

Module 1

Working with Families

by

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Learning Objectives

1. To identify the complex influences of an infant with multiple disabilities on the family
2. To describe the role of the interventionist in family-centered practice
3. To describe recommended practices for gathering information from and sharing information with families

Introduction

Having a baby with a disability creates an enormous impact on family life. The family of a child with multiple disabilities learns to love and care for a child differently than they had ever expected and differently from their other children. Examples of some of the unique challenges created by the birth of an infant with multiple disabilities include:

- Frequent visits to hospitals, clinics, and therapies that necessitate a significant time commitment to record keeping, appointment times, and case management.
- Many different people in the home, including early intervention service providers, nurses, and childcare providers.
- A change or loss of previous social and support networks. Friends and extended family members cope differently with disability.
- A change in the amount of time allotted to other family activities. Siblings often receive less attention given the increased amount of time required by the infant with multiple disabilities.
- A different way of responding on the part of the baby that is not expected or yet understood by family members.

Paradoxically, it is often difficult for families to ask for help, as many feel they can “go it alone” and rely on their own strength and resources. The importance of a positive family/professional relationship cannot be stressed enough — once families acknowledge that they need support, the nature of that support becomes a crucial part of how successful parents feel in raising their children as well as the developmental progress of the child.

An approach that respects the

- competence,
- priorities,
- culture, and
- decision making

of families leads to parental skills that will allow the family to support the child more successfully throughout life.

In the transactional model, the child's optimal development results from the successful, reciprocal interactions between a child, caregiver, and the environment. Thus, the family plays a central role in the child's development.

Teaching families the necessary skills and strategies for engaging in these successful interactions requires not only a positive relationship between parent and child, but between parent and the interventionist, and to a degree, between the interventionist and his or her peers and supervisors. Interventionists must now be skilled in the principles of adult learning and take a role of coach and supporter, as well as source of expertise.

Remember that a positive family/professional relationship is built on trust and open communication. Trusting relationships take time to develop. Listening is an important skill in building trust. Family stories are rich in information and convey emotion, hopes, and fact (Bernheimer & Weisner, 2007). Concerns are articulated and the hard work and worry of caring for a child with multiple disabilities may be expressed. A positive, family-centered service delivery model begins with certain assumptions:

- Parents are the primary influence in the young child's life.
- Parents are equal partners in the early intervention process.

- Parents know their child better than the professionals know the child.
- Parents want to do a good job raising their children.
- Family stories are a rich source of information about the child as well as family life as a whole.
- Family report of developmental skills is reliable.

Theoretical Bases

The traditional role of early intervention service providers may be described as designing activities and using strategies to promote:

- child progress,
 - growth and development,
 - independence, and
 - adaptation to disability.

However, the child does not live in isolation. He or she is part of a group that functions as a system. Each member functions under different roles and responsibilities, yet all are interrelated. Parents, siblings, grandparents, extended family members — even best friends and neighbors — all play a part in the child's life. Early intervention plans and activities affect all members of this system as they interact with each other and with the child.

The role of the early interventionist must be extended to include the following objectives:

- Support the functioning of family life and well-being (for example, in establishing the provision of respite care or accessing health care resources).
- Identify existing strengths and resources of children and families and help to build new family strengths and resources. This may include helping families develop parent-to-parent activities or parent education opportunities through early intervention program-sponsored activities.
- Collaborate with other service providers and help design an integrated program of intervention supports and services.

Reactions to the Diagnosis

Within the family system, each member may react to the diagnosis of an infant's disabilities in different ways. Some of these reactions can be tied to the processes of grieving:

- The family may mourn the loss of the child they dreamed about, yet clear differences separate grieving with regard to disability from grieving with regard to death (Moses, 1983). These reactions may be thought of as “feeling states” not “stages,” as an individual may experience more than one at a time and in a non-sequential order. One may re-experience a state at different points in time. The child's birthday, for example, may evoke yearly feelings of sadness, as the child grows physically, yet does not develop mentally, along with his or her peers.

