



A GUIDE FOR INDIVIDUAL FAMILY SERVICE PLANNING IN PENNSYLVANIA

A Resource for Families and Professionals

Philippa H. Campbell
College of Education
Temple University

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INTRODUCTION

Individualized Family Service Planning (IFSP) for families and their infants and toddlers is a new process that is being implemented nationwide in early intervention programs. This individualized service planning process is responsive to unique needs of each family and infant and results in a written plan that documents the process. Policymakers, researchers, families, and practitioners are experimenting with various approaches to determine those that will best realize the intent of family service planning.

The IFSP document is used to describe, in writing, a planning process between families and professionals that results in family-identified desired outcomes for an infant-toddler or family. The process for developing a written IFSP and examples of forms used to document this collaborative planning process have been described in numerous publications and articles (e.g., Campbell, 1990; Hunt et al., 1990; McGonigel, Kauffman, & Johnson, 1991). In Pennsylvania, standard IFSP forms have been or are being adopted by the county MHMR office in collaboration with the Local Interagency Coordinating Council (LICC). These IFSP forms may vary from county MHMR program to program or LICC to LICC but all reflect a common philosophy and meet the standards outlined in the federal Part H statute and regulations, Pennsylvania Act 212, and the MR Bulletins on the IFSP and on Screening, Evaluation, and Assessment and Eligibility (see Appendix).

The purposes of this resource guide are to: (1) clarify the roles that professionals play in order to empower families throughout the IFSP process; (2) describe ways that professionals can talk with families to learn about their concerns, resources, and priorities, as well as those supports and services desired by families; and (3) outline a process for individual family service planning.

The written IFSP document is the result of **process** of interaction among families and professionals. This process begins with the first contacts that a family has with the early intervention system and ends when the family and child make a transition out of the system. The written plan is developed jointly by the family and appropriate qualified personnel and is based on information derived from child evaluation and ongoing assessment of children's needs and abilities and identification of family resources, priorities, and concerns. Both the process and the resultant document are different from other planning and documentation systems, such as the Individualized Education Program (IEP) or an Individual Habilitation Plan (IHP), where professionally-determined and written goals for a child or individual "drive" the plan.

EMPOWERING FAMILIES

One of the most sensitive roles played by early intervention providers is that of empowering the families with whom they are involved. Professionals need to assume help-giving roles in their interactions with families. Being a help-giver is neither a "natural" skill nor one in which many early intervention providers have received training. Discipline-specific training is the norm within most early intervention professions. Physical therapists, for example, are trained to provide those interventions most appropriate with infants and toddlers who are demonstrating delays or disabilities in movement. Early intervention teachers are trained to focus on cognitive, social, or more general infant/toddler developmental skills. In the absence of information about the role of a help-giver, professionals working in early intervention may perform roles in ways that may not provide positive help and support for families (e.g., Dunst, 1990; Dunst, Trivette, & Deal, 1994).

Empowerment has been defined in a variety of ways. Most literally, the term means to give legal power or authority to a person or entity. Definitions used within early intervention generally include three areas of focus: (a) access to and control of needed resources; (b) decision-making and problem-solving abilities; and (c) the learning of behavior necessary to interact with others to obtain resources (Dunst, Trivette, & Deal, 1988, p. 3). The roles played by help-givers and their actions should always serve to empower the help-seeker. Many existing practices within early intervention systems may serve as threats to family empowerment. Some of these practices include: (a) help-giving professionals who use paternalistic or other types of interactions with families as is practiced, for example, within a traditional medical model; (b) the holding of belief systems that view help-seekers as unable (or unwilling) to learn needed competencies, identify their needs accurately, or make decisions; or (c) excessive intake and other procedures that must be completed before resources become available.

HELP-GIVER ROLES

Help-givers may play a variety of roles in interactions with families. The ways in which these roles are practiced influence the ways in which families function in relation to professionals. Eight typical roles of help-givers, taken from Dunst et al. (1988), are listed on the chart on the following page. One of these roles has been labeled as that of an enabler. The term "enabler" has different meanings within human services. When used in situations involving substance abuse, the term may have negative connotations. In the context of helping families, the term "enabler" means providing the means, opportunity, authority, or power to act.

HELP-GIVER ROLES

Empathetic Listener	Talks with family members using strategies that encourage information sharing and understanding.
Teacher-Therapist	Teaches family members or caregivers specific strategies and how to use those strategies within the context of family activities & routines.
Consultant	Provides information in response to family-identified needs; uses a collaborative model where all participants share a common definition of the need(s) and work together to formulate mutually-shared responses to those need(s).
Resource	Shares information about different types of supports and services as a means of providing information about which families may not be knowledgeable.
Enabler	Creates opportunities for families to develop and use skills to access resources so that families may take action on their own.
Mobilizer	Links families to other individuals or groups that may provide new perspectives about ways in which needs may be met.
Mediator	Works together with families to promote cooperation from individuals or groups with whom families may have had negative encounters.
Advocate	Provides families with necessary knowledge and skills to protect their and their children's rights, influence policies and practices, and negotiate effectively with others.

GUIDELINES FOR EMPOWERING FAMILIES

Professionals may play a variety of help-giving roles dependent upon the circumstances, resources, concerns, and priorities of families with whom those professionals are interacting. The ways in which those roles are implemented guide the extent to which families may become empowered. Twelve guidelines, identified by synthesizing information from an extensive literature review, have been identified and promoted by Dunst and Trivette (1988).

- Be both positive and proactive in interactions with families.
- Offer help in response to family-identified needs.
- Permit the family to decide whether to accept or reject help.
- Offer help that is compatible with the family's culture, values, beliefs, traditions, and activities.
- Offer help that corresponds with the family's appraisal of their needs.
- Promote acceptance of help by keeping the response low.
- Permit help to be reciprocated.
- Promote the family's immediate success in mobilizing resources to solve a problem or address an identified need.
- Promote the use of informal networks so that members of a family's natural support system (e.g., friends, relatives, church members) are strengthened and a sense of community is enhanced.
- Promote a sense of cooperation and joint responsibility for meeting family needs.
- Promote the family members' acquisition of effective behavior for meeting needs.
- Promote the family members' abilities to see themselves as an active agent responsible for behavior change.

Early intervention providers have many opportunities for giving help in ways that empower and strengthen families. Beginning from the first contacts with families, through to their transition out of early intervention, professionals can work to ensure that their actions help families use their decision-making and problem-solving competencies effectively to obtain needed resources. Family members are, and will be, a constant factor throughout their children's lives. The directed efforts of early intervention professionals to strengthen and empower provides families with skills and perspectives that will be essential in raising children, and particularly those with special needs, to adulthood.

FAMILY-PROFESSIONAL COLLABORATION

TALKING WITH FAMILIES

Within each of the steps in the IFSP process are opportunities for discussion, information sharing, decision-making, or problem-solving among families, who are the help-seekers, and professionals, who are the help-givers. Professionals learn about the dreams and expectations that families hold for their children and about family circumstances. Families learn about supports and services that may be useful to them and about the impact of their child's developmental delay or disability. Discussion, through conversations, is a primary vehicle through which professionals can demonstrate help-giver roles. The ways in which family members and professionals talk together can facilitate or serve as barriers to information exchange. Family members may be reluctant to ask questions or professionals may inadvertently intimidate families because of professional knowledge and expertise. Families may seem to be too demanding to professionals or uninterested in their children's welfare. Good communication is necessary among all individuals -- family members and professionals, advocates, and friends -- who participate in any (or all) step(s) of the IFSP process. When family members and professionals work toward mutual respect and collaboration, the individual family service planning process is more successful than when understandings among parties are confusing or unclear.

BARRIERS TO UNDERSTANDING

Many barriers to understanding communications within conversations have been noted (e.g., Webster & Ward, 1993), including:

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- Not really listening to what people are saying or are trying to say.
 - Making assumptions, judgements, or conclusions without confirming the accuracy of those impressions.
 - Not wanting to know information people are sharing.
 - Communicating disinterest through body language.
 - Not using a preferred language or mode of communication.
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A lot has been written about ways that individuals may exchange information by using statements or indirect questions to elicit more information or provide clarification about a particular thought, idea, or situation. The listener attempts to understand the *meaning* that is being expressed by the speaker's words and non-verbal behavior rather than attributing a meaning to the words being expressed. Any individuals within a conversation or discussion are at risk for attributing unintended meaning to a speaker. All of us listen and understand within the perspective of our own experiences, biases, values, culture, or preferences.

Each of us has a preferred way of communicating. Some people share information easily and willingly. Others may be more reluctant about the types of information shared or the people with whom they are talking. Some people may prefer not to share their feelings about particular situations or events while others talk about ideas or feelings easily. Although talking or discussing are primary ways of communicating, some individuals may prefer to share information through writing. Understanding our own sensitivities about communication, and knowing that there are many different ways of sharing information, helps us to understand and respect the ways in which family members may prefer to communicate with us.

Some family members prefer to communicate information about their children and families through "storytelling" (e.g., Turnbull & Turnbull, 1990) where they share with professionals a "story" about themselves, their children, or their family. Storytelling functions as an indirect way of communicating feelings, ideas, or information selected by the storyteller. A mother told a story about how a professional greeted her son, who had a severe physical disability and who was unable to speak, and then waited, what seemed like endlessly to the mother, for the child to respond by vocalizing and raising his hand in a wave. The mother communicated a number of things through telling this story. She communicated the ways in which she wanted people to interact with her son as well as her own desires to have her son respected and viewed as competent. By telling this story, she communicated her feelings and values as well as specific information about her child's ways of interacting. This was a less direct, and more time consuming, way of sharing information than if the mother had been questioned directly about her son's communication. Some professionals may be interested only in knowing the answer(s) to specific questions and, within the context of planning meetings (e.g., IFSP or IEP), may feel that direct questions are a more efficient way of sharing information. Seeking information through direct questioning, however, may establish communication as "confrontational" by placing parents in roles of responders rather than equal communication partners.

Storytelling, as well as other ways of communicating, often provides information that professionals (or others) may be unwilling or reluctant to hear. Knowing information may make professionals feel "responsible" for things in which they may choose not to be involved. For example, if a professional is unaware of domestic violence within a family, the professional may not feel obligated to address that issue. Knowingly or unknowingly, professionals may structure interactions so that families are able to provide only that information about which professionals are interested in learning.

FACILITATORS TO UNDERSTANDING

Sharing Information Through Conversations

1. Body language sends initial messages. Create a positive physical environment where all people who are part of the conversation are equal. Look at the person who is speaking so that you convey interest. Staring into space, writing, looking away from the speaker, talking to someone else while the speaker is talking, facial expressions, and other "body language" may be interpreted by the speaker as attitudes of disinterest, boredom, or with other similarly negative meanings that you may not have been meaning to convey.
 2. Act in such a way that the person with whom you are communicating thinks that you are interested and knowledgeable. Maintain a balance in speaking. Try not to be so quiet, so non-communicative, that the person with whom you are talking thinks that you are not interested or are not following what they are saying. Try not to monopolize the conversation or talk so much that the person does not have a chance to say anything.
 3. Respect people's feelings and the fact that they may share very personal things with you. Try not to question people or push them for information that they may not feel comfortable sharing or move from one topic to another so quickly that they only get a chance to make one response or lack opportunities to talk more about a particular question or topic. Always react empathetically to what other people share with you.
 4. When you talk with families, try to do so in ways that encourage discussion and sharing rather than question-answer series. Provide opportunities for people to talk more about something. Giving your opinion about something, providing too-quick solutions, or sharing your own experiences before you are sure that the person has said all that he/she wishes to say may serve to inhibit their conversation.
 5. Questions that require a "yes" or "no" answer inhibit information sharing and, in a sense, are judgmental answers. Try not to ask questions that require a "yes" or "no" answer... unless you are doing so to gain confirmation (e.g., "If I understand what you have said, you seem to think that Jose takes his bottle poorly because he doesn't suck well. Is this correct?")
 6. Always ask follow-up questions to make sure that you have the full UNDERSTANDING or MEANING of what the person is trying to say -- not just the knowledge of the words that have been said to you.
 7. Be sure you are understanding accurately the meaning a person is trying to convey by making confirmation statements (e.g., "It sounds as though everyone in your family is pleased about Sarah's progress.")
 8. We understand people through our own filters of personal values, preferences, beliefs, observations and experiences. Sometimes we may be too quick to attribute meaning that may not at all be what the person was trying to say. The speaker's values, beliefs, observations, and experiences may be different from yours. Listen and understand their perspective (even if you may not hold that perspective yourself.) Be respectful -- not judgmental -- of these differences.
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GUIDELINES FOR FAMILY CONVERSATIONS AND INTERVIEWING

Remember our goal is not to get information from people so that we can judge their abilities, competencies, decisions, or values. Our goal is to better understand what the world looks like through their eyes.

