication link to ensure parents are part of the team
  - a "cultural gauge" for knowing what is/is not relevant to a family's cultural context
- Ask the participants to take a few minutes and think about what cultural mediators can add to the process in early intervention services.
- Have the participants share their thoughts on the topic with the large group**.**
- Acknowledge their responses and show **Values Essential to the Use of Cultural Mediators/Interpreters/Translators** slide **(Slide 103):**

If: The diversity of families is acknowledged and honored
Then: Their knowledge of and dreams for their children are believed and valued and they are recognized as the key decision-makers for their children

If: The child must be viewed in the context of their family, culture and community
Then: Supports and services will be culturally resonant with the child and family's culture

If: Interactions with the child and family occur in their primary/preferred language
Then: Cultural mediators, interpreters, and translators need to be effectively utilized as key team members, integral to the process of working with families from culturally and linguistically diverse backgrounds

Source: Moore S., Pérez-Méndez C., Beatty J. and Eiserman, W. *Effective Use of Cultural Mediators, Interpreters and Translators*. The Spectrum Project and Project A.C.T. University of Colorado at Boulder.

- Show **Who Is an Effective Cultural Mediator?** slide **(Slide 104)** and go over the following qualifications of a cultural mediator:
  An effective cultural mediator is:
    - proficient in English and the family's language
    - trained for their role
    - aware of the boundaries of his or her role
    - willing to take directions from the supervisor
    - able to maintain confidentiality
    - well-versed in use of appropriate terminology
    - skilled in interpersonal relations yet is able to remain neutral and objective
    - an individual who has knowledge of the early intervention service system and community resources.
    - not a member of the child's family
- Address any questions the participants might pose.

3.3. Activity: Pathways of Support for Each and Every Family

DI Assistants will participate in an activity to identify pathways of support for each family in the community or that they will work with.

3.3.1Steps

- Show **Activity: Pathways of Support for Each and Every Family** slide **(Slide 105)**
- Ask participants to form groups of four and generate situations in which despite good intentions, the basic ethical responsibilities with regards to working with families could be breached by a DI Assistant.
- Remind them to reflect on the previous knowledge gained with regards to working with families in the **Early Intervention Teamwork Academy** (focus on the limitations of roles, responsibilities of the DI Assistant, confidentiality issues) as well as the early intervention team's appropriate use of the DI Assistants' funds of knowledge with regards to community's language, culture and resources covered in this Academy.
- Have participants share the gist of their group discussion.

Use **Key Messages for DI Assistants in Facilitating Pathways of Support for Families** handout and slide **(H35, page 109 / Slide 106) and** sum up the discussion.
As DI Assistants, you:

  - Maintain confidentiality of all information regarding infant/toddler's and their families
  - Respect the dignity of every child and their families at all times
  - Communicate with families only as directed by the supervisor
  - May assist the service coordinator/team with family access to culturally resonant services under the direction and with the approval of the supervisor
  - Act as cultural mediator/ translator/interpreter when directed by the supervisor. You will need appropriate training for this role.
  - Communicate with team regarding family challenges or concerns that you become aware of. Emphasize that any questions/situation that you encounter in their work with families is best addressed through consultations and discussion your supervisor and team member's .DO NOT ACT ON YOUR OWN.

- Address comments and reactions or questions.

Goal 4: Develop an understanding of the concept of family leadership and its impact on the family.

4.1 Activity: Parent Leadership and Advocacy

DI Assistants will participate in an activity to define the meaning and the importance of family leadership in early intervention services.

4.1.1. Steps:

- Show **Promoting Family Leadership** slide (**Slide 107)** and ask the participants to look at the key words on the slide – *Leadership, comfort, confidence, capable, empowerment…..*
- Ask them to keep these words in mind as they relate to the next slide.
- Show **Meaning of "Parent leadership" and "Parent advocacy"?** slide **(Slide 108)** and ask them to form small groups.
- Discuss the meaning of "Parent leadership" and "Parent advocacy" in the context of early intervention services.
- Have the groups share their insights with the large group.
- Show **Road to Parent Advocacy and Leadership** slide **(Slide 109)** and point out that the parents who have a recently identified child with a special need are often consumed with how they will handle all the new information and access supports. As families understand their situation over time, they grow in their desire and ability to become a strong advocate for their child and eventually reach out to other parents or families in similar situations. As an outcome of Part C EI services is to support families in their quest for confidence, comfort, and capability as a "voice" and advocate for their child.
- Show **Importance of Parent Advocacy and Leadership** slide **(Slide 110)** and ask participants to discuss in their groups: Why is family leadership important?
- Have them share responses in the large group.
- Show **Take Away Messages** slide **(Slide 111)** and add any of the following key points not mentioned by the group with regards to the importance of family leadership:
    - Families are their children's best resources.
    - Families provide support to other families.
    - Families provide input on program and community services.
    - Families directly experience how systems work and can provide valuable insights.
    - Families work in systems to advocate on behalf of all children and families.

4.2. Activity: Open the Door

DI Assistant will participate in an activity to identify strategies and supports that have helped parent leadership and advocacy after they watch a video.

4.2.1 Steps:

- Present **Activity: Open The Door** slide (**Slide 112**)
- View the first 7-10 minutes of the Open the Door video clip.
- Show **Activity: Open The Door** slide **(Slide 113)** and ask the participants to form groups of four.
- Request them to generate a list a list of strategies and supports for parental advocacy and leadership seen on the part of families in the video.
- Discuss the lists generated by small groups in the large group.

- Distribute **Strategies for Parent Advocacy and Leadership** handout (**H36, page 110)** and go over the list connecting it with participant responses wherever possible:
- Show **Strategies for Parent Advocacy and Leadership** slide **(Slides 114)**
    - Relationships are the foundation for beginning the family-service provider that nurture family leadership opportunities.
    - Encourage families to share their perspectives, ideas and suggestions.
    - Listen and respond positively to family priorities.
    - Provide families with information, resources, and support so they can make decisions for their child and family.
    - Use of well trained cultural mediators, interpreters, and translators.
- Show **Strategies for Parent Advocacy and Leadership** slide **(Slide 115)**
    - Facilitate a variety of opportunities for families to come together e.g. parent groups.
    - Offer training for families who want to assume more formal roles of support.
- Show **Strategies for Parent Advocacy and Leadership level** slide **(Slide 116)**
    - Create opportunities for families to participate in committees, policy council, etc.
    - Provide mentorship, training, and orientation by other families or service providers.
    - Provide information about leadership opportunities to all families.
- Use **Important Messages** slide (**Slide117)** that highlights the boundaries of the DI Assistant role and emphasize that it is important for DI Assistants to be aware of all the strategies discussed above but implementation of any strategy or idea by them should happen under the direction and with the approval of their supervisor.

4.3 Activity: Final Wrap Up

DI Assistants will review their journals and reflect on key messages that they learned in the **Working With Families Academy.**

4.3.1 Steps:

- Use **Wrap Up** slide **(Slide 118).**
- Ask **participants** to answer the following questions:
    - What personal reflections about the information shared in this Academy do you want to remember?
    - What did you learn that will stay with you while working with families as a DI Assistant.

Working With Families Handouts

H1 Working With Families Academy Goals

Module A: Understanding the Evolving Concept of Family through a Cultural Lens

The DI Assistant will:

1. Describe what makes a family and the different family constellations.
2. Explore and strengthen the understanding of the concept of Family-Centered Practices.
3. Describe cultural differences, the danger of stereotypes as a barrier to individual consideration.
4. Identify challenges and barriers to building relationships given linguistic diversity among families.
5. Identify socioeconomic factors that frame a family picture

Module B: Impact of Illness and Identified Disability on Family Life: Cross Cultural Perspectives

The DI Assistant will

1. Recognize the family as a system that changes over time.
2. Identify stages and characteristics of the grieving process and how it might apply to families with infants with developmental disabilities.
3. Identify factors of strength and resilience in families that DI Assistants can support.

Module C: Supporting Each and Every Family

The DI Assistant will

1. Explore the vision of supporting infants and toddlers with identified challenges and their families in culturally responsive and inclusive settings.
2. Develop an understanding of the importance of listening to family perspectives and stories.
3. Examine the strengths and limitations of their own role in connecting families with team resources and community supports.
4. Develop an understanding of the concept of family leadership and its impact on the family.

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Module A: Handouts

H2 Definitions of Family

A Family is:

> “big, extended, nuclear, multigenerational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be temporary as a few weeks, or as permanent as forever, we become part of a family by birth, adoption, marriage, or from a desire for mutual support…”*

> ….A family is a creature unto itself, with different values and unique ways of realizing its dreams; together our families become the source of our rich cultural heritage and spiritual diversity…our families create neighborhoods, communities, states, and nations” *

In a Report from the House Memorial 5 Task Force on Young Children and Families, New Mexico, 1990,

Parents’ Quotes:

> “To make progress and have a family go in a positive direction, the family has to feel valued… that the information they are sharing is just as important as is the information the professionals are sharing…for the family to feel this is critical to success” Linda Roan Yager ~ Parent

> “What they need… they need to know about our culture… how we raise our kids… what we do when they are sick… when they are with adults… when they eat, and when they go to school. They need to learn how we think and feel as a family about our kids.” Maria Sandoval ~ Parent

H3 Family-Centered Practices

"The family is the constant in the child's life while the service systems and personnel within those systems may be involved only episodically" (Crais, 1990).