These feeling states include:

- Shock — Denial — Guilt — Anger
- Sadness — Adjustment — Reorganization

- Reactions to the birth of an infant with disabilities may also be affected by one's culture, personal experience with disability, religious beliefs, and the reactions of close friends and extended family members.
- The experience of these states changes over time and relates to changes in the child's and family's life.
- The family may experience changes in values, priorities, and family activities as caregivers evaluate the profound impact of a child and his/her disabilities on their lives. A "regrouping" may occur as families identify what needs to be done, establish new goals and dreams, and re-align family activities and functions to accommodate the child with disabilities. This "regrouping" is a dynamic process that occurs over time and may take years.

As an empathic listener, the service provider may play an important role in helping families at this time. As families build trust and reveal their thoughts, the service provider can introduce ideas and information that will support the family's new goals.

The Nature of Family Support

Family support may take many forms, based on identified priorities. Respite care may allow parents to spend more time with siblings, pursue a personal interest, or simply catch up on chores or much-needed rest. Introducing parents to other parents of children with disabilities can decrease feelings of isolation, encourage friendships, and promote a sharing of tips and tricks that all families develop. Accompanying a family to a Parks and Recreation activity may help the family re-enter typical community activities and help the child participate in everyday childhood experiences.

Providing information to families also may take many forms. Service providers may design a "class" based on topics requested by families (e.g., First Aid/cardiopulmonary resuscitation, feeding strategies, infant massage).

Service providers may also bring information to the family at home or provide other interventionists, family members, or community personnel with information, adaptations, and strategies relevant to the child.

Family support and education activities overlap and are not provided in isolation. They play a part in the delivery of all early intervention services.

The Impact of Multiple Disabilities on Families

The fields of early intervention and early childhood special education are characterized by their absolute commitment to working in partnership with families, understanding families within a systems framework, and understanding infants and young children within the context of that family system (Turnbull, Turnbull, Erwin, & Soodak, 2006). The notion of a transactional relationship in which the infant and family influence one another (Sameroff & Chandler, 1975) is important in this model. The importance of this view of families is heightened when the infant has multiple disabilities.

Infants born with multiple disabilities present an immediate and intense impact and present many unique challenges for families. For example, parents may feel they need to be an expert (and many are) in a variety of disciplines, including medical specialties. Because of the complexity of the infant's disabilities, there is increased pressure to "manage" their child's complicated care — requesting records, organizing information, maintaining medical supplies, coordinating schedules and appointments, and so on.

Parents often must attempt to coordinate all information from service providers and synthesize it into reasonable activities and routines. Yet, information from each discipline may not quite fit their child, given the presence of the other disabilities. For example, if a child has both hearing and vision impairments, traditional strategies for enhancing hearing as a primary modality won't substitute for vision if it is also impaired.

Family members may discuss the frustration and fragmentation they experience from this limited information, as well as from the lack of clearly coordinated explanations and plans for their child. Families communicate with each specialty, but rarely do they feel that all providers in their child's life, including medical, educational, and social service personnel, talk and plan together to develop a comprehensive and useful program.

Video Clip 1.1

Parent Discusses Child's Medical Needs



Listen to this mother as she describes her son's complicated medical needs.

What assistance could an early interventionist provide?

[Click here](#) to play the Video Clip

While some primary caregivers may prefer to do their own service coordination, all too often they do so by default. Service coordination is a mandated service under the Individuals with Disabilities Education Act (IDEA) (Pt. C, Section 303.12). An early interventionist can often provide significant assistance and support to a family by taking on or supplementing this critical service coordination role.

Consultants should use caution that they don't simply add a list of activities to a family's already busy schedule or hold an expectation that all skills can be practiced at all opportunities. Rather, developing coordinated activities and routines and facilitating the use of cues and other communication strategies can be done step by step with families.

Communicating with the child with multiple disabilities can be challenging and complex for families. Children with multiple disabilities often require increased response time. Their responses can be subtle, inconsistent, and mediated by health, physical comfort levels, and arousal status.