Family members and professionals may learn a great deal through conversations with each other. Information about children and families, services, supports, and resources may be shared when people are able to communicate well. The guidelines outlined in this section are general ways in which professionals can communicate more effectively in order to learn about others -- not just to tell other people, such as families, our professional perspectives.

Use of these strategies is illustrated in a later section of the manual, "Conversations with Families," which provides examples of how the strategies were used by professionals in early intervention.

Most early intervention professionals view themselves as good or natural communicators; learning how to communicate or talk with others may seem unnecessary. Talking with other people fulfills at least two purposes. One purpose is to share information about our own values, views, decisions, beliefs, or preferences. This is a traditional role played by early intervention professionals in situations such as planning meetings where professionals may assume a communicative role of "advising" or "telling" parents. Another purpose of communication is to gather information. This aspect of communication is often overlooked by early intervention professionals and important information about a family's ideas, preferences, decisions, beliefs, or values may be lost or unheard. Strategies, such as those described below, allow professionals to expand their communication and conversation skills so that families may share information. This sharing of information provides professionals with knowledge and establishes a collaborative and equal basis for interactions.

Begin with "grand tour" questions. These are general questions designed to establish an area of focus -- not necessarily to result immediately in a full answer. Additional questions or statements made need to be used to establish the real MEANING or essence of what the family member wants to say/share.

- Grand Tour questions facilitate story telling.
- Grand Tour questions allow the speaker to define what the speaker wishes to share rather than responding to specific questions or focusing on particular areas.

Examples of Grand Tour Questions

- "Tell me about your child and family."
- "Tell me how you think your circumstances might be different if Billy were able to walk."
- "What things do you think Jonathan most likes."

As a general rule, don't stop with the family member's first response. Follow this response with questions or statements that facilitate conversation. You want to keep people talking until you really understand what they are trying to say.

- Continuing a conversation provides the listener with more information that may be helpful in understanding the meaning of what the person is trying to say.
- By continuing a conversation, the listener is provided with opportunities to clarify what the speaker is saying and reconstructs the interaction as a conversation and discussion rather than as a "question/answer" session.

Examples of Ways to Continue Conversation

- Pause -- try not to jump in and respond.
- Make non-judgmental statements such as "I am interested in what you are telling me" that provide the speaker with opportunities to speak more about a topic/area.
- Restate your understanding of what the person has said with statements such as "You have to feed Sarah 15 times a day...."
- Ask the speaker to talk more about the area -- "Tell me more about how often Sarah eats each day."

Use indirect questions and statement techniques to gain more information, to clarify what you are hearing, to confirm meaning. Remember that people sometimes need to talk about something for a little bit in order to express what the person really means or to gain time to really think about the response.

Examples of Techniques To Clarify, Confirm, and Learn More

- Restate the person's words back (repeat what has been said) with either confirmation or a questioning inflection to encourage the person to expand...
"you're worried that Jose is not eating more."

- Use phrases designed to have people talk more:
 - "Tell me more about...." ("Tell me more about what foods Jose likes to eat.")
 - "Can you explain to me more about" ("Please explain more to me about Jose's eating. I'm not sure what you mean.")
 - "What other things might worry you about Jose's eating?" (You may want to preface a question of this type by restating what the person has said -- "You told me that you think Jose does not suck fast enough and that's why he has trouble eating. Are there any other things that worry you about the way he eats?")

- Express ignorance as a means of eliciting more information:

"There are no young children in my family -- so I don't really know what it's like to have a baby who doesn't eat well."

"I'm not sure what happens when you take a child in a wheelchair and who is using a ventilator to a shopping center."

- Express interest in what the person is saying by:

Pausing and waiting for the person to go on.

Using questions/statements like "Is there anything else you'd like to tell me about"

Restate so the person knows you are listening by saying things like, "You have noticed that Jose doesn't suck well. Having trouble sucking often makes it take longer for babies to eat." Then pause to see if the person wants to say more.

Restate the purpose of asking the questions with statements such as "We're interested in knowing more about Jose's eating since this worries you and since we might be able to help this go better."

Confirm the importance of what the person is saying so that they

know you value their opinion/observations with statements such as "You are the person who feeds Jose every day. The things you notice about the way he eats are really important."

- Break an answer into smaller parts to get more information:

"You told me that you're worried about Jose's eating. Is it the bottle or eating foods....."

- Ask questions that get at differences or contrasts:

"Is there something different about the way Jose takes the bottle? What happens when you give him solid foods?"

Try not to ask questions that are intrusive or too direct such as "What do you mean when you say Jennifer doesn't eat well" or "why doesn't Jennifer eat well?". These types of direct questions may send a message that the person is NOT communicating well. You want to send the message that you value what they say and that information they provide to you is important.

A PROCESS FOR INDIVIDUAL FAMILY SERVICE PLANNING

The formal IFSP meeting is the result of a series of interactions that begin with a family's first contacts with the early intervention system and end with a written IFSP document. These interactions are guided by a philosophy, or mission, about early intervention that has been adopted within a program, county, or LICC. The IFSP document is a point within a total process of early intervention. Throughout this process are many opportunities for professionals to empower families by enhancing their abilities to become active planners for their children. The IFSP process is both flexible and ongoing. Major steps have been described by the federal IFSP Task Force (McGonigel et al., 1991) as well as by others (Campbell, 1990; Vincent, 1989; Zipper et al., 1993). The process generally includes the following steps:

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- **Philosophy and Values**
 - **First Contacts**
 - **Child Evaluation**
 - **Determining Desired Outcomes**
 - **Specifying Supports and Services**
 - **Implementation**
 - **Review of Outcomes and Updating of the IFSP Document**
 - **Transition**
-

Professionals can function in help-giver roles in order to ensure that families are empowered throughout the various activities in the IFSP process. Different help-giver roles are likely to be practiced by service coordinators (case managers) and by the professionals who will provide interventions for children and families. The ways in which service coordinators and interventionists carry out help-giver roles allows families to make and carry out their decisions about their families, themselves, and their children. The various roles played by service coordinators and professionals are outlined in the chart on the next page.

Family members play important roles within each of the phases of IFSP development. However, within the context of this chart, family members are viewed as "help seekers" and professionals and service coordinators as the individuals who can play a variety of roles in giving help to families.

**Primary Help-Giver Roles Played By Professionals
Within the Various Phases of the IFSP Process**

Step in IFSP Process	Service Coordinator	Interventionists
Establish Philosophy, Values, and Guiding Principles	Empathetic Listener	Empathetic Listener
First Contacts: Identification of Family Resources, Priorities, & Concerns	Empathetic Listener Resource Enabler Mobilizer Advocate	
MDE Child Evaluation	Empathetic Listener Mediator	Empathetic Listener Teacher-Therapist Consultant Resource
Determine Desired Outcomes	Empathetic Listener Resource Mobilizer Mediator Advocate	Empathetic Listener Consultant Enabler Resource Mobilizer
Specify Supports and Services Necessary to Attain Outcomes	Empathetic Listener Advocate Mediator Enabler Mobilizer	Empathetic Listener Resource Enabler Mobilizer
Implementation of the IFSP	Empathetic Listener Mediator Advocate	Empathetic Listener Teacher-Therapist Consultant Resource Mobilizer Enabler
Step in IFSP Process	Service Coordinator	Interventionists

Periodic Review and Updating of the IFSP	Empathetic Listener Advocate Mediator Enabler Mobilizer	Empathetic Listener Resource Enabler Mobilizer
Annual Review of the IFSP	Empathetic Listener Advocate Mediator Enabler Mobilizer	Empathetic Listener Resource Enabler Mobilizer
Transition	Empathetic Listener Advocate Enabler Mobilizer Mediator	Empathetic Listener Resource Enabler Mobilizer

STEPS IN THE IFSP PROCESS

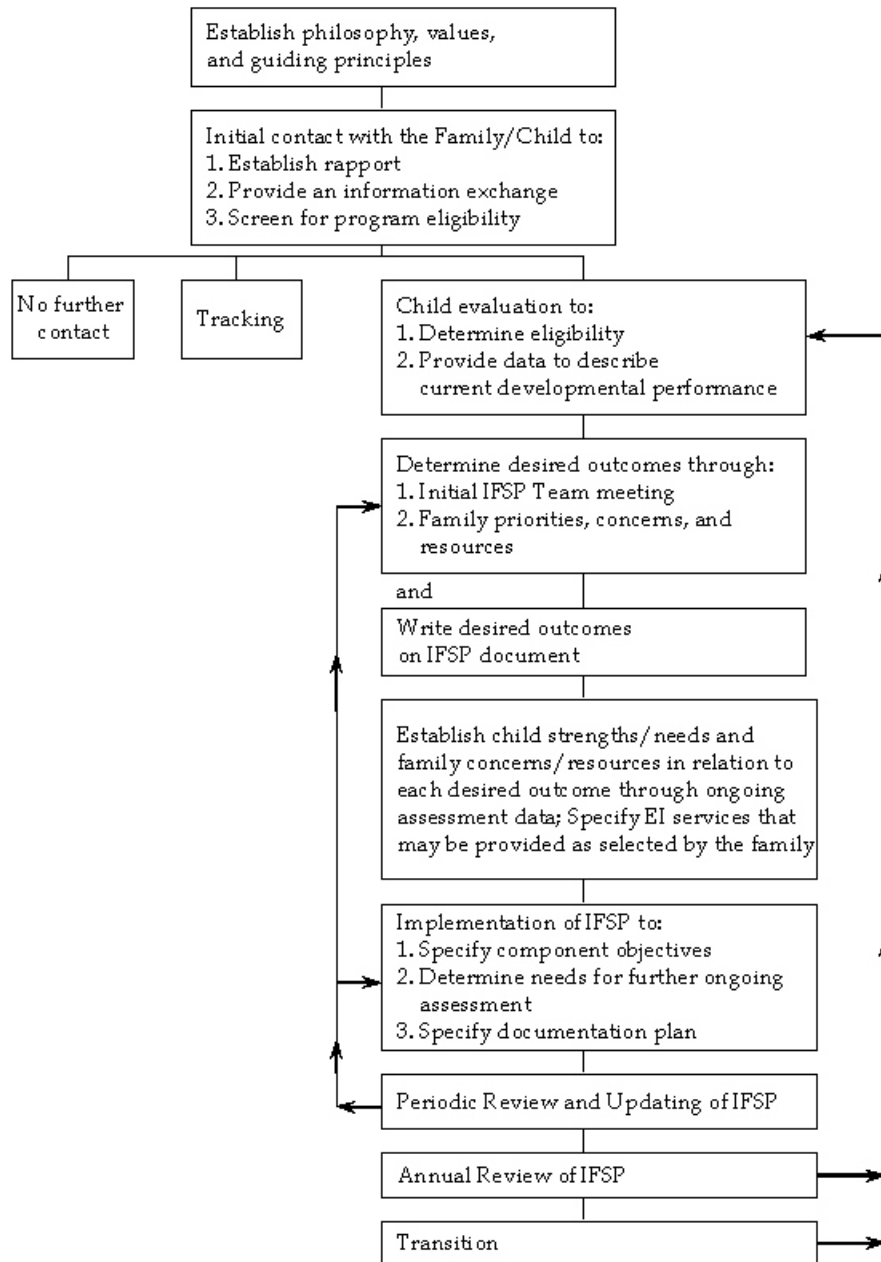
Woven through each step in the IFSP process are the interactions that occur between family members and professionals and among children, professionals, and families. The ways in which these interactions occur may enhance a family's capacity to care for their children over time. Families are the constant in their children's lives and will be responsible for their children long after their involvement with the early intervention system has ended. When early intervention professionals function in a variety of help-giver roles, families receive support and assistance in the care and raising of their children. These positive relationships establish a confidence and competence in families that will be useful throughout their children's' school and adult years.

The steps in the IFSP process are illustrated on the next page. While each of these steps is represented as somewhat separate and distinct from other steps, the activities, actions, and interactions that occur are interwoven throughout the process. Professionals may have a tendency to view each step as a separate activity due to early intervention requirements. The links between steps that result in their inter-relatedness comes from the interactions among people involved within the early intervention system.

Establishing Philosophy, Values, and Guiding Principles.

Staff members of each early intervention program and, ideally, of all early intervention providers within a community need to examine their own philosophies and beliefs concerning families, child rearing practices, cultural sensitivity, and other related issues. Professionals and families from each provider or, working together through a Local

A Process of Individual Family Service Planning



Interagency Coordinating Council (LICC), should develop a consensus position on the philosophy of the program or LICC regarding individualized family service planning and early intervention services. Ideally, this position is written, adopted formally by individual providers or the LICC and shared openly with all families and professionals. A written statement about philosophy is critical as a means to represent collaborative values and provide the framework under which individual family service planning will occur. Many families will receive early intervention services from a variety of agencies. Families have the right to participate in the development of philosophy statements and to be informed about the philosophy and practices within a particular provider or the LICC.