DEC Recommended Family-Based Practices Definition

"a philosophy or way of thinking that leads to a set of practice in which families or parent are considered central and the most important decision maker in a child's life and that service systems and personnel must support, respects, encourage and enhance the strengths and competence of the family."

Factors That Enhance Family-Centered Practice

Professor Dorothy Scott has written extensively about family-centered practice. She recently outlined the factors that can enhance family centered approaches. These include:

- A genuine commitment to working with the whole family;
- A conceptual framework which allows us to understand the ecological or natural contexts of children, families and communities, in the wider society;
- A recognition of the skills in engaging families, nurturing their hopes and aspirations for their children, building on their strengths; and
- A focus on inter-agency, inter-professional cooperation.

Challenges for Early Intervention Providers:

1. ____
2. ____
3. ____
4. ____
5. ____
6. ____
7. ____
8. ____

H4 Culture

Definitions of Culture:

Cultures are systems of behaviors and customs passed from one generation to the next. The rules, language, religion, family systems, recreation, and education that a group of people share provide predictability and safety in their daily lives. When people are bound together by common beliefs and practices, they understand each other and the world around them has meaning. *Everyone has a culture, but often individuals are not aware of the behaviors, habits, and customs that are culturally based*" Hall, 1976

"Culture is the way of life of a group of people, including shared views of the world and social reality, values, beliefs roles and relationships and patterns or standards of behavior (such as communication style). Cultural features are linked to a sense of shared ancestry and continuity with the past and can be based upon race, ethnicity, nationality, geographic locations, as well as other dimensions of diversity (Chen et al, 1998)

A culture is a complex and evolving pattern of life, rooted in tradition as well as place. Culture is indelibly a part of each person's identity, but individuals also influence culture. It defines how we see ourselves and how we perceive others (Ina Corinne Brown, year???).

The Nature of Culture:

Culture is not static: it is dynamic and ever- changing

Culture, language, ethnicity, and race are not the only determinants of one's values, beliefs, and behaviors

In describing any culture or cultural practice, within group differences are as great as across group differences ….sometimes greater.

Dimensions of culture and ethnicity are typically frames in terms of differences in relation to another group…the majority/mainstream culture

Everyone is the product of one or more cultures and everyone has a culture (Lynch & Hanson, 2004)

To build relationships with families from cultures different from your own you need to:

Take differences into consideration, without letting bias interfere with your actions, and provide different supports based upon individual differences of families.

Remember stereotypes about cultural differences are often misleading. Assumptions that just because a family is Native American or any other ethnicity and they are similar to everyone else their backgrounds, can cause cultural clashes and conflicts.

Develop additive value/attitude towards cultural differences or multicultural perspectives –you may not believe in the same things, but that you recognize and respect differences and celebrate families that are rich in traditions different from your own.

Avoid subtractive Attitude (which means that cultural difference is not respected and a cultural life way or language or difference is considered “less than” when compared to a mainstream

H5 Life Ways Activity: Dynamic Nature of Culture

Key messages that you heard in the family of origin about:

- babies crying
- children and food
- discipline
- children with disabilities

H6 Continuum of Cultural Identification

Assimilation is when identified groups give up their culture and adopt the mainstream values and beliefs of the mainstream culture "mainstreamers"…Assimilation can be forced (e.g. American government & American Indians) or a reaction to fear of discrimination and prejudice for many immigrant populations or a choice by those wanting to adopt the life ways of the majority culture.

Examples:

Acculturation is described as a process from those who hold fast to their traditional life ways and beliefs to those who not only operate primarily with the dominant culture, but adopt the standard values of the mainstream culture…Families may move about on this continuum ….often associated with choice (bicultural) to maintain aspects of cultural identity while adopting aspects of the mainstream or dominant culture.

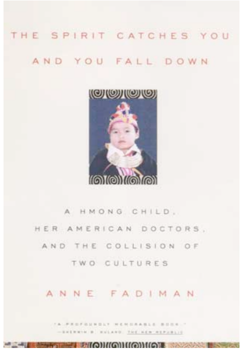
Examples:

- **Marginalization** - Culturally marginal individuals are those individuals who essentially follow their own way and do not identify with any particular cultural group. In some instances they reject their own culture of heritage and also do not accept the values and life ways of the mainstream.

  Examples:

H7 Story of Lia

The Spirit Catches You and You fall Down



Lia was the youngest daughter of a family who had come to the United States from Southeast Asia after spending several years in "camps" waiting to join relatives in California. On October 24, 1982, three-month-old Lia Lee was carried into the emergency room of the county hospital in Merced, California. Lia's parents, Hmong refugees from the hill country of Laos, spoke no English; the hospital staff spoke no Hmong.

On a later visit, Lia's doctors would determine that she was suffering from a severe case of epilepsy, a misfiring of the brain's neurons. Her parents, however, believed that her seizures were caused by the flight of her soul from her body and called her condition by its Hmong name: *qaug dab peg* ("the spirit catches you and you fall down"). They believed that Lia's soul left her body after her sister slammed a door. Consider that this family had very different beliefs about illness and had come to mistrust Western medicine. After many visits to the hospital and many prescriptions for seizure medication, the physicians following this child felt the parents were not caring for her appropriately and were not giving her the dosage of seizure medication she required and reported the family to social services. The Lee's believed that their visiting a shaman and other remedies consistent with their culture was the best ways to handle Lia's problems and actually took very good care of her physically and loved her very much.

When there are such conflicting beliefs about ways to handle medical issues, who gets to decide a course of action in the best interests of the child. How might this family have benefited from a translator or cultural mediator who could have explained to them why the doctors were prescribing medicine for Lia and how to administer it appropriately? How do you think the Lees felt about the doctors who could not communicate with them or explain their child's illness to them? Do you think the parent and family members of this child were conflicted about their life in America and how they were treated? What could have been done differently?

(This story is from *The Spirit Catches You and You Fall Down* by Anne Fadiman. It has won many awards and is often read as an experience in how we can change systems to make it more understandable and easier to help families who believe differently than the mainstream about the benefits of western medicine and how our system of medical care works or doesn't work for families.)

H8 Guidelines for Building Relationships with Families

- Listen to the whole story before reacting.

- Don’t operate on assumptions.

- Affirm or repeat to be sure you are hearing the story correctly.

- Ask permission before acting.

- Respect differences in spiritual beliefs and child rearing practices, even when different from your own.

- Be careful of stereotypes based on others opinions.

- Avoid judgments as they can cause harm.

- Immediately seek appropriate resources and supports when there are linguistic differences that are barriers to communication.

H9 Stages of Cultural Competence

Cultural Awareness involves a provider's sensitivity to his or her personal beliefs, values and biases and how they might influence perceptions of a family.

Cultural knowledge involves provider's seeking information and knowledge of a family's cultural world view and expectations.

Cultural skills involve the provider's ability to intervene in a manner that is culturally sensitive and relevant

(Sue, Ivey & Peterson, 1996)

Your Cultural Lens

Each of us brings our own culture, values beliefs and experiences to each relationship we build with families…our background and experiences affect everything we do…they provide us a "cultural lens" through which we view how we ourselves raise our children, how we organize our household, how we talk and use language, how we view disability…we need to enlarge our cultural lens to "wide angle" to understand other's experiences, values, and beliefs and how these influence each and every family.

(Hall, 1976)

H10 Reflection: Worldview of Families from a Different Culture

- Think of a family from a different culture than yours that you work with or know in your community.
- Reflect on the following questions:
  - What is their worldview and adherence to traditional life ways?
  - How is their worldview different than yours?
  - What aspects of child rearing and beliefs about this family will impact your work as a DI Assistant?

H11 Marta's Story

My name is Martha Carrillo. My parents are Mexicans. We come from a family of 2 languages. As young children we spoke Spanish at home. And as adults we decided to change our cultures a little bit. But our culture is Hispanic. My school was in Mexico and it was all in Spanish.

I was raised in a mining town with about 500 families. We all knew each other; it was a town with lots of traditions. I have 6 brothers. They all had the opportunity to go out of town to go to the University. I was the little one and my dad couldn't give me a career, so I left school.

At 18 we moved to Camargo, Chihuahua. I started working there.

My grandmother, she was a US citizen, but she never had her papers in order, because since she was a baby her father brought her to live in Mexico. At 65 she decided to get her papers and benefits in order as a US citizen. She was successful and then she was able to apply for citizenship with all her children. Then we all wanted to be together, first one then another and then me, and that is how we all immigrated until we established our self's here.

Life in the US for me has being very good, here is where my life has changed completely. I can, I want and I will do more with my life, I will improve more. I want to speak English at 100%

I have 2 children. My daughter is 8 years old and my son will be 5 years old in February and we always live in 2 cultures the American and the Mexican. My husband is American. We are combining both cultures we don't want to lose either one. With Spanish and English is the same: if my husband says the colors in English I say them in Spanish. When my daughter was 2 ½ years old she was able to say everything. My son couldn't, he only pointed to things, and used gestures. So I was very worried about what was happening with him.

We made an appointment with his pediatrician and he did a checkup and told us the he was fine. That it will take him longer to talk because of the two languages, but he said he was fine. I said to myself that I couldn't be sitting and waiting 8 years for him to talk; I couldn't as a mother just wait. I didn't believe that. Ok, he may not have any problems but I felt the need to do something; to look for information. I needed to find help, who could help me? I was not satisfied so I called the University. They gave me an appointment right away. At this time, this date etc., we will come to your house to have an interview and see about the next steps for your son.