Medical issues may cause families to feel overwhelmed. Some families make frequent trips to the emergency room — an obvious disruption of family life. An uncontrolled seizure disorder interrupts the flow of daily routine and may affect the child's arousal level and ability to concentrate. Medications and their side effects also affect arousal level, vision, and other systems of the body.

Summary of Key Points

The early interventionist must have a deep understanding of how the infant influences the family system. In the case of infants with multiple disabilities there are several special considerations. These considerations, which are complex and interactive, are summarized on the next pages.

Possible Threats to the Process of Bonding and Attachment

- Intense feelings of “loss of idealized child.”
- Caregiver-infant separation if the newborn's conditions and complications require placement in the neonatal intensive care unit (NICU) for an extended period of time.
- Fear of the infant's death in those cases where newborn conditions are life threatening.
- Difficulty reading infant cues; lack of infant responsiveness.
- Absence of reciprocal interactions.

- Caregiver grief and exhaustion from complex emotional and physical demands of infant may result in depressed affect in caregiver and reduced emotional availability to the infant.
- Caregiver reactions to inability to successfully nurse or bottle feed baby.

Impact on Family Roles and Functions

- Infant may require frequent re-hospitalizations.
- Families are often in “crisis-mode.”
- A child’s multiple disabilities may require numerous, time consuming in-home medical procedures.
- Spousal interactions and interactions with siblings, as well as interactions with extended family members, can all be very significantly impacted by severity and complexity of infant’s conditions and needs.
- The child’s multiple needs require dealing with multiple agencies and multiple service providers. This is not only time-consuming, but it is also very often confusing as caregivers receive conflicting and unclear information.
- Often coordination of multiple services is inadequate; effective team collaboration is rare.
- Perception that “more is better” results in families placing unrealistic and exhausting demands on themselves as they seek to provide every possible service for the infant.

- Primary caregiver becomes caught up in “infant management” functions, often abandoning or compromising other roles and activities (e.g., career, hobbies, social relationships, relationships with spouse and siblings, etc.).

Impact on Caregiver-Infant Interactions

- Caregiver behaviors may become routinized and mechanical if caregiving requires a number of “procedures.”
- Because of severity of disabilities and possibly life-threatening conditions, caregiver expectations of infant may be reduced. (This may be an important protective/coping strategy on the part of the caregiver.)
- Infant cues may be subtle, or atypical, therefore difficult for caregiver to read and respond to.
- Some infant behaviors (e.g., persistence of primitive reflex or sensory threshold overload) may be interpreted as rejection of caregiver.
- Infant’s disability may interfere with ability to perceive/experience caregiver response.
- Attempts at reciprocal interactions may be asynchronous.
- Infant may have problems with self-regulation and maintaining homeostasis, may be difficult to arouse or difficult to calm, and thus may not be available for interactive and emotional engagement with caregiver.

Intervention Strategies and Techniques Gathering Information from Families: “Family Stories” Technique

A current trend includes holding a family conversation rather than the more traditional parent interview. Information is gained about family life, including concerns, interests, and goals. In this process, information flows between parent and professional rather than solely from the parent and the professional. Although questions are raised, the service provider poses topics for conversation, centered on the activities of family life as well as the family’s concerns, priorities, resources, hopes, and goals. These provide the foundation for the Concerns, Priorities, and Resources section of the Individualized Family Service Plan.

When first practicing family assessment skills, the early interventionist should remember that being a careful and non-judgmental listener will go far in establishing trust and rapport with families. As the early interventionist becomes more experienced with family conversations, he or she will determine which topics elicit useful information and which topics may be less useful for discussions with particular families. Over time, the early interventionist will gather a rich collection of stories, strategies, and insights that will inform his or her work.

[Click here](#) to see an example of a
conversational approach.
[Module 1 — Appendix A]

Caregiver Participation in Child Assessment

Families should also participate in gathering information about the child. Recording sheets from developmental assessments can be shared with families, either during the assessment or beforehand, so that parents understand what is being assessed and can contribute a more informed perspective. Parent report is a very reliable mechanism for obtaining information about a child's behavior and development. Parents have insights into their particular child's responses and changes over time. The interventionist has insights into the typical response patterns of a number of children with similar needs. Together, they can more accurately describe a child's strengths and needs and progress.