First Contacts with Families.

The purpose of this step is to initiate exchange of information among families and professionals. Service coordinators are likely to make the first contacts with families but these initial contacts may occur in other ways as well. For example, those individuals who will provide the Multidisciplinary Team Evaluation (MDE) may have involvement with families prior to the actual MDE. A focus of these first contacts, which may take place in many locations including the family's home, is for professionals to build rapport with families, provide information, and set the stage for families to be active decision makers in services for their child and themselves (Vincent, 1989). Families are provided with opportunities to explain their experiences with their children (i.e., provide a history in their own words and language and with their own emphasis), describe their priorities and concerns, and share information about their children's development. Parent-to-parent contact, parent training opportunities, or other parent support and education opportunities, written material, videotapes, or other mechanisms can be used to provide information about early intervention and the IFSP process. The specific method(s) used are determined by the family. What works best for one family may not be appropriate for another family.

Service coordinators are the professionals with the greatest contact with families during the first contacts phase. The ways in which they interact with families sets the stage for family-professional collaboration throughout the entire IFSP process. Listening to families in ways that elicit information is critical. Knowing what are important priorities for the family and the child, learning about family resources, and determining concerns are critical at this step. Service coordinators also serve as resources by providing families information about early intervention and other formal and informal resources in their communities. Through their contacts and conversations with families, they establish an interactional pattern of advocacy for families, helping them to learn to mobilize and enabling them to make decisions about access and use of resources.

Two important functions -- screening and preparation for the MDE -- are provided by service coordinators during their first contacts with families.

Screening

Infant characteristics and behavior may be screened during early contacts with the family to determine needs for a full MDE and subsequent eligibility for services. A variety of screening procedures may be used to determine those infants and toddlers who are likely to be eligible for early intervention services under the definition of developmental delay adopted by the state in which the family resides (Meisels & Provence, 1989). In Pennsylvania, infants and toddlers with various diagnoses that are indicative of a high probability of developmental delay such as children with Down syndrome, cerebral palsy, or significantly impaired vision or hearing as well as children who demonstrate a 25% or 1.5 standard deviation delay in one or more areas of development are eligible for early intervention services. The screening process determines the extent to which infants and toddlers require an evaluation to determine eligibility.

The service coordinator (or in some counties, the intake person) reviews all previous records, obtains information from the family, or may arrange for or conduct a developmental screening using a particular instrument. Arrangements are made for the child to have an MDT when eligibility is not possible to determine through the screening process, when further information is desired, or when the family wishes to receive a full evaluation for their child.

Preparation for the MDE.

Family members require information about the MDE evaluation of their child and their roles in evaluation before the evaluation takes place. In this way, professionals can learn about any concerns the family has about their child's development and can provide families with information about what will happen during the evaluation session. This information may be provided by the service coordinator or by members of the MDE team. Completing a series of questions such as those outlined by Project Dakota (Kjerland, 1988) or included in several other publications (e.g., Hunt et al., 1990; McGonigel et al., 1991) may be helpful in enabling families to be active participants in the MDE evaluation process. These questionnaires may be completed by families by themselves or used by professionals, in combination with the procedures for conducting interviews with families, described in the preceding section of this resource guide. Families need to know who will participate in the MDE and why (e.g., what professionals will be present and what they will be doing), how their concerns about their children will be addressed, the roles families will be expected to play, and the outcomes/purposes for the evaluation.

Child Evaluation: Multidisciplinary Team Evaluation

Child evaluation is designed to determine eligibility for services and obtain information necessary to describe current status in each of five areas (Campbell, 1991; Gibbs & Teti,

1990). These developmental areas include: (1) physical (e.g., health, posture and movement, vision, hearing); (2) cognitive; (3) communication; (4) social or emotional; and (5) adaptive skills.

The first contacts between family members and those individuals who may play a role in intervention occur during the MDE or during the IFSP meeting, dependent upon the ways in which MDEs are provided in a particular county. In many counties, the initial MDE is provided by professionals who are separate from the professionals who will provide early intervention services. These evaluators will have contact with a family only during the MDE process and are not likely to be the individuals who will provide any ongoing needed supports and services. The ways in which these professionals interact with families during the evaluation may help to empower families. Professionals need to listen to families to understand and address any concerns, actively involve families in the evaluation by using the evaluation as a means of teaching or providing information for families, and function as a resource in providing information. The service coordinator serves as a mediator if differences occur between the family and professionals.

In Pennsylvania, the Multidisciplinary Team (MDE) evaluation follows a screening process and is conducted with the service coordinator and by one or more professionals of disciplines most related to the child's suspected or known areas of delay. The outcomes of the MDE include: (a) determination or documentation of a child's eligibility for services; (b) information about the child's developmental competence and health status that is used, in combination with other information, to write statements that describe a child's current status and performance; and (c) information that addresses any concerns that a child's family may bring up or that prompted the referral to early intervention. The instrument(s) selected for eligibility determination yield data that, when combined with other measures, (i.e., review of medical records; observation of the child; family interviews or reports), can be used to write developmental performance descriptions - the initial link between the IFSP document and the evaluation process. These descriptions are not listings of test scores in each developmental area but are positive statements that objectively describe the child's abilities in each developmental area.

Information from the MDE is supplemented by ongoing child assessments completed at any time during a child's involvement with early intervention. These assessments are used to obtain information about the supports and services desired by the family for themselves and their child(ren) and to gain information about strategies that may be helpful in addressing the desired outcomes. Ongoing assessments frequently target a specific area of child need. For example, a speech and language pathologist or an occupational therapist or even a specialized team of professionals may conduct an assessment of a child's eating abilities to gain further definition of the issues concerning eating and of the possible strategies that may assist a child to eat in the ways defined as part of the outcome statement.

In addition to the ongoing assessments of the child's behavior, early interventionists and service coordinators need to continually identify family issues. Family priorities, resources, and concerns are likely to change over time as family situations change, families learn more information, or children change. Family issues may relate to any one of the following areas: (a) information about their child's disability, child development in general, or various aspects of parenting; (b) intervention for the child including services or supports, frequency or type of early intervention; (c) supports that may be helpful for the family or child such as parent-to-parent, other programs such as WIC, or financial assistance; and (d) help with other family members such as with other children in the family (Seligman & Darling, 1989; Darling & Baxter, in press).

Determining Desired Outcomes.

Desired outcomes are not long-term goals; rather, outcomes are statements of something that families would like to have happen in the future. In this sense, outcomes are "visions" or "hopes" or "dreams." They are not measurable long-term goals, nor can outcome statements be task analyzed into a series of steps that, once achieved, result in achievement of the long-term goal.

Family desired outcomes are a cornerstone when using an empowerment model of help-giving within family service planning. Help-givers perform a number of roles when assisting families to determine desired outcomes. Primary among these roles is to function as active and empathetic listeners. Professionals give help by using strategies, such as those mentioned earlier in this resource guide, to help families share information about things that are important for them and their children. Professionals do not use direct questioning such as "What are your visions for your child?" or "What outcomes would you like to see?" or "What do you need?". Rather, professionals converse in such a way that opportunities are provided for families to share information and clarify, often for themselves, those things that are important for them. Professionals use their help-giver roles of serving as a resource to provide families with information about options so that choices and decisions can be made.

Each family is likely to have unique expectations, priorities, resources, and concerns about themselves and their children. Despite these uniqueness, there are some commonalities among the types of outcomes that families are likely to establish. While *all* families will not share identical outcomes, many families will establish both child-oriented and family-oriented outcomes.

What types of outcomes are families likely to establish?

Outcomes represent areas of concern or priority for a particular family. The decisions that a family may make about what is important to them at a particular point in time are likely to vary across a child's and family's involvement with early intervention services and supports (Darling & Baxter, in press). Some outcomes that families establish will be oriented around concerns and priorities about their children; other desired outcomes may

focus only indirectly on the eligible child and more directly on issues related to other members of the family or to family circumstances. Outcome statements such as "I would like Roberto to walk" are more clearly focused on developmental abilities than are statements such as "I need more information about oxygen systems and suppliers" or "I need to go back to work and need help in working out child care arrangements for Karen."

The extent to which families state outcomes that do not directly focus on children's development or health is probably related to a number of factors. Families come to the early intervention system with varying degrees of expectation about how the system may work for them and are not likely to focus on areas

which the system (or their perceptions of the system) are not likely to address. The information that they have received from the service coordinator as well as from other individuals or sources (e.g., pamphlets) prior to the MDE or initial IFSP meeting may influence their perceptions of what the system has to offer. Many professionals have advocated the use of checklists or other more formal ways to provide families a way of expressing their needs.

The identification of family priorities, resources and concerns is undertaken on a **voluntary basis** by families. Programs that provide a variety of options for helping interested families define their priorities, resources, and concerns provide a variety of means by which families may provide this information. Interview procedures may be supplemented or enhanced through other formal or informal procedures such as use of checklists, questionnaires, or rating scales (see Darling & Baxter, in press; Dunst, Trivette, & Deal, 1988 or McGonigel et al., 1991 for examples of existing scales and checklists.) A number of checklists have been developed to summarize family needs, family supports, or family strengths. Many of these checklists or scales were designed to gather research data from a large number of parents and may not be as appropriate for use with all families within the context of early intervention programs (Bailey & Simeonsson, 1988). Program-developed checklists have been generated by a number of early intervention providers. Families are either given these checklists to complete at their own convenience or the checklists are used by professionals, frequently service coordinators or social workers, to guide interviews with families.

Allowing families to express any type of outcome relates largely to the messages that professionals send to families about the early intervention and the services and supports to which families may be accessed. When professionals hold a restricted view of early intervention as only those services and supports that relate to children, families may be not express other needs or priorities. On the other hand, some families may not wish to share all of their needs and priorities with professionals whom they view as being most likely to help children. Using open-ended questions such as "Tell me about the things that are easiest (or hardest) for your family" may help professionals to learn about the broadest areas of family concerns, priorities, and resources. It is important for service coordinators and early interventionists to remember that they may be able to assist families in addressing their needs – all needs do not have to be met directly by themselves or by an

individual early intervention program or provider.

Examples of Family-Determined Outcome Statements

Examples of Child-Oriented Outcomes	Examples of Family Oriented Outcomes
Our meals really take a long time. I wish Susie could eat faster but I know she's just learning to feed herself.	We just learned a few weeks ago that the reason Matilda doesn't walk yet is that she has some sort of palsy. We'd like to know more about this.
When I try to get dinner at night it is really hard because Julio wants my attention and he can't really play by himself yet.	Louisa has been getting PT -- practically since she was born. We like the therapist but have no idea why she does certain things with Louisa or what we might do to help her when she is with us.
Mary seems so shy or something -- I'm worried about whether she's ready to go to school.	Our family is really stressed out right now. My husband just lost his job and is looking for work. We don't know what Julia needs or how we will provide it for her. The doctor told us that Ryan has Down syndrome and we've read up about this but don't really know what it means. I wish Louis could talk a little better since nobody ever understands him.

Can *all* families establish *appropriate* outcomes?

Two barriers to family-driven service planning are cited often by professionals. The first barrier relates to the abilities of **all** families to identify **appropriate** outcomes. Professionals may encounter families who are viewed as being unable to state outcomes, or those who apparently have no desired outcomes. Particularly problematic are those families who state desired outcomes that are viewed as "unrealistic," perhaps because the system will be unable to deliver the outcome or because the child is viewed as not capable of attaining the outcome (Campbell, Strickland, & La Forme, 1991). Perspectives such as this one are incongruent with an empowerment model of helping, of which an underlying feature is a belief that people are competent or have the capacity to become competent through proactive interactions with help-givers (Dunst & Trivette, 1994).

Outcome statements that are generated by families are not directly based on the results of an evaluation, as is true in other planning approaches, but are based on a perspective that families know their own expectations, priorities, and concerns better than individuals, such as professionals, who are tangential to the family system. As a result, outcomes may focus on the concerns that families have for themselves or their children (Darling & Peter, 1994). What is important is to understand that families determine these outcomes from a different base than that from which professionals determine goals. Professionals in early intervention have been trained to determine goals from a child-focused developmental base, usually operationalized as a developmental evaluation of some type. This view of development may be comprehensive, as is the case with developmental psychology, or may include a view of only one aspect of development, as is the case with physical

therapy, occupational therapy, or speech/language pathology. In essence, the professional view of needs (or concerns) is restricted to those that involve development whereas the family view of concerns is likely to be much broader and include areas other than a child's development. It is not surprising, then, that families are likely to generate outcomes with which professionals may initially feel uncomfortable, particularly when outcomes do not emphasize concerns about a child's development. Professionals may feel even further vulnerable in this process since their involvement is based on a perceived need that a child is or may be deviant in some way in development and on an underlying premise that the professionals have unique skills regarding development.