This is when I realized that they spoke my language. That was my problem. How will I talk to them if I don't speak good English, and they don't speak Spanish? My English is very minimal. They introduced themselves and we talked in Spanish, perfect! They asked me lots of questions and did paperwork and then they said they didn't see any problems but will do an evaluation just to be sure. For us that were the support we needed. They gave us information, suggestions on how we could help him to support his language.

Mac didn't need individual therapy. He just participated in El Grupo. He started participating more with other children, he started doing the things the other children were doing. He might have known how to do it before, but he felt confident to do more and express more his needs. We noticed that on him and we started using the strategies from El Grupo here at home and now we give him more time and find more time for him. It really has worked for us and this year, as he is being part of El Grupo, he is talking more and talking in both languages. That was the support he needed; he is a very healthy and intelligent boy.

In the Hispanic community the language is the biggest barrier. Sometimes we have the information in our hands, but we are fearful to make a phone call because we don't know the language. What can I do if they answer in English? People hang up. After my experience with my son, some people asked me how you got my information. Or sometimes I'm asked: How old is your child? Is he 3 years old? Is he talking? No not yet… No don't wait.

After El Grupo, he was in school that year and we were asked if we could give permission to do a screening on him. We gave our permission. That school is English only; they don't have a bilingual staff. And when the results of the test were given to us, they said that he had a problem with his hearing and with his language development. I went back to the University and asked if they could help me with these findings. I asked for help again and they said yes and did another hearing test, vision and we had an interview and they saw him and everything was OK again. But it was a warning again. What is happening!!!!! Aren't you aware? Aren't you seeing this? The problem was that his school is not bilingual; the teachers didn't know that he was bilingual.   It's normal that an English-speaking kid is different than a kid that is bilingual; it's normal that if you are bilingual you may be below a little bit. Mac is bilingual and he is very strong in English.

Now in his new school, it's clear for the teachers that Dad is American and speaks English and Mom is Mexican and speaks Spanish and both languages are spoken at home.

Mac speaks more English but he is trying to speak Spanish and he says: "I speak English and Spanish", and he says it with a lot of pride.

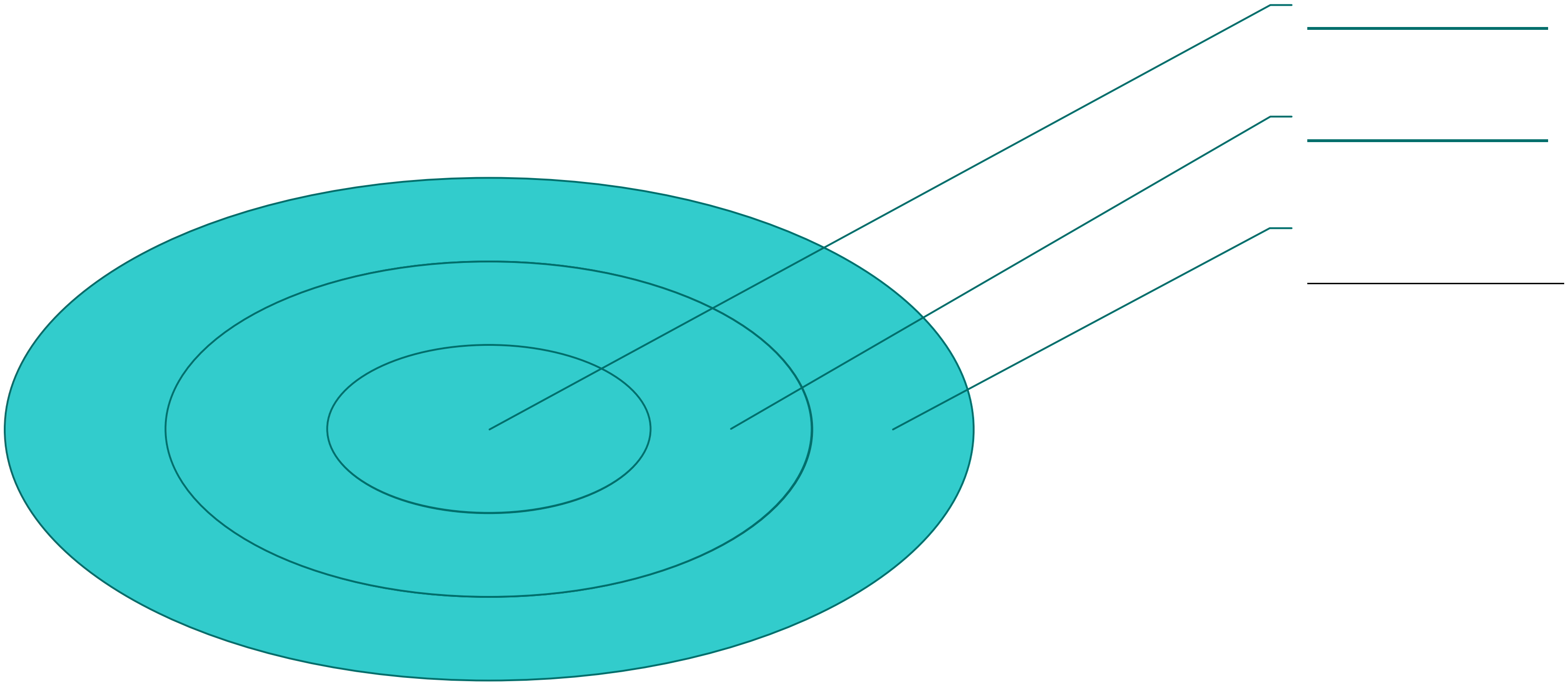
H12 Power of Language: Valuing Linguistic Differences

- Power of language is great because language and culture are so interdependent, communicating with families from different cultural and linguistically different backgrounds can be very complex.
- When language of the family and the provider are different it is clear that communication may be severely compromised. However, speaking the same language does not guarantee communication.
- Providers cannot learn 114 different languages that are spoken in homes of Children in Colorado but they can value the diversity and power of languages and seek ways to communicate with families as they build relationships
- Researchers now believe that far from being a problem, the process of acquiring two languages from a very early age has academic, economic and social advantages.

H13 **Unequal Childhood Scenarios**			
	Daily Routines	Priorities	Values
Scenario One: “Laughing and yelling, a white toddler named GT splashes around in the swimming pool with his nanny in the backyard of his 4 bedroom house in the suburbs. As on most evenings, after a quick dinner his father drives him to Gymboree at the local rec center. His brother has a baseball game as a different location…as they rush out of their works clothes and get the children ready for activities; the boy’s parents are harried…			
Scenario Two: Only 10 minutes away, a Black 2 year old AW, is riding home from child care with his mother in their beige, leather upholstered Lexus. A’s mother is tired but talks with her son about school…She has a long Thursday ahead of her. She will get up at 4:45 to go out of town on business and arrive home at 9:00 that evening. The next day she will chauffeur A to a private Suzuki violin lesson, followed by a visit to his Nanna and then a soccer game for her older child…Discussions between parents and children are a hallmark of middle-class child rearing…			
Scenario Three: Farther away a Black two and a half year old boy, HM, plays outdoors in the housing project in which he lives, with his two male cousins. After giving up searching for a basketball, they come in to watch sports on TV and then go back outside for a water balloon fight. People sit in white plastic chairs outside the apartments and music and TV can be heard.			
Scenario Four: Only 20 minutes away in a “blue-colored neighborhood and slightly farther away in a public housing project, childhood looks different. Mt Y, a white working class father picks up his son, Billy, from his Head Start child care program. He has a beer while his son watches some TV, then rides his “trike’ and plays on the sidewalk outside of their apartment. Other nights he and his Dad might sit on the sidewalk and with cars and trucks. At 5:30, B’s mother arrives home after work as a house cleaner and makes dinner. They all sit down together as a family and await the visit from an uncle who typically stops by to talk.			

Module B Handouts

H14 **Who is in Your Circle?**



H15 You Are Not Alone: For Parents When They Learn That Their Child Has a Disability

When parents learn that their child has a disability or a chronic illness, they begin a journey that takes them into a life that is often filled with strong emotion, difficult choices, interactions with many different professionals and specialists, and an ongoing need for information and services. Initially, parents may feel isolated and alone, and not know where to begin their search for information, assistance, understanding, and support. This News Digest has been developed expressly to respond to the information needs of parents—those who have just learned their child has special needs and those who have lived with this reality for some time but who have reached a transition point where they need new information or renewed support. This issue provides a starting point for families in their search for information and resources. We hope that it will also be useful to professionals who work with families who have a child with a disability, helping them to understand how having a child with a disability can affect the family and providing them with a ready resource to share with the parents with whom they work.

In the following article, "You Are Not Alone," Patricia McGill Smith speaks candidly to parents about the emotions that many parents of exceptional children experience and offers a perspective for living and coping with the impact of disability upon the family.

You Are Not Alone: For Parents When They Learn That Their Child Has a Disability

by Patricia McGill Smith

If you have recently learned that your child is developmentally delayed or has a disability (which may or may not be completely defined), this message may be for you. It is written from the personal perspective of a parent who has shared this experience and all that goes with it.

When parents learn about any difficulty or problem in their child's development, this information comes as a tremendous blow. The day my child was diagnosed as having a disability, I was devastated—and so confused that I recall little else about those first days other than the heartbreak. Another parent described this event as a "black sack" being pulled down over her head, blocking her ability to hear, see, and think in normal ways. Another parent described the trauma as "having a knife stuck" in her heart. Perhaps these descriptions seem a bit dramatic, yet it has been my experience that they may not sufficiently describe the many emotions that flood parents' minds and hearts when they receive any bad news about their child.