Routines-based Assessment

Increasingly professionals in the field of early intervention use what are referred to as “routines-based” assessments in which parents discuss and reflect upon their needs and their child's needs and abilities within daily routine activities (McWilliams & Scott, 2001). As the interventionist conducts a focused interview around daily routines, and in some cases observes these routines, the caregivers and the early interventionist can collaboratively identify priority goals and objectives, as well as identify ecologically valid opportunities in which to work on these goals.

In some families, life is so hectic and unpredictable that routines can be difficult to identify. The early interventionist can assist the family in structuring routines into the day by establishing consistent sequences in activities (Klein, Chen, & Haney, 2000).

Strategies for Sharing Information with Parents

- ▶ Before an assessment, the service provider should discuss with the family what information will be gathered, how it will be used, and in what way the family would like it presented to them. For example, some families wish to know the age ranges in which their child's skills fall. Other families may not want this information.
- ▶ Families differ in how they prefer to receive information. Some families like information in writing. Other families have limited literacy skills and may prefer information presented verbally. Some interventionists have developed sensitive questions about a family's literacy levels and whether they wish further assistance in learning to read.
- ▶ Perhaps above all, in sharing information with family members it is important to be honest, in a sensitive, respectful way. Don't try to protect families from the "bad news" of delays in developmental domains, and don't refrain from reporting information to families that you will report elsewhere. On the other hand, be sensitive to a parent's feelings and emotional state.
- ▶ Share strengths as well as needs. Families of children with multiple disabilities often do not hear "good news." Further, strengths can be used to design intervention strategies and to address areas of concern. A strengths-based approach should not be confused with an approach that avoids areas of need.
- ▶ Carefully and meaningfully define acronyms and unfamiliar terminology. Families are interested in learning everything they can to help their children — acronyms and professional language can be taught to caregivers. Such knowledge will help families access the special education system for years to come.

- ▶ Some families are interested in information about special education systems at the local, state, and federal level. Many opportunities exist for parent involvement at all of these levels. A parent may wish to participate even if he or she feels currently overwhelmed by the child's needs (for it provides a way to “give back” to the field, to “get out of the house,” and to develop professional skills). Kroth and Edge (1997) discussed a continuum of parent involvement that may range from receiving information and basic communication related to the child's progress, to more active participation in the child's classroom, to more extensive involvement with parent groups and professional organizations, and so on. Parents need to have wide options for their levels of involvement at any point in time. There is no “correct” way for parents to be involved with their child's intervention program or education.
- ▶ Respect the family's feelings of “Too much information!” If families express that they are not interested in or do not wish to be given certain information — for whatever reason — respect this choice. You can offer the information again at a later time.
- ▶ Share information in a language that is comfortable for the family to support their understanding of emotional and complicated issues. Offer information in forms (e.g., verbal, written, video) and at a pace that is individualized for each family.
- ▶ The service provider should help the family learn about: (a) relevant services (early intervention/early childhood special education), (b) how to access and negotiate these systems, and (c) how to build preferred supports in the family's community.

Family Values and Cultural Considerations

- ▶ Understand that each family is unique. Many things will influence their interactions with service providers and their participation in the system. These include their child-rearing values and practices, their language, their resources, and their cultural background.
- ▶ Respect family and cultural values by identifying which family member(s) is the appropriate person to receive information and to make decisions.
- ▶ The service provider should examine his or her own biases and attitudes. This is at least as important, if not more important, than understanding other cultures. While we can readily access information about “other” cultures, it is very difficult to truly understand our own culture and how it influences our reactions, attitudes, and judgments of others.
- ▶ In some families, the approach described here (e.g., asking about typical family activities) may be considered intrusive. The service provider should take time to build a relationship with the family and explain why he or she needs to gather information and ask the family about the best way to do so.