Examples of Child-Oriented Outcome Statements

Examples of Professionally-Stated Goals	Examples of Family-Stated Outcomes
James will interact appropriately with at least two other children in the neighborhood on a once per week basis for at least 4 out of 5 weeks. In addition, James will play with his sister for a five minute period before dinner 4 out of 5 evenings per week and for at least 50% of the time.	We would like James to be able to make friends with other children in the neighborhood and to play with his sister.
Katie will crawl using a hand/knee pattern for a distance of 3 feet when placed in the correct position and when a toy is put in front of her.	I would like Katie to be able to get around on her own.
Larry will play during free time with a minimum of 3 toys for a 10 minute period, three out of five days.	I would like Larry to play by himself for short periods.
Julia will go on family outings with her family once a week for three months.	Our family would like to be able to take Sadie on trips to the park and other family outings.
Jose will communicate his needs and wants during meals by looking at a picture of "drink" or "food" to indicate which he wants for half the meal, with at least 50% accuracy, on five consecutive days.	We would like to know what Jose wants when he cries or makes noises.

The examples of professionally-stated goals illustrated above represent measurable statements of behavior; this approach to goal-setting has been used to write goals under planning formats, such as the Individualized Education Program (IEP.) which are characterized by:

- Goals typically derive directly from evaluation results; generally an emphasis is placed upon remediation -- establishing as a goal the performance of a behavior that is not performed independently by the child.
- The goal can be broken down into smaller steps, or objectives, using task analysis. For example, the goal, "Larry will play during free time with three toys for a ten minute period," can be broken into objectives by time ("Larry will play during free time with a minimum of three toys for one minute").

- Goals and their related objectives are measurable through the criteria statements attached to the goal. For example, Larry has achieved the play goal when he plays with a minimum of **three** toys for **ten minutes** on **three out of five days**.

The overall frame of reference for this type of goal setting has been referred to as a bottom-up approach (e.g., Campbell, 1991) because goals are initiated from a remedial or deficit-based focus and because of the sequential focus taken when breaking these larger goals into objectives. Both the bottom-up and top-down approaches are illustrated on the figure on the next page (Campbell, 1991; 1995). Some family outcome statements may relate to the family rather than directly to the child. Outcomes such as "I would like to meet other mothers of children with Down syndrome" or "We need someone who can babysit for Rachael once in awhile so that we can go out for dinner" may be established by families and included on the IFSP. Again, these are examples of outcomes that reflect an individual family's priorities, resources, and concerns and are included on the IFSP as outcomes.

How are family-determined outcomes broken into objectives?

A second barrier to family service planning relates to the skills of help-givers in planning supports and services from a top-down perspective. As the figure illustrates, goals derive from the next steps in a perceived sequence when a bottom-up perspective is used. We expect that a child will sit and crawl, for example, before standing or walking. In a top-down approach, the outcome represents the end result. Walking may be established as a desired outcome or expectation, even when a child is not yet able to sit or crawl.

Desired outcome statements are broken into objectives based upon what is necessary to attain the outcome. For example, an outcome of "I would like Larry to have several toys and play independently" might include two objectives: (1) obtaining the toys; and (2) teaching Larry to play with those toys by himself. Assessment procedures are used to determine the possible barriers, or interfering factors, to Larry playing independently (e.g., he has so much spasticity in his hands that he cannot hold a toy; he is so destructible that he doesn't attend for longer than one or two seconds) as well as the facilitating factors or strengths (e.g., he really is interested in the red robot toy and likes any toy that moves). These objectives are written on an intervention plan that accompanies the IFSP document. Similarly, an outcome such as "I would like to meet other mothers of children with Down syndrome" may be broken into objectives such as providing the family's name to the local parent-to-parent group and following through with the family to make sure that the outcome has been attained.

The information needed to develop child outcome statements into a series of objectives typically does not come from the MDE evaluation but from assessments that are carried out and that allow professionals and family members to identify the strategies that will be used to work towards attainment of the outcome (e.g., Campbell, 1993). The objectives may be increased in number to reflect both ways of getting around a barrier (e.g., teach Larry to use switch-operated toys to bypass his difficulties with spasticity in the hand) and of improving performance (e.g., decrease spasticity in the hands and increase manipulation

skills so that he can manipulate toys directly). In this example, the intervention plan might describe three objectives:

- Help Larry's mother obtain toys for Larry to play with.
- Teach Larry to use switch-operated toys.
- Decrease spasticity in the hands and improve manipulation abilities so that Larry can play with toys.

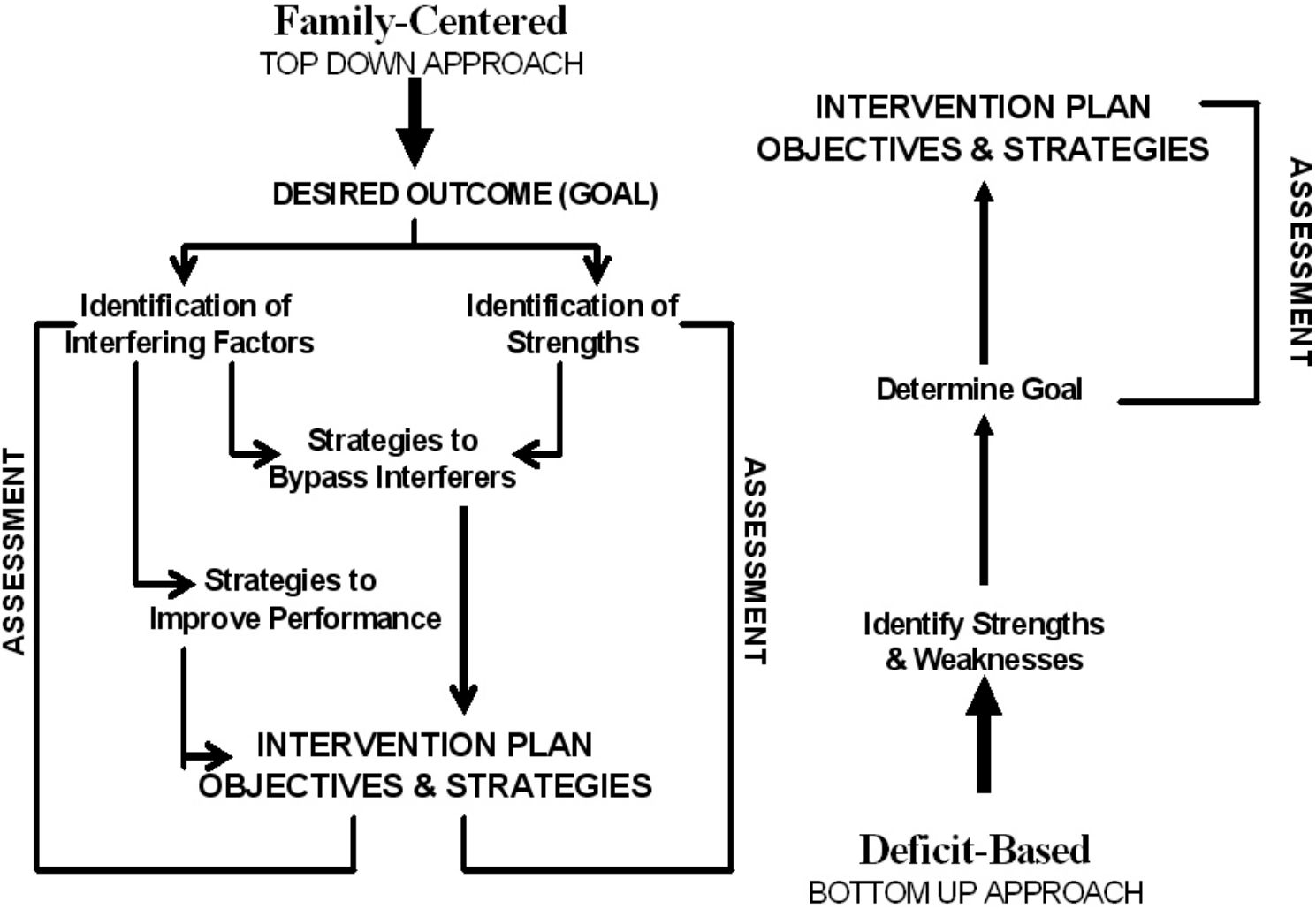
The outcome of wanting to better understand what the physical therapist was doing with their child and ways in which they could help the child at home is broken into smaller objectives through a process of further conversation with the family. This conversation performs the same purpose for professionals as does carrying out further child assessment. As professionals, we are not assessing families but are talking with them further in order to gain more information about what is important and how those areas of importance might be addressed. In talking further with Louisa's family, the service coordinator realized that Louisa's mother dropped her off with the physical therapist and then attended a parent group during the time Louisa spent in PT. There was little time for the PT and Louisa's mother to communicate after Louisa's session since another child was already waiting for therapy. This information helped the service coordinator to find out that Louisa's mother really valued the parent group but did not have respite care for Louisa. The service coordinator arranged for care for Louisa so that her mother could both attend the parent group and Louisa's PT session. The PT, service coordinator, and Louisa's mother also had a meeting to further discuss the family concerns and needs. In this case, the objectives for this outcome included:

- Decrease muscle tone in Louisa's legs (Louisa's mother wants to learn how to do this so that dressing and changing are easier.)
- Provide opportunities for Louisa's mother to observe PT and to learn what is being done and why.

Specify Supports and Services Necessary to Attain Outcomes

The supports and services that are available to families include early intervention supports and services as well as informal supports and services from other agencies or

Multidisciplinary Evaluation Approaches



programs. Supports and services are selected by families and include those the family views as helpful in attaining desired outcomes. Help-givers play important roles in empowering families to access, obtain, and use resources. Being an empathetic listener and holding conversations with families is a critical role when empowering families to determine services and supports. Through the process of conversations and discussions, professionals can serve as help-givers by finding out family circumstances, values, and beliefs that need to be considered when considering services and supports. Serving as a resource is critical, also. Many families who are new to the early intervention system may be unaware of the variety of services that may be helpful for themselves or their children. They may be unfamiliar, also, with services and supports that are available through their communities. On the other hand, professionals may not be knowledgeable about the informal supports of families or of their use of services and supports provided outside the early intervention system. Help-givers, such as service coordinators, play roles of enablers, where they help families to take action on their own, or of mobilizer, where they link families to other individuals or groups who may be helpful to them.

How are Services and Supports Determined?

The chart illustrated earlier contrasts the differences between traditional bottom-up approaches to identifying needed supports, services, and interventions and the top-down approach that is used within a family-centered approach (Campbell, 1991). In a top-down model, ongoing assessment is used to identify the interfering factors and facilitating factors (or strengths) that need to be addressed or accommodated when determining the intervention plan. Various assessment protocols are used to provide information necessary to make decisions about programming objectives for children (Campbell, 1995). Some objectives may be related to improving performance or skills while others may relate to teaching a child to perform a function in a new way. Information from assessment is used, also, to determine the most desirable strategies (or methods) that will be used to help a child be able to continue to learn and develop.

In a traditional bottom-up model, professionals administer developmentally-based evaluations as the basis from which goals are developed; in turn, goals may be matched with a particular discipline. A goal of walking, for example, may be matched with physical therapy or a goal of improving manipulation abilities may be matched with occupational therapy. Professionals are likely to determine the frequency and duration of those services and may offer families options regarding location.

In a model where families establish outcomes, typical early intervention services of education and therapy are only a small range of services and supports that may be needed or valued by families. Exactly what might be helpful often is determined on the basis of assessment. The possible services and supports are defined so that families may select those viewed as important as are, ideally, their frequency, duration, and location.

Assessment activities are designed to be ongoing, identify the unique needs of the child and family, and determine the services needed to address unique needs. Child assessment provides objective information that helps to: (1) further subdivide desired

outcomes into component parts or objectives; and (2) to determine specific services and strategies that may be helpful in realizing each of the stated components. Assessment of children includes a variety of approaches that provide information or data about child performance **as related to a specific outcome** (e.g., Campbell & Forsyth, 1993). These measures include observation, assessments of the environment and its effects on children's abilities (e.g., ecological analyses), portfolios where examples of child performance over time are stored, and a variety of other measures designed to obtain samples of children's behavior within various environments over time. Assessment is different than evaluation in that an emphasis is placed upon observing and recording performance within natural environments as opposed to identifying specific skills that infants and children may perform irrespective of environmental conditions (see Campbell, 1995).