Many things can be done to help yourself through this period of trauma. That is what this paper is all about. In order to talk about some of the good things that can happen to alleviate the anxiety, let us first take a look at some of the reactions that occur.

Common Reactions

On learning that their child may have a disability, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and this enormous challenge. One of the first reactions is

denial—"This cannot be happening to me, to my child, to our family." Denial rapidly merges with **anger**, which may be directed toward the medical personnel who were involved in providing the information about the child's problem. Anger can also color communication between husband and wife or with grandparents or significant others in the family. Early on, it seems that the anger is so intense that it touches almost anyone, because it is triggered by the feelings of **grief** and inexplicable **loss** that one does not know how to explain or deal with.

Fear is another immediate response. People often fear the unknown more than they fear the known. Having the complete diagnosis and some knowledge of the child's future prospects can be easier than uncertainty. In either case, however, fear of the future is a common emotion: "What is going to happen to this child when he is five years old, when he is twelve, when he is twenty-one? What is going to happen to this child when I am gone?" Then other questions arise: "Will he ever learn? Will he ever go to college? Will he or she have the capability of loving and living and laughing and doing all the things that we had planned?"

Other unknowns also inspire fear. Parents fear that the child's condition will be the very worst it possibly could be. Over the years, I have spoken with so many parents who said that their first thoughts were totally bleak. One expects the worst. Memories return of persons with disabilities one has known. Sometimes there is guilt over some slight committed years before toward a person with a disability. There is also fear of society's rejection, fears about how brothers and sisters will be affected, questions as to whether there will be any more brothers or sisters in this family, and concerns about whether the husband or wife will love this child. These fears can almost immobilize some parents.

Then there is **guilt**—guilt and concern about whether the parents themselves have caused the problem: "Did I do something to cause this? Am I being punished for something I have done? Did I take care of myself when I was pregnant? Did my wife take good enough care of herself when she was pregnant?" For myself, I remember thinking that surely my daughter had slipped from the bed when she was very young and hit her head or that perhaps one of her brothers or sisters had inadvertently let her drop and didn't tell me. Much self-reproach and remorse can stem from questioning the causes of the disability.

Guilt feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, "Why me?" or "Why my child?" many parents are also saying, "Why has God done this to me?" How often have we raised our eyes to heaven and asked: "What did I ever do to deserve this?" One young mother said, "I feel so guilty because all my life I had never had a hardship and now God has decided to give me a hardship."

Confusion also marks this traumatic period. As a result of not fully understanding what is happening and what will happen, confusion reveals itself in sleeplessness, inability to make decisions, and mental overload. In the midst of such trauma, information can seem garbled and distorted. You hear new words that you never heard before, terms that describe something that you cannot understand. You want to find out what it is all about, yet it seems that you cannot make sense of all the information you are receiving. Often parents are just not on the same wavelength as the person who is trying to communicate with them about their child's disability.

Powerlessness to change what is happening is very difficult to accept. You cannot change the fact that your child has a disability, yet parents want to feel competent and capable of handling their own life situations. It is extremely hard to be forced to rely on the judgments, opinions, and recommendations of others. Compounding the problem is that these others are often strangers with whom no bond of trust has yet been established.

Disappointment that a child is not perfect poses a threat to many parents' egos and a challenge to their value system. This jolt to previous expectations can create reluctance to accept one's child as a valuable, developing person.

Rejection is another reaction that parents experience. Rejection can be directed toward the child or toward the medical personnel or toward other family members. One of the more serious forms of rejection, and not that uncommon, is a "death wish" for the child—a feeling that many parents report at their deepest points of depression.

During this period of time when so many different feelings can flood the mind and heart, there is no way to measure how intensely a parent may experience this constellation of emotions. Not all parents go through these stages, but it is important for parents to identify with all of the potentially troublesome feelings that can arise, so that they will know that **they are not alone**. There are many constructive actions that you can take immediately, and there are many sources of help, communication, and reassurance.

Seek the Assistance of Another Parent

There was a parent who helped me. Twenty-two hours after my own child's diagnosis, he made a statement that I have never forgotten: "You may not realize it today, but there may come a time in your life when you will find that having a daughter with a disability is a blessing." I can remember being puzzled by these words, which were nonetheless an invaluable gift that lit the first light of hope for me. This parent spoke of hope for the future. He assured me that there would be programs, there would be progress, and there would be help of many kinds and from many sources. And he was the father of a boy with mental retardation.

My first recommendation is to try to find another parent of a child with a disability, preferably one who has chosen to be a parent helper, and seek his or her assistance. All over the United States and over the world, there are Parent to Parent Programs. The National Information Center for Children and Youth with Disabilities (NICHCY) has listings of parent groups that will reach out and help you. If you cannot find your local parent organization, write to NICHCY to get that local information.

Talk with Your Mate, Family, and Significant Others

Over the years, I have discovered that many parents don't communicate their feelings regarding the problems their children have. One spouse is often concerned about not being a source of strength for the other mate. The more couples can communicate at difficult times like these, the greater their collective strength. Understand that you each approach your roles as parents differently. How you will feel and respond to this new challenge may not the same. Try to explain to each other how you feel; try to understand when you don't see things the same way.

If there are other children, talk with them, too. Be aware of their needs. If you are not emotionally capable of talking with your children or seeing to their emotional needs at this time, identify others within your family structure who can establish a special communicative bond with them. Talk with significant others in your life—your best friend, your own parents. For many people, the temptation to close up emotionally is great at this point, but it can be so beneficial to have reliable friends and relatives who can help to carry the emotional burden.

Rely on Positive Sources in Your Life

One positive source of strength and wisdom might be your minister, priest, or rabbi. Another may be a good friend or a counselor. Go to those who have been a strength before in your life. Find the new sources that you need now.

A very fine counselor once gave me a recipe for living through a crisis: "Each morning, when you arise, recognize your powerlessness over the situation at hand, turn this problem over to God, as you understand Him, and begin your day."

Whenever your feelings are painful, you must reach out and contact someone. Call or write or get into your car and contact a real person who will talk with you and share that pain. Pain divided is not nearly so hard to bear as is pain in isolation. Sometimes professional counseling is warranted; if you feel that this might help you, do not be reluctant to seek this avenue of assistance.

Take One Day at a Time

Fears of the future can immobilize one. Living with the reality of the day which is at hand is made more manageable if we throw out the "what if's" and "what then's" of the future. Even though it may not seem possible, good things will continue to happen each day. Worrying about the future will only deplete your limited resources. You have enough to focus on; get through each day, one step at a time.

Learn the Terminology

When you are introduced to new terminology, you should not be hesitant to ask what it means. Whenever someone uses a word that you don't understand, stop the conversation for a minute and ask the person to explain the word.

Seek Information

Some parents seek virtually "tons" of information; others are not so persistent. The important thing is that you request accurate information. Don't be afraid to ask questions, because asking questions will be your first step in beginning to understand more about your child.

Learning how to formulate questions is an art that will make life a lot easier for you in the future. A good method is to write down your questions before entering appointments or meetings, and to write down further questions as you think of them during the meeting. Get written copies of all documentation from physicians, teachers, and therapists regarding your child. It is a good idea to buy a three-ring notebook in which to save all information that is given to you. In the future, there will be many uses for information that you have recorded and filed; keep it in a safe place. Again, remember always to ask for copies of evaluations, diagnostic reports, and progress reports. If you are not a naturally organized person, just get a box and throw all the paperwork in it. Then when you really need it, it will be there.

Do Not Be Intimidated

Many parents feel inadequate in the presence of people from the medical or educational professions because of their credentials and, sometimes, because of their professional manner. Do not be intimidated by the educational backgrounds of these and other personnel who may be involved in treating or helping your child. You do not have to apologize for wanting to know what is occurring. Do not be concerned that you are being a bother or are asking too many questions. Remember, this is your child, and the situation has a profound effect on your life and on your child's future. Therefore, it is important that you learn as much as you can about your situation.

Do Not Be Afraid to Show Emotion

So many parents, especially dads, repress their emotions because they believe it to be a sign of weakness to let people know how they are feeling. The strongest fathers of children with disabilities whom I know are not afraid to show their emotions. They understand that revealing feelings does not diminish one's strength.

Learn to Deal with Natural Feelings of Bitterness and Anger

Feelings of bitterness and anger are inevitable when you realize that you must revise the hopes and dreams you originally had for your child. It is very valuable to recognize your anger and to learn to let go of it. You may need outside help to do this. It may not feel like it, but life will get better and the day will come when you will feel positive again. By acknowledging and working through your negative feelings, you will be better equipped to meet new challenges, and bitterness and anger will no longer drain your energies and initiative.

Maintain a Positive Outlook

A positive attitude will be one of your genuinely valuable tools for dealing with problems. There is, truly, always a positive side to whatever is occurring. For example, when my child was found to have a disability, one of the other things pointed out to me was that she was a very healthy child. She still is. The fact that she has had no physical impairments has been a great blessing over the years; she has been the healthiest child I have ever raised. Focusing on the positives diminishes the negatives and makes life easier to deal with.

Keep in Touch with Reality

To stay in touch with reality is to accept life the way it is. To stay in touch with reality is also to recognize that there are some things that we can change and other things that we cannot change. The task for all of us is learning which things we can change and then set about doing that.