See Chen, Mclean, Corso, and Bruns (2005) and Lynch and Hanson (2004) for additional discussion on this topic.

Vignette

Read about Charlie and Christine. Think about the questions posed at the end.

Charlie and Christine

by P. Salcedo

Charlie is an 18-month-old little boy who lives with his mother, Christine, in a small house in the downtown area. Charlie was born at 25 weeks' gestation. He uses oxygen and an apnea monitor at home, and he is reported to have Retinopathy of Prematurity (ROP) and possible motor concerns. Charlie has a serious look about him, often furrowing his brow and frowning, and he appears to his family and friends to be quite robust and engaging. His mother, however, worries about his fragile health, his poor grasp, and his difficulty taking a bottle and eating. Charlie's medical services are provided at the local university hospital and paid by Medicare. Christine has asked for suggestions for mealtimes and ways to encourage Charlie to walk.

Charlie's vision is "good" as described to Christine by the ophthalmologist. Christine wonders if Charlie sees at certain times and not others or in certain areas. She is unsure of the "Stage" and "Zone" of the ROP. The medical reports received to date contain conflicting information. Christine feels she never has enough time with the ophthalmologist to have all her questions answered.

When Christine holds Charlie, he often arches his back and kicks out his legs. This contributes to the difficulty she has when feeding him. Charlie has regular appointments with a neurologist. Christine speaks English, Spanish, and a Native-American language. At home, Christine and extended family members use Spanish so this is Charlie's home language, although he does not yet communicate using gestures, vocalizations, or speech.

Christine has not been back to work since Charlie's birth, and most of her time is spent taking care of Charlie's medical needs. She does not own a car and does not have a phone. Charlie's dad, Arturo, no longer lives with the family. He is affectionate towards his son but his visits are not regular. Arturo occasionally takes Charlie to medical appointments. He tends to forget the appointment time or the specific doctor, and this frustrates Christine.

Christine's extended family members visit as often as possible. Her sisters and nieces live in the area and provide support and friendship. However, since everyone works or attends school, their time is limited. Christine's sister has offered to take phone messages for her. Sometimes, however, Christine does not receive notice of a cancelled appointment.

Christine's parents are elderly and in poor health. They live out of state on an Indian reservation. Christine visits when she can and would love for her parents to have the opportunity, at least once, to play with Charlie. Pictures of family members fill the house, as do Native American artworks — and many toys for Charlie.

Charlie has been referred to the local school district infant program for early intervention services. At the Individualized Family Service Plan (IFSP) meeting, the service coordinator strongly advised Christine to obtain telephone service.

She wondered if Christine wanted to go back to work. Christine has experience in accounting and would very much like to work, both for the enjoyment she receives and because she believes in supporting her family. She would love to own a car again and move to a home in a quieter neighborhood. However, Charlie's intensive needs require all her resources and attention. She would like him to attend a childcare program, if she were assured that he would be safe, be loved, and receive proper care. Christine feels strongly that an acceptable childcare facility would have to demonstrate competence in handling potential medical emergencies. She has stated that Charlie's well being is her first priority.

The IFSP team is ready to write outcomes and design services for Charlie and Christine. Christine has identified concerns and wishes, as well as demonstrating her strengths and values.

Analyze this vignette:

1. Given information that Christine has shared with the early intervention team, what family outcomes would you identify? What services would you suggest to support these outcomes?
2. What questions would you ask Christine about her support system? What might the early intervention program do to enhance these supports? How might this affect service delivery?
3. What are the differences between the goals of the family and the goals of the early intervention team? What strategies might you use if the goals, values, or philosophy of the family differ from those of the intervention team members?

Module 1 — Self-Assessment

Read each question and then select the correct answer.