Professional training emphasizes a help-giver role of providing skilled interventions. Traditionally, this role has included evaluation, assessment, and provision of direct services. Within a family-centered model, professionals must expand their help-giver roles to include at least those of empathetic listener, teacher-therapist, and consultant. By listening actively and reflectively, professionals learn about and understand the perspectives of families as well as share their perspectives with families. As teacher-therapists, professionals teach families strategies that can be used to help attain a desired outcome or objective. Professionals work with families to identify the activities and routines into which interventions can be infused. As consultants, professionals are available to provide information in response to family-identified concerns, working collaboratively with families to provide information that is useable within the context of a family's values, priorities, and circumstances.

One of the best ways of gathering information about family concerns, priorities, and resources as well as of understanding what information, supports or services may be helpful for families is to talk with them. These conversations may follow a structured format, such as an interview, to ensure that similar information is gathered across a number of families or they may take place informally. Formats may be helpful because they prompt professionals about how to conduct the interviews as well as provide spaces for recording of the conversation. When informal conversations with families or more formal interviews are used as a means of gathering assessment information, the professional (typically, the service coordinator) plays roles of: (a) eliciting information from the family member(s); (b) listening to and understanding what they are saying; and (c) recording this information. The information provided earlier in this manual, **Guidelines for Family Conversations and Interviewing**, can be used to help guide these interactions.

Another helpful activity for some families is the availability of a resource library that includes information about community services, day care or other programs for infants, toddlers, and children, lists of national resources including disability groups such as UCPA or ARC, information centers for families such as NICHY, and books and pamphlets especially for families. Many local libraries or family centers may have established information sections about children with disabilities or these may be maintained by the LICC, county MR agency, or other state groups. In some areas, existing parent-to-parent

groups have a wide array of resources available for families to use.

Involving families in decisions about supports and services occurs when professionals listen to families in order to empower families to make their own decisions about what will be helpful for themselves and their children. At this stage, professionals may tell families what is necessary/needed rather than explore sufficiently what the family views as important. Help-giver roles of enabler and mobilizer are critical at this phase. When professionals act in ways that enable families to attain desired resources themselves, families are empowered to make their own decisions independently.

Implementation

The most important aspect of the IFSP process is the implementation of the plan -- the delivery of comprehensive early intervention supports and services designed to meet the unique needs of the family and child. Implementation activities are the direct result of the IFSP meeting and are related to the outcomes selected and included on the IFSP document. The general implementation plan determined by the IFSP team addresses the family concerns and priorities and child strengths and needs in relation to each specified outcome. Service providers (i.e., special instruction, occupational or physical therapy, health services), who will be involved with the child and family, together with the family, develop an intervention plan.

Intervention plans may take a variety of different forms and may be developed at the time of the initial IFSP or at the point that a specific support or service has been identified. Intervention planning serves to: (a) outline additional data that need to be collected through assessment procedures; (b) subdivide outcome statements into objectives; (c) establish criteria by which attainment of the objective will be documented and measured; and (d) describe the strategy (method) that will be used for intervention.

A format for intervention planning may be developed and used in a particular program or a standard format may be used across all providers in a particular county. Areas, other than those listed above, may be included on intervention plans. Some plans include notations of environmental observations or ecological analyses that may be necessary, the service approach to be used (e.g., remediation; promotion), or the model(s) by which service will be provided (e.g., direct; consultation). Intervention planning provides a mechanism for representing the collaborative focus of families and professionals toward outcome attainment by representing planning by outcome statement rather than by professional discipline or service (Campbell, 1990).

Intervention plans describe the ways in which interventionists will interact with children and families. Professionals may rely on playing traditional roles of direct service providers. In this capacity, professionals may inadvertently remove control from families. Interactions at this phase serve to promote family empowerment when professionals listen, teach families strategies that may be helpful with their children or themselves, provide information in response to family-identified interests or concerns, access families to additional resources, and enable families to seek out and obtain needed resources.

Review of Outcomes and Updating the IFSP Document

Infants and toddlers grow and mature within relatively short time spans. Family circumstances, and therefore, their priorities and concerns, may change quickly, also. IFSP outcomes are required to be formally reviewed and updated at the minimum of every 6 months, and the IFSP written document is completed on an annual basis. Annual review means that the child's present level of functioning will be described, those supports and services that have been received are discussed, outcomes are reviewed and altered, and decisions are made about what supports and services are presently needed.

When goals have been written in measurable terms (i.e., Peter will point to the picture of milk three out of five times on three consecutive days), attainment of the objective can be determined on the basis of the criteria included in the goal statement. Outcomes are statements and do not necessarily include, as part of the statement, the criteria necessary to determine attainment.

One way of determining the extent to which desired outcomes have been attained is to consider the outcome attained when each of the objectives into which the outcome has been subdivided have been attained. A more appropriate way is to ask families to make those judgments, alone, or together with other team members. Criteria (modified from those used by Dunst, Trivette, and Deal, 1988) may be used to determine the status of each outcome written on the IFSP. Criteria are assigned by families (or through team consensus) and provide families an opportunity to judge that an outcome is no longer important. Criteria include:

- Attained or no longer important;
- Partly attained or nearing attainment;
- Progress steady; partly attained;
- Minimal movement toward attainment; and
- Unresolved; no change.

Outcomes rated as "minimal movement toward attainment" or "unresolved/no change"

require discussion of the objectives and, in particular, the intervention strategies that are being used. The most likely reasons for limited change are that the objectives are not representative of the outcome statement or, more than likely, the interventions being used are ineffective (or minimally effective). Other interventions need to be designed and tried when attainment of an outcome remains important.

When professionals have actively played help-giver roles throughout the IFSP process, interactions in both periodic and annual reviews represent positive collaboration. When professionals have not assumed help-giver roles in their interactions, families may come to this phase of the process with a confrontational mind-set or beliefs, often founded, that professionals need to be confronted in order for families to have their decisions either understood or acted upon. When professionals have actively listened to families throughout the IFSP process, there should be "no surprises" at annual IFSP review meetings. Rather, these meetings should serve as a means of reviewing past activities and collaboratively planning activities that will occur in the upcoming year.

Transition

Due to the rapid changes in children's abilities and needs as well as changing family circumstances, children may not need early intervention until the age of three years -- or, they may not need special education and related services (e.g., FAPE, Free and Appropriate Public Education) following early intervention. Transition planning is critical when a child and family will be leaving the early intervention system. Equally critical is the smooth transition of a child and family into early intervention supports and services such as when planning for a child who is being discharged from NICU care **into** early intervention services.

Planning is initiated for infants and toddlers who are older than two years of age to move from early intervention into community preschools (e.g., private nursery schools, public school or I.U. programs). Ideally, planning begins approximately six to eight months before the toddler will turn three years of age. Transition planning is a process that involves the family/child, professionals in the sending agency, and those from the receiving agency. These individuals are present during the transition planning process following the point at which the family has selected the program into which their child will be moved. A number of future placement options are possible for children moving from early intervention services into preschool-aged placements. Assessments performed by receiving agency personnel may be necessary to determine eligibility for public school preschool placements and to assist in providing data necessary for developing the Individualized Education Program (IEP).

Information for transition planning is provided by the child's family, the early intervention service providers (the sending team), and employee(s) (the receiving team) of the program which has been selected for the child. Together, these individuals form a transition team for the purposes of carrying out activities to: (1) prepare the child for transition; (2) prepare

the family for transition; (3) prepare the receiving facility, staff, and children; and (4) undertake other activities to ensure smooth transfer from one provider to another.

Transition is a term that is often restricted to mean movement of a child and family from early intervention or from preschool into kindergarten. Transition into the early intervention system may be equally important. Some infants or toddlers may be identified as in need of early intervention services when receiving other types of services, such as medical or social services. The most common example of this situation is infants who are receiving early intervention services through a hospital's NICU and who will be provided with services through community agencies upon discharge from the hospital. An initial IFSP may serve as both the discharge and transition plans for infants moving from the hospital to home, or the discharge plan may be combined with a transition plan to provide for coordination between hospital and community-based services following discharge.

RECORDING PLANS AND DECISIONS

The MDE and IFSP Documents

Both state and federal policy discuss little about the process of individualized family service planning but include specific requirements about components of the process. For example, policy establishes requirements for the MDE and specifies when the IFSP document must be completed, who should attend the meeting, and outlines information that must be included on the MDE or IFSP documents. It is important to remember that the IFSP document is simply an **outcome** of a process of interactions and collaboration among families and professionals -- a process which begins at the point that the family and early intervention system come together and ends when the child and family transition from the system. Along the way, and interspersed within these interactions, are formal points in time when a written IFSP document must be completed. These times include: (a) 45 days following referral into the system - or the initial IFSP; (b) 6 months following completion of the initial and any subsequent IFSP documents for informal review; and (c) annually following the completion of the initial IFSP document for formal review. These formal reviews take place during IFSP meetings that include a variety of participants.

Reprinted in a later section of this manual are copies of the Pennsylvania Department of Welfare Mental Retardation Bulletins that relate to Evaluation, Eligibility, and the IFSP. These Bulletins outline the *essential requirements* of each of these components of the Commonwealth's early intervention system and may be used as a reference to design local systems and procedures for both the MDE and IFSP that are in compliance with the Commonwealth's requirements.

Professionals may have tendencies to view the IFSP process only in terms of those interactions that occur through formal meetings and at the episodic and required times specified in federal and state policy. Many families, on the other hand, view review and rewriting of an IFSP document as a fluid and ongoing process that may be updated at any time through either informal contacts or formal meetings (e.g., Campbell et al., 1991; Hunt et al., 1990; Kramer, McGonigel, & Kaufmann, 1991). The formal meetings are important as "touchpoints" in time; however, the ongoing interactions among professionals and families are equally important. Children change rapidly during their first three years of life, and family circumstances may change equally rapidly. Both informal interactions and meetings serve as vehicles for altering the contents of the IFSP document.

Families of children with disabilities are likely to participate in many formal meetings throughout the lives of their children. Meetings where the results of an MDE are discussed or where the services and supports that will be provided are outlined on the IFSP document are the first of these meetings. Professionals can do a great deal to make these meetings comfortable and productive for families. Families are likely to develop positive views and expectations of the service system when professionals actively create a climate of equal partnership where families' opinions are heard and respected, and where services

and supports are negotiated to be congruent with a family's values, priorities, culture, and preferences.

GUIDELINES FOR COLLABORATIVE PLANNING MEETINGS

Conversations among family members and professionals may take place by phone or through informal or formal contacts and meetings. Meetings that are more formal in nature may include sessions to summarize and discuss the results of the evaluation (MDE), write the IFSP document, plan or discuss activities, supports, or services, review the child's progress formally at six month intervals, or conduct the annual review of the IFSP. Many other contacts and conversations will occur informally through interactions around children's activities (e.g., parent learns from a therapist how to carry her baby) or to carry out particular family-focused strategies (e.g., complete Social Security application).

Meetings that empower families as team members and enable them to express their concerns, resources, and priorities are the result of: (a) adequate information to and preparation of family participants **before** the meeting occurs; and (b) careful leadership within the meeting to ensure that family input is sought and respected. A commitment to family involvement and respect for family members and their opinions is essential.

The IFSP document is written during a meeting among professionals and family members as well as any other individuals invited to participate by the family. A few guidelines will help ensure that this meeting is a successful collaboration and that families have opportunities to state the outcomes desired for themselves and their children and to express their concerns, priorities, and resources.

Setting up a meeting among families and the professionals who are involved with the child and family.

1. Families select the meeting time. This does not mean that families may select just any time but rather that they can select the most convenient time from a series of possibilities. Meetings are scheduled at a time when both parents may attend, if desired. Other significant family members (e.g., grandparents) or family friends or advocates may be involved, if desired by the family. Arrangements concerning work time for staff may need to be adjusted to allow meetings during non-traditional working hours. An essential purpose of meetings is to plan and make decisions. The professionals that families desire to have present at a meeting are invited to attend, including those professionals who are involved with the family but are not employed by or contracted through the early intervention system. These professionals may include human service workers, public health nurses, private providers, or anyone else whom a family feels would be important in the planning and decision making process.

Families have different preferences in terms of people who may attend a meeting,

and these preferences may change over the time of their involvement with the early intervention system. Some families prefer to have *all* individuals involved in the meeting; other families are comfortable with meetings that include those individuals who are critical to the decisions that may result from the meeting discussion. Families may be more comfortable with *everyone* present until relationships are developed with various team members. Other families may be intimidated by meetings that include themselves and numerous professionals -- especially those with whom they have had only episodic or short-term involvement. The service coordinator (case manager) is responsible for helping the family define whom they would like to have present at the meeting, for scheduling the meeting, and for ensuring that arrangements have been made so that all individuals whom the family views as important to this process may attend.