Remember That Time Is on Your Side

Time heals many wounds. This does not mean that living with and raising a child who has problems will be easy, but it is fair to say that, as time passes, a great deal can be done to alleviate the problem. Therefore, time does help!

Find Programs for Your Child

Even for those living in isolated areas of the country, assistance is available to help you with whatever problems you are having. NICHCY's *State Resource Sheets* list contact persons who can help you get started in gaining the information and assistance you need. While finding programs for your child with a disability, keep in mind that programs are also available for the rest of your family.

Take Care of Yourself

In times of stress, each person reacts in his or her own way. A few universal recommendations may help: Get sufficient rest; eat as well as you can; take time for yourself; reach out to others for emotional support.

Avoid Pity

Self-pity, the experience of pity from others, or pity for your child is actually disabling. Pity is not what is needed. Empathy, which is the ability to feel with another person, is the attitude to be encouraged.

Decide How to Deal With Others

During this period, you may feel saddened by or angry about the way people are reacting to you or your child. Many people's reactions to serious problems are caused by a lack of understanding, simply not knowing what to say, or fear of the unknown. Understand that many people don't know how to behave when they see a child with differences, and they may react inappropriately. Think about and decide how you want to deal with stares or questions. Try not to use too much energy being concerned about people who are not able to respond in ways you might prefer.

Keep Daily Routines as Normal as Possible

My mother once told me, "When a problem arises and you don't know what to do, then you do whatever it was that you were going to do anyway." Practicing this habit seems to produce some normalcy and consistency when life becomes hectic.

Remember That This is Your Child

This person is your child, first and foremost. Granted, your child's development may be different from that of other children, but this does not make your child less valuable, less human, less important, or in less need of your love and parenting. Love and enjoy your child. The child comes first; the disability comes second. If you can relax and take the positive steps just outlined, one at a time, you will do the best you can, your child will benefit, and you can look forward to the future with hope.

Recognize That You Are Not Alone

The feeling of isolation at the time of diagnosis is almost universal among parents. In this article, there are many recommendations to help you handle feelings of separateness and isolation. It helps to know that these feelings have been experienced by many, many others, that understanding and constructive help are available to you and your child, and that you are not alone.

H16 Examples of Influence from Belief Systems

- Cultural: “If only I had worn the keys during the full moon as my mother told me, my baby would not have been born with a cleft palate”
- Cultural: “This child is sacred and must be sheltered and protected as a child with special powers”
- Cultural: “If Lia’s sister had not slammed the door, her soul would not have left her body”
- Religious: “It is God’s will”
- Religious: “It is punishment from God”
- Religious: “ It is a blessing from above”

List additional examples from your own experience:

H17 An Unexpected Journey

- Key reactions of the families to their child’s situation…emotions and feelings of guilt, pride, fear, frustration, sadness, etc.

- The impact on the lives of all family members.

- Specific strategies used by the hospital “team of providers” supported families given different situations and concerns as they traveled this journey.

H18 Welcome to Holland

By Emily Perl Kingsley, 1987.

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this......

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away...because the loss of that dream is a very significant loss. But...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

H19 What You Should Know About My Child

Remember that he is, first of all, my child.

Let me see him smiling in his sleep and let me think about how handsome he is
and not about how delayed that smile was in coming.

Help me not lose sight of my son in the shadow of his limitations
I know that you care for my child and that you work hard with him.

I need your expertise to help him become all that he is capable of being.

You need my help in understanding who he really is
and in following through at home with things that are important.

Remember, though, that you send him home at night and have weekends off and paid vacations.

Let me have the luxury of having a vacation, sometimes physically,
sometimes just emotionally, for a day, a week, a month, without your judging me.

I will be there for him when you are long gone.

I love my child with an intensity that you can only imagine.

If on a given day I am tired or cross with him, listen to me,
lighten my burden, but do not judge me.

Celebrate with me, rejoice in who he is and who he will become
but forgive me if from time to time I shed a tear for who he might have been.

- Author Unknown

H20 Supporting Transitions to Home

How can we support families transitioning to home?

- Recognize that some families need to have time to absorb what has happened and adjust to it.
- Some families may want to deal with the feelings of fear, confusion, helplessness, anger, guilt, and need more time to deal with these issues.
- Affirm that feelings are real, and respond with empathy.
- Other families may need a "sounding board" or someone to just listen to their fears and other feelings associated with their circumstances.
- Listen without judgment
- Refer to service coordinator and other team members as appropriate.
- Provide information when asked.

Additional ideas:

H21 Tapping into the Family's Internal Resources

- **Unconditional positive regard:**
  - Is blanket acceptance and support of a person regardless of what the person says.
  - Is essential to healthy development.
  - If not experienced by people (i.e. lack of unconditional positive regard), may result in seeing themselves in the negative ways that others have made them feel.
  - Can be facilitated by keeping in mind the belief that all people have the internal resources required for personal growth.

- **Resilience**:
  is a response to adversity is considered an innate capacity bolstered by environmental "protective factors" such as family cohesiveness and external supports... the same supports that nurture us all.

- **Protective Factors:**
  - The supports and opportunities that buffer the effect of adversity, crisis, or challenges and enable development to proceed …
  - Family strengths, assets, as well as outside influences such as productive alliances with other families and positive family professional partnerships
  - All parents have following inner strengths or resources that can serve as a foundation and can be utilized to build their resilience.
    - ✓ faith, flexibility, humor, communication skills, problem-solving skills, mutually supportive caring relationships, the ability to identify and access outside resources and services when needed.

    All of these strengthen the capacity to parent effectively, and they can be nurtured and developed through concrete skill-building activities or through supportive interactions with others.
  - Community services that help families in crisis include early intervention programs that focus on culturally competent, family-centered care. Research suggests they appear to transcend ethnicity, social class, geographical locations and historical boundaries and predict positive outcomes for anywhere from 50-80% of a high risk population
  -

Take Away Message Resilience is based upon "protective factors" such as individual family strengths, family supports, and supports provided by early intervention and other services that can serve to "buffer" the adverse impacts of having a child identified with a disability.

H22 **Resilience Factors of Families**

Name of Family____

Families' Strengths	**Sources of Information**	**Supports**	**Other Factors**

H23 Beach Center Stories: Anthony's Story

Making a Sustainable Difference in Quality of Life

When the circle stays unbroken: Family support and Anthony

Porscha was 19 years old at the time of Anthony's diagnosis. But she had begun to suspect that something was wrong when Anthony was six months old. "He had tantrums but as he got older, they grew worse. When he lashed out at a newborn in the doctor's office one day, I knew it was time."

She and Anthony saw a specialist who Porscha says "beat around the bush" about the diagnosis. "He didn't use the word autism. He said Anthony had PDD (Pervasive Developmental Disorder)." Porscha took Anthony to teaching hospital in a nearby city where autism was confirmed. "I kept thinking it couldn't be right. But I was pregnant with my second child and had no choice. I had to accept it."

During this period, Porscha faced many challenges that seemed overwhelming at times. However, she did not give up on herself or her son and, thanks to the support of her extended family, Porscha persevered.

Close-Knit, Extended Family

Today Anthony lives with his mom and his little brother, Christian. Anthony's grandparents and great-grandparents live within a mile of his house. Porscha works during the day and her mother cares for Anthony. In fact, Porscha says her mother was her "biggest support system" during the summer when Anthony's diagnosis was confirmed. Anthony's father left and Porscha says "my whole world fell apart." Her mother retired from her own job following Anthony's diagnosis so she could care for her grandson. One of the biggest sources of support for Anthony is his five-year-old cousin, Jonathan. "If Anthony hits him, Jonathan will say 'That's okay. He has autism.' Or if Anthony has a tantrum Jonathan will say, 'It's not his fault. It's because he has autism.' Jonathan has done more for Anthony than anyone could. I can't wait to see what relationship those two have when Anthony and Jonathan are older."

Porscha said, "Our family is very tight, and we have a great family support system." Porscha and other family members go to Anthony's therapy sessions so everyone can learn the recommended strategies.

Today Porscha expresses pride in herself and her extended family for all they have accomplished. According to staff at the Behavior Clinic at the University of Kansas Medical Center, Anthony has made more progress in that amount of time than any child they have seen who does not have professionals providing most of the therapy. Porscha's whole family deserves the credit. As Porscha says, "Why have professionals done it when we are perfectly capable of doing it ourselves?" 2

The Role of an Affirming Provider

Porscha met Martha, an early intervention service provider, through TARC. She not only directs their family support services but helps the family capitalize on learning opportunities throughout the day and provides emotional support.

According to Martha, "I offer information and support the decisions the family makes. At the beginning Porscha received conflicting information from different doctors, especially about medication. It's overwhelming when the family has lots of information from everywhere. I told them not to feel bad if they didn't take everyone's advice. My job was to affirm their choices."

To address Anthony's temper tantrums, Martha taught the family how to massage Anthony to help him calm down. Martha also taught Anthony how to calm himself down. Martha introduced Porscha to the local Community Developmental Disabilities Organization (CDDO), which provided case management and financial information to Porscha. Porscha feels that Martha is a wonderful partner. "When I melt down and cry, she is always there for me."

Helping Anthony Transition

Anthony's vocabulary today exceeds 100 words. He has participated in playgroups of children his age and is in a preschool classroom for children with autism. Martha hopes that ultimately Anthony will attend a general preschool program part-time as well.