Question 1

The view that the child's development results from reciprocal interactions among the child, the caregiver, and the environment is known as:

- A Transactional model
- B Parent-professional partnership
- C Family-centered service delivery model
- D Routines-based assessment

Question 2

The so-called grief process:

- A Proceeds in clear stages
- B Is completed once the family reaches a level of acceptance
- C Tends to fade over time
- D May be re-experienced at different points in time

Question 3

Threats to bonding and attachment posed by multiple disabilities in an infant include:

- A Fear of infant death and caregiver exhaustion
- B Caregiver's inability to read infant cues
- C Extended hospital stays
- D All of the above

Question 4

The intervention needs of an infant with multiple disabilities:

- A Do not usually affect siblings and extended family members
- B Often result in families choosing a minimum of service options
- C Often result in multiple agencies providing confusing information
- D Are usually addressed through services from a single agency

Question 5

Gathering information from families:

- A** Can be informal and conversational
- B** Has a standardized protocol
- C** Should be done by a social worker or family therapist
- D** Should address family stressors and risk factors

Discussion Questions

Discussion 1

A new family has been referred to your program. Discuss how you will find out about the family's concerns, priorities, and resources.

Discussion 2

How can you involve families in the child's assessment? Why is family participation in child assessment important?

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Module 1 — Appendix A

A Conversational Approach to Gathering Information from Families

The IFSP requires that information be provided related to family concerns, priorities, and resources (i.e., “CPR”). The information gathered from the family to identify these areas of strengths and needs is essential in designing a meaningful Individualized Family Service Plan and effective early intervention strategies.

A few assumptions underlie this information gathering process:

- Parents are the primary influence in the young child’s life.
- Parents are equal partners in the early intervention process.
- Parents know their child better than professionals.
- All parents want to do a good job raising their children.
- Family stories are a rich source of information about the child as well as family life as a whole.
- Family report of developmental skills is reliable.

Features of a “Conversational Approach”

1. Explain the purpose of the Conversation.

- You wish to gather information about the child and family and explore the family’s goals and concerns regarding their child.
- Ask only what you need to know, respecting the family’s right to privacy.

2. Explain how the information will be used.

Description of Child.

Find out what skills the child has, and figure out what the next steps are in the child’s development.

Program Planning.

Based on what is said about strengths, favorite activities, areas of concern and next steps, and what services and supports will help the family meet its goals, develop a plan.

3. Explain that the information is confidential.

- Keep it that way!

4. Use commonly known words.

- Define acronyms and avoid jargon when speaking with families and when writing reports.
- You can use this opportunity to teach families the language of special education.

5. Hold the conversation in the family's native language.

- Use interpreters. Take the time to educate interpreters as to the purpose of the meeting and discuss any technical terms you may use. Such terms do not always easily translate into other languages.

6. Use open-ended questions and statements to introduce topics. More information will be gathered than with direct questions.

- Can you tell me about your child's day?

7. Remain non-judgmental.

- More honest information can be gathered. When families believe you have a certain agenda, they may be more likely to censor expression of their true feelings and concerns.

8. Ask for clarification.

- Asking for clarification can highlight topics you want family members to explore in more depth.

9. Read First!

- Try to avoid questions and topics that the family has already discussed repeatedly.

Topics to Address

Now you are ready to talk to the family. The following themes may provide you with useful information for planning outcomes and services.

1. Program Service and Supports

For example:

What are your greatest concerns, questions, or challenges related to your child?

I'd like to share some information about our program.

Let's talk about some of the services and supports that might help your family.

Now that you've learned about our program, what do you think we might help you with?

2. Child's Preferred Activities

Please help me learn about your child, for example:

What are your child's favorite activities?

Who does your child enjoy being with?

Tell me about the places your child enjoys.

What new things would you like your child to learn?

3. Daily Routines and Activities

For example:

Tell me about your child's typical day.

Are there times of the day that are difficult for your child that we might be able to help you with?

We want to fit the intervention strategies into your daily activities — into the things that you already do, your daily routines. What happens during meal times?

4. Family Support Systems

For example:

Are there people, other than your family, who you can count on for help?

Are there other services or agencies that have been helpful?

5. Family's Preferred Activities

For example:

Let's talk about what you like to do together. Where do you like to go?

Continue to another module ...

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