2. Families choose the location for the meeting (e.g., home, center, hospital, agency, school).
3. Most initial IFSP meetings require at least an hour and a half for families to have the opportunity to obtain needed information from professionals and to express their concerns, priorities, and resources. Later (review) meetings may require shorter periods of time when the IFSP process is ongoing and parents and professionals have established positive, collaborative, and trusting relationships with one other. Some meetings need to be scheduled in two closely spaced sessions in order to clarify and synthesize information. Being flexible in the amount of time allocated for these formal IFSP planning sessions helps parents and professionals work together effectively.

Using strategies that promote respect and collaboration during the meeting.

1. Professionals may begin a meeting with statements such as "Tell me about Jon?" or "How do you think Jon has done over the past six months?" to initiate the discussion for the meeting. One of the components of the IFSP is descriptive statements about a child's current status in a variety of areas. Professionals may start the IFSP meeting with a broad question like "Tell us about Christine" or with a more narrowly-focused question like "Tell us about how Christine communicates?" In this way, families may provide information about their children that the professional who is functioning as a scribe can write on the IFSP document by filling in descriptions of children's present levels of functioning as families talk.
2. Professionals provide a background for families through statements such as "a mother told me yesterday that one thing she would like for her son to be able to do is to go to Sunday school at church. What types of activities is your family interested in having _____ do?" In ways such as this, professionals establish that the IFSP will be based on **family-desired outcomes** rather than on a compilation of goals and objectives from professionals.
3. Use of various checklists or reporting forms (e.g., Hunt et al., 1990) may help

families to organize their thoughts and ideas and to participate fully at MDE or IFSP meetings. First contacts with families can be used to identify those families who would like assistance in preparing for the meeting. The family's service coordinator or a family-to-family support person may help provide the family with information about what will happen at the meeting. Most families who are entering the early intervention system for the first time have no prior experience with planning meetings concerning their children. Simply knowing what to expect, how the meeting is likely to "look" and what might be expected from them prepares families for more comfortable participation. Often a simple question such as "Tell me how I might help you prepare for this meeting?" provides families with opportunities to share both the extent to which they might like assistance and how that assistance might be provided.

Interacting with families in positive ways to seek clarification and ensure that families have expressed all desired outcomes.

1. Professionals assist families in identifying desired outcomes and do not provide these outcomes for families. Questions such as "What kinds of things do you think will be important for Lauren to be able to do in the future?" or "Lauren will be two years old in six months. Are there things you hope she will be able to do by her second birthday?" are the types of questions that may help parents express their hopes and desires for their children. Professionals must be sensitive to family perceptions of the ways in which discussions of outcomes are conducted. Questions that allow families to express their opinions are more sensitive than those that seem to "expect" or "demand" that families answer only in specific ways -- with the answer that the professionals may "expect."
2. The types of outcomes that families establish may be related to their own knowledge about what the system is likely to provide. If families view that a particular support or service is part of a system, the outcomes expressed may be matched to this previous knowledge; families may not establish outcomes that they do not "expect" to have met through a particular system. For example, many families would not expect schools to provide health services for their typical children or expect a physician to teach a child. Service coordinators, as well as professionals of all disciplines, need to be sensitive to this issue of expectations if the IFSP is to serve as a family-centered consolidating document. The ways in which the IFSP process is discussed with families provides them with information about the system. If the system is represented as an inter-agency and collaborative process designed to assist families to address their own and their children's needs, families will be more likely to establish a broader range of desired outcomes than when the system is represented as a collection of child-centered services.
3. Families may have outcomes that they desire for their family, including needs for information, intervention for their children, or supports. Professionals may obtain information about these outcomes through discussions with the family where professionals elicit information about needs and the ways in which these needs

might best be addressed. A desired outcome might be for a family "to learn more about Down syndrome." For one family, this desired outcome might be addressed through meeting other families with children with Down syndrome whereas another family might attain this same outcome through joining organizations, talking further with knowledgeable professionals, or reading books.

4. Professionals make every attempt to understand exactly what outcome(s) families desire by discussing and conversing with family members. Professionals should not judge the validity or feasibility of outcomes established by families.

Outcomes may be child-related or family-related. Child-related outcomes are likely to relate to children's achievement of independence in typical skills such as walking or talking or to activities (i.e., eating in a restaurant; going on a family outing; finding day care services) or routines (e.g., I need help giving Jamie her bath). Only very well-informed parents may be able to express that they would like their child to talk using an augmentative system or to walk using a walker. When families of children with very severe disabilities request performance of skills that do not appear to be "realistic" for the child, given the degree of disability, professionals need to expand and inform families of the ways in which the outcome may be achieved. For example, if a family of a child with a severe physical disability establishes walking as an outcome, the professional reshapes the statement by saying something like "It sounds important to you for _____ to be able to get around the house without your help. Walking independently may not be easy for _____ to learn but getting around the house by himself is something we can work on by teaching him to _____ (e.g., use a walker, motorized car, tot sized wheelchair, etc.)." In this way, professionals respect the content of a family's message without getting tied to the specific way in which that outcome might be achieved. Professionals have knowledge about all the various ways in which desired outcomes may be attained. Families do not typically have the type of knowledge until provided information by professionals.

Family-related outcomes may be expressed as desired activities (i.e., "we want to include Kathryn on our camping trips") or as personal goals, the attainment of which are likely to benefit the child (i.e., "I need help getting off of drugs"; "we need better housing;" "I would like to know more about getting financial help"). These outcomes may or may not be tied to a particular early intervention service and, in some instances, may require knowledge, resources, and skills that are outside the expertise of the traditional early intervention system. What the early intervention system can do in all instances is to assist families to access and use the resources available within their communities in order to attain the desired outcome. Neither the service coordinator, for example, nor typical early intervention service providers are likely to be able to directly assist a mother or father to become rehabilitated from substance abuse; however, the service coordinator can assist a mother or father in learning about and using the resources that are available to help attain this desired outcome.

Establishing that the IFSP is an ongoing process where families have ownership of the plan and its review.

1. Professionals establish at the initial IFSP meeting that the document and plan may be reviewed at any time the family desires and provide families with information about how to request a revision (i.e. "Tell your service coordinator whenever you would like to convene a team meeting or meeting of any professionals to revise the IFSP.")
2. The service coordinator, or other professionals, check back regularly and informally with families to ensure that the plan is revised, as needed.

CONVERSATIONS WITH FAMILIES

The following three stories provide examples of ways in which family members and professionals communicated at different points in the IFSP process. There are two versions of each story. In the first version, professionals drew conclusions about the meaning of what they heard the families say. These conclusions, in turn, indirectly influenced the recommendations made and the actions taken by the professionals. In the second version, professionals used the strategies discussed under "Guidelines for Family Conversations and Interviewing." The use of these strategies allowed professionals to develop a clearer understanding of what families were communicating. This clearer understanding, in turn, resulted in collaboration among families and professionals that led to more desirable services and supports.

Julia and Jimmy: First Contacts

Julia Harrison had been asked to tell the service coordinator about her child. She responded by saying, "Jimmy is really a good baby. He seldom cries but when he does he becomes really stiff and hard to hold or console.... nothing seems to work to calm him down. He eats well and has been gaining weight. Last week, he started sleeping through the night." *The service coordinator concluded that Julia was not really focused on Jimmy's developmental abilities at this time -- probably because she was only 15 years old and didn't know much about babies and how they developed. In scheduling Jimmy for an initial MDE, the service coordinator told the professional evaluators that she was pretty sure that this mother did not know much about development and that they should try to explain the evaluation carefully so that the mother would be able to learn about her baby.*

Julia and Jimmy: First Contacts

When Julia finished talking about Jimmy, the service coordinator paused and said, "You describe Jimmy as if he is really easy to care for."

"Yes," Julia answered. "Sometimes I wonder if he is too easy but Jimmy is my first. I hope my next baby will be just the same... so many of my friends have babies that seem to cry more or are hard to get to eat. Jimmy doesn't cry much but, when he does -- look out!! One of my girlfriends had a baby about a month before Jimmy, and Raul doesn't sleep through the night yet."

"Even though Jimmy seems like a happy baby, it sounds as though he is difficult to calm down whenever he might cry. Tell me about what happens when he starts to cry."

The service coordinator used a number of strategies to gain more information about Julia and Jimmy.

- She **repeated back** what Julia had told her to gain confirmation when she said, "You describe Jimmy as easy to care for." She also **used a broad statement** to encourage Julia to talk about anything that had to do with caring for Jimmy. This strategy allowed Julia to talk more and allowed the service coordinator to learn more about the ways in which Julia defined "easy to care for."

The service coordinator learned that Julia had girlfriends with babies to whom she compared Jimmy and that the crying might be a real concern.

- She **focused the discussion** on the crying and asked Julia **to describe** what happened when Jimmy cried. She did not provide solutions to the crying ("Maybe if you rocked him it would help.") or ask Julia yes/no questions such as "Do you think he is hungry when he cries?"

"Well, I start to feel crazy," said Julia, "since I know he will not stop crying very easily. First, I pick him up and try to rock him a little bit and check to see if his diaper is dirty or wet. If it is, I change him. If his Pamper's OK, I try to see if he is hungry. I put my finger near his mouth to see if he sucks. If he is crying too hard, I get the pacifier or a bottle and try to put it in his mouth. Sometimes, I think he doesn't know whether he is hungry or not. If he doesn't take the bottle or the pacifier, I hold him real close to my body like the visiting nurse showed me. She said that sometimes a baby needs to be held real close. I don't talk to him or make any noise or even look at him. I try to make things real calm so it is just him and me. I try that for a few minutes and if that doesn't work, I put him in his bed and just wait for him to stop crying. Sometimes that works -- then, maybe my mother comes and tries stuff, too. I think that sometimes he just cries so hard and so long that he puts himself to sleep."

The service coordinator was pretty impressed. She had no idea that Julia knew so much about Jimmy -- nor was she aware that Julia and Jimmy had a visiting nurse who came to the house. "It sounds as though you get Jimmy to stop crying most of the time or that your mother helps. How often does it happen that he really cries and that you can't figure out how to calm him down?"

Not too often," Julia said. "Actually, I think that he cries about when you would expect a baby to cry -- several times

She learned that Julia had a number of strategies and that she was receiving some sort of services from a visiting nurse.

- She commented that Julia was usually able to get Jimmy calmed down but **explored further** by trying to figure out how often the crying was a real issue.

She learned that Julia viewed Jimmy's crying as pretty typical of what she thought babies should do and that the

during the day -- but only once in awhile -- maybe once a week or so, does he get the crying jag. I asked the doctor about this and he said that babies cry. But I do worry a little bit because his crying really annoys my dad."

"Are there more things that you think you need to know about Jimmy?," the service coordinator asked.

"Well," Julia answered, "my girlfriend has a swing for her baby and it really helps that kid to stop crying. He loves being rocked and all you have to do is put him in the swing, turn it on, and wait. I wish I had a swing for Jimmy but I haven't been able to get the money together."

"Maybe we can work on that. There may be someone who can donate or lend you a swing for Jimmy. Are there other things about Jimmy that worry you besides how hard he is to calm down sometimes?"

"Not really," Julia answered. "I think he plays good for a baby his age and he is really active. Last week he sat up all by himself -- my girlfriend's baby isn't doing that yet -- and he really likes my mom -- smiles at her all the time. The doctor told me maybe I should have

problem crying occurred about once a week. She learned that this crying was a problem because Julia felt that her father was annoyed when Jimmy cried.

- She followed the discussion with a **broad question** by asking Julia if there were more things she needed to know about Jimmy. This allowed Julia to continue to focus on the crying or to change the topic. It allowed Julia, also, to provide her perspective about what might be helpful.

She learned that Julia felt that a swing would be helpful for Jimmy but that she was unable to afford to buy one.

- She **confirmed** that Julia wanted a swing by suggesting ways in which one might be obtained and **refocused the discussion by asking another broad question**, "Are there other things about Jimmy that worry you besides how hard he is to calm down sometimes?"

She learned that Julia was pretty knowledgeable about what Jimmy was doing developmentally and that his development was not a major concern. She learned, also, that Julia had contacted early intervention because a physician had told her to do

some help with him so that's why I called you. You've seen him now a couple of times, do you think he's doing OK?"