Transitioning to new situations remains one of the hardest challenges for Anthony. According to Martha, "A strong, trusting relationship between the teacher and Anthony will be the most important factor for his successful transition to school." One strategy that has worked with Anthony is music, such as songs that help him shift from one activity to another. One of these is a "clean-up" song that engages children in picking up a play area.

Transitioning is not only important during school, but also when moving from home to public places. A year ago, Anthony's family could not even imagine going out for a picnic or dinner because he was not able to sit in public places for extended periods of time without having a tantrum. Today, little by little, the family is going to restaurants, and he can sit in public for about 20 minutes. This represents tremendous progress for Anthony and his entire family. "We can take him shopping now," Porscha said. "The whole family is stepping out into society again. A year ago I would not have thought in a MILLION years that we would be where we are today."

Looking Back…and Then Forward

Martha feels that her main strength in supporting the family has been "to support the family and not to add stress to the situation. Professionals need to listen to families. Try to have empathy because the family is probably going through a rough time. Ask honestly what you can do to help. Have open communication and don't take it personally if the family rejects an idea."

Martha didn't come into Anthony's life to "teach him" but "I tried to build a relationship. I gained his trust and took it one step at a time. Porscha gave me the feedback that this was the way to approach Anthony. If he was forced to do something, he would shut down." 3

In the long run, Porscha says she is thankful to have a child with autism. "I've met so many wonderful people and I've also seen how cruel the world can be. I am grateful I have Anthony, thankful that he has done so well, for all the support I've had."

Porscha's positive outlook and confidence are a result of her sincere commitment to her son. Porscha states, "I'm not giving him up on him. His success or failure lies in our hands. We're not going to let him fail."

Miracles Do Happen

Porscha strongly believes that miracles do happen. "Anthony is living proof of that. With Anthony the sky is the limit and there are no limits on how much he is going to achieve in life. Although we are faced with autism every day, Anthony is not letting that stop him from making new progress. Without the help of my mother and father and their support, I have no idea of where Anthony would be today. There are not a million words I can say to you except, 'Thank you Mom and Dad for everything. I love you.'"

H24 Beach Center Stories: Caleb's Story

Partnerships Make All the Difference for a Family in Crisis

It was a parent's worst nightmare for first-time moms Joy and Jeanine. Their infant son, Caleb, born healthy at the Holistic Birthing Center in Topeka, KS, suddenly developed jaundice within a few days of returning home. While not uncommon in newborns, for Caleb it became a life-altering condition, potentially causing auditory damage and mental retardation. Three days after his birth Caleb got "really sick really quickly," Joy recalls. A test showed that Caleb's bilirubin measured 33 (6 is normal; 15 is considered high). Caleb was transported to a comprehensive children's hospital 40 miles from home and immediately underwent a blood transfusion. "The prognosis going in was severe brain damage," Joy said. "At the very least they expected him to have complete hearing loss."

With an IV, a respirator, and "tubes everywhere," Caleb's health crisis became a terrifying experience for his parents. Fortunately, a social worker from the hospital stepped in and provided support for Joy and Jeanine, not only for Caleb but for a range of financial and personal emergencies bearing down on the family all at once.

Finding Resources

First, Joy and Jeanine were told they could stay at the hospital's Ronald McDonald House during Caleb's hospitalization, relieving them from the additional stress of traveling to and from home. A hospital social worker ensured they had a pediatrician they liked and provided a host of other resources. Caleb's condition improved although the long-term picture remained uncertain. After two long weeks, Caleb was released.

The hospital social worker referred Joy and Jeanine to the Infant-Toddler Coordinating Council (ICC is now known as **tiny-k Early Intervention**) www.douglascountytinyk.org/ in their local community. The ICC coordinator visited their home and assessed what the family needed--medically, financially, and emotionally. Those needs weren't insignificant. A few days before Caleb's birth, Jeanine had undergone reconstructive knee surgery and was still unable to work. Joy was out of a job, too. Their relationship was showing signs of stress due to Caleb's health, Jeanine's physical limitations, and the family's money woes. "We were at the breaking point," Joy admits.

Susan, a clinical social worker who specializes in early screening and intervention, was part of the ICC team that went to work for Joy and Jeanine. She immediately collaborated with the family to not only determine what they needed but to build rapport and establish their trust. "The family identified its first priority, which was the need for financial support and assistance," Susan said.

Food and Finances

In response to the family's need, Susan called local community action agencies willing to provide assistance to help stabilize the family's situation. She contacted programs that agreed to pay the family's home heating and other utility costs, a significant expense for any Midwestern family in the winter months. Susan also pinpointed other long-term sources of support, such as a private food pantry that only asked Joy and Jeanine to donate community service in return.

Susan also worked with the couple to resolve communication problems stemming from money worries. While in the past Joy and Jeanine had resolved financial decisions amiably, even something as commonplace as car repair was suddenly a point of contention. "We couldn't discuss anything when Susan first came to us," Jeanine said. "She helped us communicate and made us listen to each other," Jeanine said.

A third member of the ICC team was Lindsey, a speech-language pathologist. Considered the primary provider on the team because of Caleb's potential bi-lateral hearing loss, Lindsey provided in-home developmental and hearing screening for Caleb and talked to Joy and Jeanine about hearing aids.

Good News At Last

Ironically, Lindsey's role on the team changed dramatically when, at around five months, Caleb passed his hearing screening. In fact, to date Caleb has reached all his developmental milestones and is a happy baby boy described by one of his mothers as "wonderfully behaved."

Still, the experience of coping with Caleb's illness and the need for professional help taught Joy and Jeanine several lessons. Well-educated, mature women, they battled preconceived notions in their dealings with health care professionals. Jeanine is a nurse although she is quick to admit, not a pediatric nurse. "The doctors would spend most of their time talking to me. People assumed we knew more than we did." They also sensed that their family and professionals felt that, as two female caregivers, Joy and Jeanine would be able to manage everything. However, Joy and Jeanine needed support and guidance, as well. Because two women were involved that Caleb had plenty of nurturing. But who needed nurturing, too, were Joy and Jeanine.

Assessing What Worked

What made the intervention relationship work in the case of Joy, Jeanine, and the professionals who were their allies? It came down to a combination of professional and interpersonal skills and a willingness on the part of the family to ask for help.

"I try to create a close relationship with every family," Lindsey said. She gave Joy and Jeanine her cell phone number and spent time with them as well as with their baby. Jeanine cited Lindsey's accessibility as central to their relationship. "It has been wonderful for Lindsey to keep coming over even after Caleb passed the screening. It takes such a load off your shoulders."

" Originally when I came in I was trying to work with the family on finding funding for hearing aids and work on meeting other development milestones. It was really great to find out he did not need hearing aids and I am down to once a month visits now."

Knowing Human Behavior

Susan said her ability to establish a rapport quickly with Joy and Jeanine is an important skill. "At heart I am a diagnostician. I know and understand human behavior and relationship patterns. You have to have the ability to assess that dynamic." Susan described her role on the ICC team as the hub of a wheel with various spokes: delegation, networking, and facilitating. “Networking with community resources and agencies tends to come naturally to social workers because of their training. If you are a helping professional and need assistance with collaborating and networking, I recommend connecting with someone who can provide this service as part of the team.”

Joy and Jeanine feel that their team brought a unique element of trust from the first moment they met. “We’re very good at appearing good at our very worst,” Joy said. “To let them see us in crisis was a big deal.” Lindsey and Susan credit the family for accepting outside help when this did not come naturally to them. According to Susan, people in the middle and upper economic income groups are sometimes overlooked for services because it’s assumed they have other resources, such as grandparents. “But we all need supportive networks and a sense of community.”

Joy and Jeanine still work with Susan to resolve their financial and communication difficulties while Lindsey is winding down the services she provides to Caleb.

“It’s night and day between now and then,” Jeanine said. Joy says she and Jeanine have definitely been empowered by the experience. “You need to keep asking the questions you need to ask. It was a tough lesson to learn.”

H25 Beach Center Stories: Charlie's Story

It will be a rollercoaster ride

Immediately after birth, Charlie was transported by ambulance to an intensive-care neonatal clinic at Children's Mercy Hospital http://www.childrensmercy.org in Kansas City, Mo. During his 17-day hospital stay, Charlie underwent major surgery and had numerous tests to assess his medical condition. To this day his mother, Dana, remembers what a difficult time it was for the entire family. "We didn't even have time to ask about getting any kind of support from anyone. My emotional difficulties didn't even matter. It was about getting **him** through it."

Once home, the family was contacted by the local early intervention program, Toddlers and Infants Need You-Kansas (TINY-K) , http://www.tiny-k.org referred by a social worker at the hospital. Knowing multiple surgeries were in Charlie's near future, the family anticipated considerable financial stress. Dana recalls, "It was a huge relief to know that kind of intervention program existed and that it was free of charge." The TINY-K director visited Charlie's family and explained what services Charlie would receive. Dana and her husband, Leland, took comfort in the fact that the team took control, freeing the family from that responsibility. Charlie received in-home occupational, physical, speech and language, and nutrition from then until his third birthday.

An Eclectic Approach

Cassi, Charlie's physical therapist, described the treatment approach she and her team use as "an eclectic mix of the coaching model http://www.coachinginearlychildhood.org/presentations.php, routine-based intervention http://www.vanderbiltchildrens.com/interior.php?mid=1394, and the trans-disciplinary play-based model." According to Cassi, there are three main strengths of this approach. One, it allows every Individualized Family Service Plan (IFSP) http://www.birth23.org/Families/IFSP.asp to be dynamic and tailored to the needs of each child and family by taking into account family priorities, schedules, daily routines, culture, and lifestyle.