"The way in which we usually find out if a baby is doing what he is supposed to be doing is to give a test where we see what the baby is doing and mark it on a piece of paper. This is called a developmental screening test. We watch the baby and the mother helps by telling what the baby can or cannot do. Sometimes we give the baby a particular toy to see what will happen. All this information -- our watching the baby and what the baby's mother or caregiver tell us -- gets marked on a paper next to ages at which babies typically do these things. This way we can tell if the baby is doing what he is supposed to do for his age. Jimmy is seven months old now and we can give him this test to see if he is doing the things that most seven month old babies do."

"That sounds really good," Julia said. "I bet my girlfriend would like to have that for her baby, too. It's really hard to know what babies are or are not supposed to be doing even though I have a class about that from the people where Jimmy goes to day care when I am in school. Where do I take him to get this?"

"I can arrange for someone to come out here to your house or you can take him to a center in North Philly. Is there a time that would be good for us to schedule this?"

so. She learned that Julia wanted confirmation about Jimmy's development.

- The service coordinator **avoided directly answering Julia's question** about Jimmy's development by **providing information about screening procedures**. She talked about these procedures generally and then focused them more specifically on Jimmy. She did not provide excessive information (such as the name of the test, what developmental areas would be measured, etc.). She **focused upon** Julia's role in the screening process.

She learned that Julia viewed this as helpful -- so helpful that she thought her friends might like the same thing for their babies. She learned that Julia has been taking a class about children's development as part of her highschool program.

- She **offered options** about when and where the screening could be conducted.

"I go to school every day with Jimmy until about 2:30. I could be home by 3:00 but then I have to feed him. Could someone come to the house about 4:00 or so. Any day would be fine."

"I think that will work out. Let me try to make the appointment and I will call you and let you know the exact day. I think we should be able to get this done within the next week. In the meantime, I'll also work on finding a swing."

"That would be great. I would love to have a swing. I know it would be helpful since Jimmy likes to be in Raul's swing. It will also be great to know how he is doing. I worry sometimes because his dad doesn't come by too much or seem to interested in Jimmy although my mom and dad really make up for that!! We really want him to do well."

She learned that Julia preferred to have the screening done at home and after school.

- She concluded the conversation by stating the next steps (the service coordinator would arrange the appointment and call Julia to confirm). She provided general timelines for when the screening might take place and she confirmed that she would try to help get the swing.

She learned that the baby's father is not very involved and that Julia gets support from her mother and father. She learned that Julia wants Jimmy to do as well as possible.

Linda and Maya: Determining Initial Outcomes

Linda Luis was in an IFSP meeting about her daughter Maya. It was the initial IFSP meeting for this 15 month old who had just been diagnosed as having mild cerebral palsy when seen in the Neonatal Follow-Up Program at the hospital where she had been born. When asked what she would like to see happen with her child in the next several months, Linda said, "I would like her to walk and I would like her to talk." The physical therapist and the speech and language pathologist were somewhat taken aback since Maya was unable to sit well and was making only very few sounds. Both decided to put these desired outcomes onto the IFSP and to work toward them, at least indirectly. Nobody wanted to challenge Linda about her unrealistic outcomes.

Linda and Maya: Determining Initial Outcomes

Linda described what she wanted to see happen in the next several months by saying that she wanted her 15-month-old daughter to walk and to talk.

The service coordinator looked at Linda and said, "You've said that you would like Maya to walk and talk during the next several months."

"Yes," said Linda, "I think I'm like every other mother. But I don't know if it will be possible for Maya to walk only in a few months. She's gone through so much in her short life -- 5 surgeries and being really sick. We've only had her home for about six months -- but she is getting pretty heavy to carry and I just found out that I am pregnant."

The service coordinator waited for Linda to go on.

"I don't know how I feel about this next baby. I was so surprised to find out that I was pregnant again. We thought we were being so careful. It seems like we're just getting to know Maya and now someone else is on the way. The doctor says that if I take care of myself, this baby should be OK. I hope he is right. We have so many medical bills -- even with insurance.

"It sounds as though you have concerns about the pregnancy and about Maya's medical bills," responded the service

Attending the IFSP planning session were Linda, her service coordinator, John, the physical and occupational therapists, an early intervention teacher, a speech pathologist, and a psychologist. Linda had come to the EI Center, as requested, at 2 o'clock in the afternoon in order to gain an understanding of the MDE evaluation results and to discuss Maya's IFSP.

- The service coordinator **restated** what Linda had said and paused.

The team learned that Linda is pregnant and that Maya had a lot of medical complications following her birth. They learned, also, that Linda would like Maya to walk but that she doesn't know exactly what it will take for her to walk or when this might happen.

- The service coordinator's **pause** allowed Linda to continue talking.

The team learned about Linda's concerns about her new pregnancy.

- The service coordinator used a **statement to confirm understanding** about Linda's concerns, followed by a **"grand**

coordinator. "Tell us about things that might be helpful or make things easier."

"I'm not sure if I really know. We need help with Maya's medical bills. What if the new baby is also premature and we get even more bills? I don't know what happens when you can't pay your bills...and, I need to know more about Maya. All along the doctors have said how well she is doing since she's been home and now they're telling me that she might be mentally retarded and that she probably has mild cerebral something. I was so surprised that I think I went into shock when they tried to explain everything to me. We thought she was doing so well. Neither Jose or I or Maya's grandparents have noticed anything wrong with her. She is such a pleasant and cute baby -- she seems fine to us and we love her."

"I think we can help see if there are any programs for which you might qualify that might help with Maya's bills. And, I think we can also help you learn more about Maya," said the service coordinator.

"It sounds as though you're interested in knowing more about how Maya is doing in comparison to other babies," said the physical therapist. "When we visited you last week at your home, the things that we did with you and Maya were to help us figure out how she is doing. We wanted to meet Maya and learn more about her. One of the things we were looking at is how well Maya is doing in various areas -- like how well she sees, moves around, and uses her hands. We were able to see some of the things that

tour" statement to explore her concerns in greater depth.

The team learned that the family is trying to pay their own medical bills that were not covered by insurance and that some assistance might be helpful. They learned, also, that Linda was surprised when the physicians in the Neonatal Follow-Up Program identified Maya as potentially having mental retardation or cerebral - the team, guessed - palsy. They learned that Linda would like more information about Maya.

- He **confirmed and agreed to address the concern** for help with Maya's bills. He also focused the conversation on Linda's second concern -- understanding more about Maya.

- The physical therapist **restated** Linda's concern and used a more narrowly focused statement to shift the discussion to understanding more about Maya's development by saying "Let's talk about..."

she does. Let's talk about some of the things you and your family notice that Maya is doing."

"Well, we're really proud of her because she is able to pull up to standing when I put her on the sofa. You saw her when you were out last week. One thing she started doing, though, since you were there is moving her feet up and down. She looks like she is dancing up there on the couch."

"It sounds as though Maya is learning to move her feet -- That seems really important to you."

"Well, I figure that if she is doing that, walking can't be far behind!!"

"One of the difficulties that we noticed when we observed Maya is that her muscle tone is low in her trunk but higher or more stiff in her legs and sometimes in her arms," continued the physical therapist. "Muscle tone allows babies to be able to counteract gravity and stay upright. Without enough muscle tone, babies kind of sink down into the floor or have to have support in order to stay upright. When Maya leans on the sofa with her body, the sofa provides support to her trunk and

The team learned that Maya stood at home. They had observed her behavior during their home visit, as well, but they had not seen her move her feet. While Linda was talking, the occupational therapist, who had been designated as the scribe, began writing Linda's statements on the IFSP under the current performance category. She wrote the information about standing and moving her feet under the physical area of development.

- The physical therapist **restated** Linda's information.

The team learned that Linda interpreted Maya's behavior as an indicator that Maya was almost ready to walk.

- The physical therapist felt very frustrated in trying to explain what she had observed the previous week to Linda. Maya was not at the meeting so she could not demonstrate what she was describing verbally. She wished she had demonstrated this during the MDE, but the team had been conducting the MDE and Linda had been an observer. At the end of her explanation, she **paused** to allow Linda to comment or ask questions.

reduces the effects of gravity. Her legs also get stiff. With the stiffness in her legs and by leaning on the sofa, she is able to hold herself upright in standing. You may remember when we tried to get Maya to stand on the floor when we were with you last week and she sort of collapsed and leaned forward and her legs got so stiff that she was standing on her toes."

"I don't know if I remember that exactly," Linda said. "But I do know that her legs seem to get stiff a lot, especially when she is crying or if I try to hold her or sit her on the floor when she doesn't want to sit. I always thought she was just having a bit of a baby temper tantrum. Should we be doing something about her legs?"

"This stiffness is probably what the doctor noted when she talked with you about Maya. In the reports that you asked to be sent to us from the Clinic, the doctor describes Maya as having cerebral palsy -- this condition usually effects a child's muscle tone. With Maya, what the doctor is doing is giving a label, a diagnosis, to the stiffness in Maya's legs and the low tone or "floppiness" in Maya's trunk muscles. These things might make it difficult for Maya to learn to walk all by herself. To walk all by herself, she needs to be able to stay upright but her legs can't be so stiff that she can't move them to take

The team learned that Linda had noticed the stiffness in Maya's legs but learned, also, that Linda attributed the stiffness to somewhat normal factors

-- an expression of Maya's anger.

- The physical therapist continued the conversation by **discussing the impact** of the muscle tone on Maya's walking, **clarified** an interpretation of, and **defined**, walking as being fully independent, and **responded** to Linda's question about whether or not something should be done about Maya's legs by confirming that both the team and Linda could address this issue. She then **paused** so that Linda could continue.

The team learned that Linda and her family were interested in helping Maya and viewed themselves as able to do things.

steps. These are things that we can work on and help you work on while you're doing things with Maya at home."

"We will do anything to help Maya --- just tell us what to do," Linda responded. "She has come so far since being born. I just want her to continue to do things."

The occupational therapist spoke next. "That's the reason that we are writing this plan, this IFSP, so that we can agree on what services and supports might be helpful for you and Maya. It sounds as though we have to help Maya physically so that she gets better muscle tone in her trunk and so that her legs don't get stiff so that she can learn to walk. Under the physical section of the IFSP, I have written that Maya is able to stand with support and that she is starting to move her legs. Are there other statements, Linda, that you might want to make to describe her current motor abilities?"

"Let's see," Linda said. "She is able to sit by herself and play on the floor although now that you have mentioned this muscle tone problem, I see that she flops forward a lot and can't really play with two hands. Her hands have to be on the ground or I have to lean her against the sofa or a chair.... She is crawling but she doesn't get her belly off the ground exactly. Her crawling is more like pulling along the floor -- but she is good at getting somewhere. She pulls herself up to a standing position by holding onto my legs or the sofa or something... and, like I mentioned before, she is starting to move her feet when she is standing."

- The occupational therapist used this opportunity to **summarize** the previous discussion and to **solicit input** about Maya's current performance in the physical, motor, area. She addressed the question to Linda in order to provide her an opportunity to speak first.

The team was really impressed by what Linda said. She seemed to be very observant of her child's abilities. In fact, everything that Linda mentioned matched the team's observations of Maya's abilities during the MDE.

"Maya is able to do a lot of things," the service coordinator said. "Are there other things that anyone else noticed and wants to mention?"

"We noticed during the MDE that Maya is able to do lots of motor activities," the PT said. "I think that Linda's statements really describe her abilities at this point. You're observations are so good," the PT said to Linda, "that you have been able to see how her low muscle tone effects her sitting, crawling, and pulling up to standing. When we compare the things that Maya is able to do with other babies of her chronological age, her motor abilities are not yet quite as competent as we would expect from other babies who are 15 months old. But, because Maya was two months early, we actually are comparing her performance to her corrected age of 13 months. Her motor skills are not as good as an average 13 month old but what is more of an issue is the reason why she is showing this delay. This delay in motor skills seems to be related to her muscle tone and we can certainly work to improve her tone and to reduce the impact of these muscle tone problems on her abilities to perform various skills although she is not likely to ever have fully normal muscle tone."

"You mean that she will always have muscle tone problems no matter what we do?", Linda asked.

- The service coordinator **commented on Maya's strengths and abilities** and refocused the question to the professionals to obtain any further input.

- The physical therapist **confirmed** that Linda's observations were accurate and that the team did not have anything to note that Linda had not noted. She used this as an opportunity to **reinforce** Linda's competence as an observer and as an opportunity to **discuss and explain** a new area of developmental delay and the relationship between the muscle tone -- cerebral palsy -- and the current delay in motor abilities.

- Linda **asked a question** to gain more information about something that was not clear to her.