Second, the approach promotes collaboration between parents, providers, teachers, and caregivers to ensure everyone's on the same page. For instance, Charlie's team of providers met once a week to collaborate and discuss progress toward goals, to address new strategies, and to plan their next steps as a team. "This meeting is a necessity when utilizing a trans-disciplinary approach," Cassi explained. For example, the occupational therapist shares strategies she is using to encourage Charlie to use a pincer grasp (thumb and pointer finger). This collaboration then allows Cassi to incorporate the OT's ideas during PT squatting activities to develop Charlie's leg strength for future walking.

Finally, the eclectic approach empowers the parents to become their child's most important interventionists and advocates. "As role model parents with a child with special needs, Leland and

"We didn't even have time to ask about getting any kind of support from anyone. My emotional difficulties didn't even matter. It was about getting **him** through it."

Dana truly understand and fully accept this role," Cassi said. “They know it is their responsibility to carry out the plan and they do an excellent job embedding as many strategies as they can throughout Charlie’s day. This dedication and role acceptance is the ultimate reason why Charlie will be able to meet his full potential.”

Feeling Overwhelmed

Despite their acceptance and absolute admiration for their son, Leland and Dana were overwhelmed with Charlie’s developmental challenges and ongoing medical care. Initially, they couldn’t help comparing Charlie to their typically developing nephew or niece, the neighborhood boy playing in a yard, or the girl running down the aisle at the grocery store. These children were a reminder of Charlie’s current and future challenges and of how his challenges would affect their life as a “typical” family. But over time, they learned to celebrate Charlie’s progress and successes rather than focus on his challenges or what he couldn’t do.

“I changed my attitude,” Dana said. “We became very excited and proud of any progress Charlie made. Everyone, including caregivers, therapists, doctors, and Charlie work hard for each bit of progress and it should be celebrated.” They also share and celebrate all Charlie’s accomplishments with family members and friends. Dana remembers calling her mother to share that Charlie said “good” to a teacher as he was leaving preschool for the day. Dana was thrilled Charlie said a new word and that it was in context. Charlie’s success was her focus and not his inability to say the whole word, “good-bye”.

Dana and Leland agree that having family, friends, and therapists who recognize and celebrate every small stride Charlie makes is both motivational and validating. “The TINY-K providers always notice and comment on Charlie’s progress and our efforts,” Dana said. “Their positive reinforcement and support validates that we are doing our best for our son.”

A Strong Marriage

Leland and Dana’s solid relationship enabled them to maintain a positive attitude throughout Charlie’s infancy. Born and raised in the same area, Leland and Dana met in grade school and have been married for several years. “We were close friends before getting married,” Dana said. “A strong relationship helped us to deal with the difficult time when Charlie was born and the ongoing challenges.” Leland agrees, “We needed to work together as a team because it was required of us.”

Cassi has now been working with Charlie’s family for more than two years. She was immediately taken by Leland and Dana’s “parental equality” in raising their son. Cassi explained, “The more time I spent with them, the more I admired their marriage and parenting style as a true partnership; something I didn’t grow up with where moms took care of the babies and dads coached Little League.”

Colleagues of Cassi’s feel it is her enthusiastic personality, positive attitude, and passion for children that makes the relationship she has with Charlie’s parents possible. Cassi explains, “Early intervention happens in family’s homes. Therefore, it fosters a level of trust and openness that you sometimes don’t have the opportunity to develop in other clinical or classroom settings.” Cassi freely offers all her families her cell phone number. “I encourage them to call me anytime to ask questions or report exciting achievements.” Like the day, Dana called Cassi to say, “Charlie is walking!”

What Keeps You Going

A year ago Charlie turned three. Transitioning out of early intervention services (Part C) into preschool services (Part B), Charlie and his family faced overwhelming conditions all over again, such as finding the right preschool environment and setting up new services. Even though Cassi transferred her responsibilities to the school district, she continues to work with them, not as a direct service provider, but as a friend and supporting team member. Dana and Leland have called Cassi many times for advice and sharing "Charlie stories" since the transition. Cassi said, "I hold a very special place in my heart for Charlie and always want him and his family to be a part of my life."

"During transitions, parents need information and advice about how to advocate for their child," Dana said. Leland and Dana decided to get involved in the community to learn how to best support Charlie throughout his life. Through fundraising activities and conferences, Dana and Leland have met parents with children with and without special needs and numerous professionals in the special education field. Through community involvement, they are gradually building a small network of individuals they can use as a resource and to advocate for Charlie. Getting to know other parents and talking to professionals and veteran parents has helped them anticipate and cope with some of the challenges of being a parent of a child with special needs.

When asked what her advice is to other parents, Dana replied, "I would tell parents that it will be an emotional roller coaster ride but it is ok to feel the way you do. There are days were you might dip down and feel very low, but it's when you see a bit of progress on another day that brings you right back up. And **that** keeps you going."

H26 Beach Center Stories: Harper's Story

Caring Providers and a Loving Family Make a Difference

For first time parents who had a normal pregnancy and typical delivery, the news was a shock. About 24 hours after Harper was born, Melissa and Jason first heard about the possibility of their daughter having Down syndrome. With no immediate health issues often present with children who have Down syndrome, no one except Jason, who is a pharmacist, questioned the possibility. He looked for some common characteristics of infants with Down syndrome but didn't notice any in his daughter. Early chromosomal testing gave an initial indication of Down syndrome and about two weeks later, Harper was referred to Children's Mercy Hospital where a formal diagnosis was confirmed.

Fortunately, their physician understood that Melissa and Jason would have many questions and asked them to write them down. Two days after Harper was born, their physician sat down with Melissa and Jason and listened to all their concerns. "We were lucky because she was nothing but positive and helpful with getting resources," says Melissa.

A Warm Welcome

When the search for a childcare program began, Melissa and Jason were able to enroll Harper into a program at the University of Kansas. "When I first called the program, I felt like the coordinator there was gushing over the telephone to get my daughter into their program," Melissa said. As the new mother of a daughter with Down syndrome, such a warm welcome was the start of a good relationship.

Melissa learned about her local Infant-Toddler Coordinating Council (ICC), now called TINY-K (check spelling) program through the coordinator in the childcare program. When Melissa first contacted ICC, she was not only impressed by the available services and support but also by the positive attitudes of the staff. Shortly after the initial contact, the ICC team visited with the family and discussed their goals, visions, and needs. "From their confidence and positive attitudes, I knew that they are going to do whatever they can do for Harper," said Melissa. From that point on, Harper has received such services as occupational and physical therapy, and speech language therapy.

To serve families best, the ICC staff team held a weekly meeting. In the meeting, the service providers, such as Cassi who is one of the primary providers for Harper, discussed where they were and what they need to focus on. According to Cassi, focusing on what every family needs and providing support based on those needs is the key role of an early intervention provider. By incorporating several different models such as the transdisciplinary model, primary provider model, and coaching model, the team was able to pursue the same goal in various ways. For example, when Cassi visited, she not only worked on motor skills but she also tried to embed Harper's speech goals into their time together.

Staying on the Same Page

Melissa and Jason wanted to provide Harper consistent support at home, at her childcare program, and during ICC visits. In response, the team came up with the idea of rotating the location of visits between the home and childcare program. Melissa said, "Harper spends seven hours at the child care program every day. It is important to keep them on same page."

After every ICC service provider visit, a note was provided containing information on what Harper did what they had worked on, and what need to be addressed next. Melissa treasured these notes not only because she could learn what had happened during the visits to the childcare program but also because of the way the notes were written. "Every parent loves to see positive comments," Melissa said.

In addition to ICC and the early childhood program services, Melissa and Jason did their best at home. When the ICC staff visited, Melissa and Jason took turns being at home and meeting the service providers. It allowed both parents to be on the same page regarding Harper and to be able to provide consistent support.

Family Strengths

One of the strengths of the family was the support they received from their extended family. The first grandchild on both sides of the family, Harper basks in the attention and love expressed by the entire family.

Jason also was a source of strength. He knew how to find information and handled it well. He always wanted to be involved in Harper's education. From the day Harper came home from the hospital, Jason read to Harper every day. Melissa calls the reading time "their thing." She strongly believes that Jason being an involved father has contributed positively to their daughter's development.

Harper's Gifts

Melissa and Jason believe that Harper has brought many wonderful things to their lives, not the least of which was getting to know people such as Cassi. Melissa and Jason believe the services they received gave them an enormous amount of support.

Currently, Jason and Melissa are actively involved in organizations such as the Down Syndrome Guild and TINY-K. The Down Syndrome Guild provides educational tools for parents, educators, and healthcare providers and sponsors social activities for parents and children. Jason and Melissa each have served on the board and assist with fundraising.

Melissa’s advice to other parents? “Don’t be afraid to ask questions.” She feels strongly that parents should have high expectations for their child; this is reflected in the expectations of service providers.

Following Harper’s third birthday, Melissa and Jason attended their first IEP (Individualized Educational Program) meeting. It was very different from what they were used to, but Cassi and another staff member were there to advocate for the family. Although Cassi is no longer the primary service provider for Harper, Melissa knows that Cassi will be there for Harper anytime. Cassi agrees. “They have my phone number on speed dial. They can call me anytime. They are my family.”

Module C Handouts

H27 Family’s Vision of Inclusion

What vision of inclusion is illustrated in the Creating Bright Futures video clip?