"Everybody -- children and adults -- have differences in muscle tone. Some people have really excellent tone -- for example, many adults work out a lot or exercise to get really good tone. With some children, their tone is not within normal limits -- their muscles are stiffer than normal or are floppier than normal. In Maya's situation, some of her muscles, like the ones in her legs, are stiffer than normal; the ones in her trunk are floppier than normal. Being aware of these differences is a first step. Then, there are ways of holding, carrying, or positioning -- like putting Maya in sitting or standing -- that will be better than other ways in helping her learn how to use the muscles in her trunk better and how not to have her legs get stiffer -- if this makes sense to you. The differences in muscle tone are easier to see than to talk about. I'm wondering how I might explain this more clearly."

"What you are saying makes sense to me. Because Maya's muscle tone is not the same as other children, this will effect how she does motor things and when she learns them. But, even so, there are special things that I can learn so that I can help her at home."

"That's exactly what I was trying to say. What we would like to see in the future is that her pattern of stiffness/floppiness does not prevent her from being able to get around and that her condition, although it will always be there, improves to the extent possible. Improvement is always possible -- Maya will still be able to do many, many

- The physical therapist provided a detailed answer that included information as background to Linda's question. She used this as an opportunity to **begin teaching and empowering** by providing Linda with information about muscle tone, generally, and Maya's muscle tone, in particular. She offered Linda an opportunity to ask further questions or gain clarification. This provided the therapist with **confirmation** about Linda's understanding.

The team, and physical therapist, learned that Linda did have an understanding of what the therapist was trying to explain.

- The physical therapist **confirmed** the accuracy of what Linda was saying and continued by **refocusing** on the outcome of walking.

things. And one of the first areas we all want to work on is improving muscle tone so that Maya will be able to get around by walking.

"I've written on the IFSP that one of Linda's desired outcomes is for Maya to walk." The occupational therapist then looked at Linda and said, "We could proceed in two ways that I can think about. We can discuss Maya's abilities in other developmental areas, like communicating or what she is doing in self-care areas, or we could discuss the next steps, like what supports and services would be helpful in getting Maya to walk. How do you think you would like to proceed?"

Linda responded by saying, "I think I understand now that we can do things to help improve Maya's muscle tone and to help her be able to walk

-- I'm not sure exactly what those things are but it would be OK to discuss them after we talk about the other things she is able to do. It seems as if we have forgotten everything else about Maya except her motor abilities."

The occupational therapist said, "We have been talking about motor abilities a lot and you're right -- motor abilities are only one area of development that is important for young children. Let's talk a little bit about the ways in which Maya communicates."

- The occupational therapist offered **options/choices** to Linda so that she could have control over the direction of the next portion of the meeting.

The team learned that Linda preferred to discuss Maya's other abilities before considering decisions about next steps.

- The service coordinator **directed** the next area of discussion to communication -- another of Linda's desired outcomes. The team members realized that Linda was not unrealistic, a lot about the family had been learned, and the PT felt really positive about the ways in which she and Linda had discussed the motor issues.

The Love Family: Next Steps

Carrie and Raymond Love attended an annual IFSP meeting after their two year old son Derek had been receiving early intervention services for about a year. When the family was asked to state their desired outcomes, Carrie said: "I want Derek to have individual occupational therapy five times a week for at least half-hour sessions. Because I want him to be in an integrated and inclusive preschool program, I would like the OT to go to that school. Participating in school will help improve his social and communication skills so I would like his preschool to be paid for through early intervention." *The IFSP professional team members felt quite vulnerable since they were pretty sure that it would be difficult to provide everything that Carrie wanted and they weren't sure if they agreed with Carrie's desires. The team wrote the family's desires down and said that they would work on them -- that what the family wanted was different from what other families wanted. The occupational therapist also stated that she did not visit day care centers or preschools because of her very tight schedule and the large numbers of children to be seen and that Carrie would have to bring Derek to the center to get his therapy. "Since you need to come here for the therapy, he might as well attend our school," the OT said, "At two, he's too young for preschool and going one place would be easier."*

The Love Family: Next Steps

Carrie and Raymond Love, in an annual IFSP meeting for their two-year-old son stated desired outcomes of having him attend an inclusive preschool program with OT provided five times per week at the preschool.

"Let's start from the beginning," the service coordinator said. "What I hear the Loves saying is that Derek has social and communication needs that the Loves believe could best be addressed in a setting with other typical children. They also think that occupational therapy is important." She turned to the Loves, and asked, "In what ways might OT help Derek?"

Carrie said, "Derek has a lot of problems in getting along with other people. I guess you'd say that he has a lot of behavior problems. If people brush up against him, for instance, he starts screaming -- sometimes, even hitting. When he goes to OT, the therapist plays with him in sand and stuff so that he gets used to how things feel. She says he needs to deal with different sensations better. His posture is terrible. He slumps around sometimes and is sort of uncoordinated. The OT told me he's a little insecure and needs activities to help build up his muscle tone and what she calls his postural security. I'm afraid that if he doesn't get therapy, he will have trouble with people his whole life. He's already "bad" and he's only two!! I don't want to think about when he's 10 or 15!"

"Your main concerns seem to focus on Derek's behavior and his ability to get along with other people," the service coordinator said.

- The service coordinator **refocused** the discussion by restating what had been said in terms of Derek's needs and outcomes, as expressed by her parents. In so doing, she negated discussion about services only and neutralized the possible differences in opinion between the Loves and the OT. She also **changed the climate** of the meeting to one of information sharing rather than confrontation.

The team learned that Carrie had real concerns about Derek's behavior and that she felt that the kinds of activities that the OT was doing with Derek would help him.

- The service coordinator **restated** what she heard Carrie say.

"That's exactly it," Raymond said while Carrie shook her head in agreement. "If Derek can be around regular kid maybe he can learn to get along while he is little. He also is hard to understand. Sometimes I think he gets frustrated because people don't know what he wants and that starts his temper tantrums, too. He's made some progress in the last year but so many kids in his class act weird like he does. What will he learn from these other kids?"

"You seem to think that Derek can learn from other children and that if he is around more typical children that he might learn from them how to act more appropriately," Derek's teacher said. "There are many different ways and situations in which toddlers, like Derek, can be around typically developing children -- parent-infant-toddler groups at the community center, day cares, recreation groups -- to name a few examples. Most of the preschools in our area with which I am familiar don't enroll children until they are three years of age. Has this been your experience?"

"We've been trying to involve Derek in as many group activities with typical kids as possible. My sisters each have young kids and we have made it a point to get together with the kids every Sunday afternoon. The grownups get kind of crazy with the 7 kids all at once, but these playtimes allow them to get to know their cousins and they are really good for Derek. He is starting to play real good with those kids. He also goes to the Sunday school group at church and Miss Rubye says he's doing real good. One of the mothers whose kid is in Derek's Sunday school group runs a neighborhood preschool group right in her house. She tells me that she'd be glad to have Derek any time. I went

The team learned that Derek's father and mother shared the same concern -- Derek's behavior -- and the same strong desire for Derek to be more social -- get along better with others. They learned that Raymond thought that Derek's difficulty expressing himself was related to his behavior.

- The teacher responded to Raymond by **interpreting his question as rhetorical** and by **focusing** on and **confirming** the importance of interactions with typical children. She **expressed ignorance** about preschool enrollments as a means of having the parent(s) provide further information.

The team learned that the parent(s) have done a lot to include Derek within their family and community. The parents had numerous situations in which to observe Derek's behavior with typical children. They learned, also, that the family had found a "preschool" (which seemed to actually be a family in-home day care.)

and visited her last Wednesday and her preschool would be just great for Derek. There are only 8 kids most of the time and Judy has all kinds of activities for them to do. All those 8 kids are real well behaved and would be good for Derek to learn from."

"How often are you thinking that Derek might go to Judy's and how long would he spend there each time he goes?", the teacher asked.

"I don't know if I've really thought about it that much," answered Carrie. "When I visited and talked to Judy, she thought that Derek could come for one or two hours to start until he got used to the kids. She thinks it would be better for him to go every morning -- he is best in the morning before he gets tired -- and she thinks every day would help him get adjusted and used to the other kids quicker. The only thing Judy is worried about is how she should react to Derek if he gets bad. I am thinking that by the OT being there every day for a little bit that she could help Judy out maybe."

"Judy certainly seems willing to try Derek, and she must know him a little bit from church and the neighborhood," said the service coordinator. She continued by saying, "This might sound a bit strange but what would you think about our doing a kind of transition plan or an inclusion plan for Derek to help us get organized and consider the best way to support Derek so that he will have a good experience at Judy's? Usually we do transition plans for children who are leaving early intervention. Derek isn't really leaving since he will still receive

- The teacher **asked a focused question** to elicit more information about what the parent(s) were thinking about in terms of sending Derek to a group program.

The team realized that Carrie and Raymond had given this option study and thought. They realized that the family knew that Derek would need supports to be successful and that whomever the teacher was would also need information, strategies, and help. The small number of children in the family day care seemed a good start in matching Derek's needs. The only thing anyone worried about was whether Judy had the credentials to manage this child with special needs.

- The service coordinator **confirmed** that Judy was interested in Derek and **suggested** the use of a particular planning strategy to ensure Derek's success.

early intervention services, but I think we need to all sit down and figure out how to best make this happen successfully -- what supports and services should be provided and what activities may need to take place. We would want you two to be involved," she said looking at both Carrie and Raymond, "and Judy should be involved, too."

"That makes good sense to me," Raymond said. "How about you, Carrie?" "I think it's a good idea," Carrie agreed. "I don't really know what a transition plan is or an inclusion plan but I am guessing that people here who know Derek, you (and she looked at the service coordinator), Judy, and Ray and myself can sit down and really talk about what Derek needs. I know this will help him but it might not be easy. He can be a real tough kid and we'll all need support and help."

"We need to talk about payment for Derek to attend Judy's," said the service coordinator. "Even though her experience may be really beneficial and helpful for Derek, day care is not an early intervention service and, as a rule, we cannot authorize payment for day care." She looked toward Raymond and Carrie and asked, "Do you have financial resources to pay for Derek in day care?"

"We're really a little tight right now," Raymond answered. "I am working pretty much of the time but I do construction and the work is kind of seasonal and unpredictable. Carrie has a job once in a while but she's not working right now." He turned and looked to Carrie, "Did you ask Judy what she charges?"

"I didn't ask her but I can call and find out. It

The team realized that the family was aware of how difficult Derek could be and they appreciated that the family understood that Derek's success was dependent on more than Judy wanting him or on simply placing him in a small program.

- The service coordinator did not know a lot about the family's financial circumstances, but she did know that Raymond was employed but she did not think that Carrie worked. She **asked** a question about their financial resources without asking specific information.

The team found out that the family might need some help but agreed that Judy's rates would be helpful to know.

would be good to know how much money we are talking about." Carrie turned to the service coordinator, "Could there possibly be other programs that we might qualify for if early intervention cannot help?"

"How does this sound?", asked the service coordinator. "It seems as though we are in agreement that a small group program setting would be an appropriate means of helping Derek develop better social and communication skills and, generally, improve this behavior. We know that Judy is willing to take him in her day care. What we don't know are the costs involved and whether or not the Loves can manage these costs or will need help from other places. We also don't know yet the exact services and supports that will help achieve an outcome of Derek's participating in a regular day care setting with typical kids. What if we plan another time to meet and, in the meantime, I think each of us has a job... Carrie will find out about Judy's rates and will invite Judy to attend our next meeting. I will schedule the meeting and see what I can find out about financial assistance for day care. Sarah and Mavis," the service coordinator looked toward the teacher and the OT, "would it be possible for one or both of you to make a short visit to Judy's center sometime in the next several weeks to see what the program looks like?"

Mavis and Sarah conferred and agreed that they could probably get to Judy's sometime soon. "What would be the best

- The service coordinator **summarized** the status of the discussion and **requested/ assigned** specific people to do specific jobs.

way for this to be set up?" they asked Carrie.

"I can call Judy and find out some times that she thinks would be good and get back to you. If you wouldn't mind, I might like to go along with you so you could help me think about situations that might be hard for Derek to manage," Carrie said.

"That would work out fine," the OT said. "It would be helpful for us to have your perspective, too."

"Well, I think that pretty much ends this meeting. I'll be getting back to everyone. At our next meeting, we will outline the objectives for her outcome and plan the supports and services. This way we'll know that the services will really help him be successful, and we can figure out how we might help Judy make this the best possible experience for Derek and the Loves."

"We really appreciate your help with this," Carrie said. "This has been a really helpful meeting for me -- Raymond, too -- and I was really nervous when we came here today. You have made us both feel like we really can help our son."

The parents seemed to agree with the idea and the teacher and therapist learned that Carrie was interested in their opinions

- The service coordinator summarized the meeting and set the focus for the next meeting.

- Carrie ended the meeting by sharing her feelings about how helpful everyone had been and how important their help was to herself, Raymond, and Derek.

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