What did you hear families and service providers say about their experiences?

H28 Value Statements: Pass the Envelope Please …

“Children are likely to live up to what you believe of them” *Lady Bird Johnson,* Former First Lady of the United States.

“Children are not things to be molded, but are people to be unfolded.” *–Jess Lair*

“When I approach a child, he inspires in me two sentiments: tenderness for what he is and respect for what he will become” *Louis Pasteur,* Microbiologist

“Life affords no greater responsibility, no greater privilege, than the raising of the next generation” *C. Everett. Koop*, Former Surgeon General of the United States.

- **What do these quotations say to you about your work with young children and families?**

- **What do they say about including infants and toddlers with disabilities and their families in community?**

Your Value Statement Relating to Working with Families:

H29 Communication with Families

- **Communication Skills with Families**: Important things to remember including:
  - Listening is key!
  - When the language of the family and the provider are different it is clear that communication may be severely compromised
  - However, speaking the same language does not guarantee communication
  - According to researchers "Communication, both verbal and non-verbal, is critical to cross cultural competence" Lynch & Hanson, 2004

- **Having a Conversation** : techniques and important things to remember include the skill to:
  - Create an atmosphere of exchange
  - Focus on parent engagement and participation
  - Recognize the specific needs of a particular parent
  - Refrain from using professional jargon
  - Provide information
  - Be sensitive to challenges

- **Verbal & Non-Verbal Communication: T**echniques and important things to remember include the skill to:
  - Recognize strengths and resilience of families
  - Be present
  - Use silence as a tool
  - Follow the lead of your partner
  - Let them know you are listening by nodding, leaning forward, eye contact (if appropriate)
  - Ask open ended questions
  - Restate or paraphrase what you heard to affirm you are listening or to clarify intent of speaker

H30 Listening Without Judgment

- What does it mean to listen without judgment when building relationships with families when their beliefs about disability, illness, death and dying are different from your own?”

- What would it look like in practice with families?

H31 Reflection

- List in your journal the strategies that you feel are important to remember as you build relationships with families.

- Reflect how or if you will change your strategies depending upon the culture and life ways of the family.

H32 Developmental Intervention Assistant Roles and Responsibilities

	Developmental Intervention Assistant Roles and Responsibilities
Assist in Delivery of Early Intervention Services	• Implement activities to facilitate IFSP outcomes as directed by the supervisor • Video tape sessions • Carry out adapted instruction according to the adaptation list provided or specific directions based on the IFSP • Facilitate parents' active participation in intervention strategies as directed by the supervisor • Translate supervisor made materials / text materials into another language • Use another language (e.g. sign, Spanish), to discuss and elaborate on concepts that have been presented in English • Monitor infant/toddler’s performance as directed • Re-teach/reinforce intervention strategies introduced by supervisor to infant/toddlers and their parents
Assist in Data Collection/ Reporting	• Observe and record infant/toddler’s progress in areas identified on the IFSP as needing improvement (e.g. infant/toddler’s behaviors, health needs, food/liquid intake, use of communication skills, adaptive equipment or devices, social interactions/initiative, peer interaction/socialization behavior) as directed by the supervisor for ongoing assessment and ongoing IFSP reviews
Activity Preparation /Follow-up	• Find/arrange materials/equipment to be used in the intervention sessions as per the direction of the supervisor • Adapt materials/equipment as specified by the supervisor for a particular infant/toddler • Construct intervention materials as directed • Construct adapted intervention materials according to IFSP or other adaptation directions provided by supervisor and other early intervention provider • Distribute supplies/materials to families as directed
Ethical Practice/ Professional Practice	• Maintain confidentiality of all information regarding infant/toddler’s and their families • Respect the dignity of every child and their families at all times • Report suspected child abuse according to the law, and CCB policies, and procedures • Maintain relationship and communication with families within their professional scope of responsibility • Provide accurate and timely information about the infant/toddler to those who have the right to know [e.g. CCB team members, supervisor, etc] • Carry out all assigned duties responsibly, in a timely manner • Protect the welfare and safety of infant/toddlers at all times • Maintain composure/emotional control while working with infant/toddlers and families • Demonstrate punctuality, good attendance, and report absences as directed • Maintain professional behavior and appearance • Protect privacy and dignity of CCB staff members, team members, co-workers etc. • Accept assigned tasks • Request direction, instruction, or guidance for new or unfamiliar tasks
Team	• Meet with transdisciplinary team as scheduled/directed • Participate in team meetings by contributing information, ideas, and assistance and

	Developmental Intervention Assistant Roles and Responsibilities
Participation /Membership	by listening carefully to the ideas of others • Engage in appropriate problem-solving steps to resolve problems • Engage in mature conflict management steps processes • Use appropriate communication actions in adult-adult interactions • Respect the dignity of other adults • Participate in learning activities as specified in growth and development plan • Participate in CCB wide growth and development activities as specified • Attend IFSP meetings as required by the individual child and family needs • Attend annual review meetings • May assist the service coordinator with family access to culturally relevant services • Participate in intervention planning sessions with supervisor • Contribute unique skills and talents if appropriate when requested by the supervisor
Clerical Work	• Help with paperwork to facilitate annual reviews • Inventory materials and fill out routine forms as directed as well as help in the maintenance of files for IFSPs, assessment reports, other program reports as appropriate

(Note to the instructor: These roles have been identified by the Curriculum Review Panel (CRP) and the state-wide Coalition of the CO-TOP* EIS project. The CRP consisted of the national and state level early childhood education experts and the coalition consists of a wide representation of expertise from the rural and urban early intervention agencies).

H33 What is Wrong with this Picture?

Sue, a DI Assistant, arrives for her appointment on time to work with an infant recently identified with overall developmental delays to find the child's mother, Maria, the mother, is close to tears, looking exhausted, as she "was up all night." Maria explains that her husband left last night after an argument. She says that they have been having problems for some time and he wants a divorce. Maria also shares that she has tried to make her marriage work but now realizes that it is beyond repair. She is really worried as has no source of income and doesn't know what to do or where to get legal advice. Sue tries to calm the mom down and tells Maria that her cousin, Kim is an attorney who volunteers at a nonprofit organization that provides pro bono legal services to low-economic families. Sue assures Maria that she will have Kim call her and talk to her.

As she is leaving the home, Sue says, "if you don't hear from Kim in a day or two, let me know; I will follow up with her?" Next day, Sue doesn't mention anything to her supervisor about the situation and how she handled it.

- Did the DI Assistant act appropriately within the boundaries of the role?

- What would have been the appropriate way of handling this situation?

H34 Cultural Mediators, Interpreters & Translators

- **Who is a Cultural Mediator**?

When an interpreter/translator goes beyond translation of language and helps

"translate" between the culture of the school environment and the child's family in order to enhance understanding, share information, and create a relationship that supports families as full participants in the process, this individual becomes a cultural **mediator.**

The cultural mediator is always trained and works under the direction of the supervisor and may become:

- a referral source for community
- a liaison with parent
- a communication link to ensure parents are part of the team
- a "cultural gauge" for knowing what is/is not relevant to a family's cultural context

Values Essential to the Use of Cultural Mediators/Interpreters/Translators

If: The diversity of families is acknowledged and honored

Then: Their knowledge of and dreams for their children are believed and valued and they are recognized as the key decision-makers for their children

If: The child must be viewed in the context of their family, culture and community

Then: Supports and services will be culturally resonant with the child and family's culture

If: Interactions with the child and family occur in their primary/preferred language

Then: Cultural mediators, interpreters, and translators need to be effectively utilized as key team members, integral to the process of working with families from culturally and linguistically diverse backgrounds

- **Who Is an Effective Cultural Mediator?**

  An effective cultural mediator is:
  - proficient in English and the family's language
  - trained for their role
  - aware of the boundaries of his or her role
  - willing to take directions from the supervisor
  - able to maintain confidentiality
  - well-versed in use of appropriate terminology
  - skilled in interpersonal relations yet is able to remain neutral and objective
  - an individual who has knowledge of the early intervention service system and community resources.
  - not a member of the child's family

H35 Key Messages for DI Assistants in facilitating pathways of support for families

As DI Assistants, you:

- Maintain confidentiality of all information regarding infant/toddler's and their families
- Respect the dignity of every child and their families at all times
- Communicate with families only as directed by the supervisor
- May assist the service coordinator/team with family access to culturally resonant services under the direction and with the approval of the supervisor
- Act as cultural mediator/ translator/interpreter when directed by the supervisor. You will need appropriate training for this role.
- Communicate with team regarding family challenges or concerns that you become aware of. Any questions/situation that you encounter in their work with families is best addressed through consultations and discussion your supervisor and team members .DO NOT ACT ON YOUR OWN

H36 Strategies for Parent Advocacy and Leadership

Strategies that open doors for families to advocate for their own child and family

- Relationships are the foundation for beginning the family-service provider that nurture family leadership opportunities
- Encourage families to share their perspectives, ideas and suggestions.
- Listen and respond positively to family priorities.
- Provide families with information, resources, and support so they can make decisions for their child and family.
- Use of well trained cultural mediators, interpreters, and translators.

Strategies open doors for families to support other families

- Facilitate a variety of opportunities for families to come together e.g. parent groups
- Offer training for families who want to assume more formal roles of support.

Strategies that open doors for families to work at systems level

- Create opportunities for families to participate in committees, policy council, etc.
- Provide mentorship, training, and orientation by other families or service providers
- Provide information about leadership opportunities to all families.