Supplemental Materials: Evaluation & Assessment Module
Planning with Families

Guiding questions: Planning with Families for Evaluation and Assessment

- What does a family want to know about their child?
- What do early intervention service providers need to know about a child/family in order to select, with families, functional outcomes and family supports/services?
- What measures are likely to yield this information?
- How can this information be collected in the least intrusive manner?

Planning with Families for Evaluation and Assessment emphasizes that effective evaluation and assessment is based on collaborative planning and decision making between family members and early intervention providers. There are two primary tasks to accomplish during planning conversations with families:

- talk with family members about what they want for their child; and

- use pre-existing medical, health and developmental information to individualize a child's evaluation and assessment for the Maryland Infants and Toddlers Program (MITP).

As noted in both the federal and Maryland regulations that accompany the early intervention section of the *Individuals with Disabilities Education Act*, evaluation and assessment each have a specific purpose:

Purpose of Evaluation	Purpose of Assessment
Determine a child's eligibility for a state's early intervention program; and Review a child's status in five developmental areas: cognitive; physical, including vision & hearing; communication; social/emotional; and adaptive.	Identify a child's unique strengths and needs; and Assist a family to identify their concerns, priorities, and resources as the basis for developing an Individualized Family Service Plan (IFSP) that will support them in fostering their child's development and participation in desired activities.

Before and during evaluation and assessment individualized, information is collected with families about how a child participates in daily activities in various settings. Family members

have their own perspectives about meaningful participation for a child in home and community activities, based on their family culture, values and traditions. Early intervention providers can prompt family members during planning conversations to:

- reflect on their desires for a child's participation in daily life situations and activities (family priorities);
- talk about the strategies, people and places that have been, or could be helpful in promoting a child's development and participation (family resources); and
- identify what still needs to be addressed (family concerns).

Thus, **planning for a child's evaluation and assessment involves assisting families to identify their concerns, priorities, and resources.** This is a **collaborative process** between family members and early intervention providers, and has been described as:

> ...the ongoing and interactive process by which families share and professionals gather information in order to determine family priorities for goals and services... a continuous process involving both family members and professionals. The primary goal is for professionals to understand what families want for themselves and their children and what they need from professionals in order to achieve these aspirations (Bailey, 1991, p. 27).

Essential Content: What early intervention providers and families need to know about planning for evaluation and assessment

a. Purpose of planning with families for evaluation and assessment

The overall purpose of planning for evaluation and assessment is to gather and exchange information between family members and early intervention providers so that meaningful early intervention supports and services can be selected during completion of the Individualized Family Service Plan (IFSP). The immediate goal is to carry out an evaluation and assessment that yields meaningful information about how a child's developmental status, as well as family resources, influence his or her participation in family life and community activities.

The planning process for evaluation and assessment actually begins with intake, when a parent or someone else first contacts one of the 24 local Infants and Toddlers Programs in Maryland. A planning conversation, however, is distinct from intake in that it involves an in-depth discussion with a family, conducted in a personal visit, to explore concerns, priorities, and resources related to a child's development. This sets the stage for identifying family-desired services and supports when the IFSP is developed (Bailey and Blascoe, 1998).

Identifying a child's functioning levels in various developmental areas is one part of the evaluation and assessment process. Prior to a child's evaluation and assessment, a planning discussion should be held with a family to elicit their perspectives regarding:

- a child's developmental strengths and needs, related to the specific activity settings in which parents would like their child to participate; and
- the resources that families have available to support their child's participation in family and community life.

Early intervention providers should use their expertise to support families in promoting a child's participation in specific settings, rather than deliver a provider-directed session in a child's home. The differences between traditional and collaborative models of early intervention can be summarized as follows:

Collaborative Model		**Traditional Model**
Support families in promoting a child's participation in specific activity settings	**Purpose of early intervention**	Improve a child's functioning in a specific developmental area
Coach family members to look for and use learning opportunities within family-selected activity settings		Provide a discipline related service, typically a provider directed session with a child

b. Key partners and their responsibilities

The key partners in planning, and carrying out, evaluation and assessment are:

- Parent(s) and/or guardians or foster parents
- Other family members/caregivers, at the request of parent(s)
- Service coordinator/Interim service coordinator
- Qualified personnel who will conduct a child's evaluation and assessment

The service coordinator (or interim service coordinator) is responsible for initiating a planning discussion with parents. This includes securing a parent's/guardian's consent to participate in evaluation and assessment procedures, and prompting family members to talk about their desires and concerns related to both their child's development and participation in daily life activities.

Qualified personnel, before they facilitate a child's evaluation and assessment, should understand what questions family members may have and in which settings they would like their child to participate. Qualified personnel should understand a family's perspective, either because they were part of the planning conversation, or were briefed by colleagues who participated in it.

Parents and other family members can reflect on the interim service coordinator's questions and prompts to share information about their priorities and concerns for their child. This information will guide early intervention providers and the interim service coordinator to plan a meaningful evaluation and assessment to determine a child's eligibility for the Maryland Infants and Toddlers Program, and plan for any family services/supports related to enhancing a child's development and participation in family life.

c. Assisting families to identify their concerns, priorities, and resources

Information provided by family members about their concerns, priorities, and resources and related to their child's development should be collected in a personal discussion during a planning conversation. Early intervention providers should understand a family empowerment approach so that they are able to view the family and child as the primary unit of service, and support family decision-making (Wyngarten, 2000). Asking open-ended questions provides opportunities for a family to talk about how early intervention services/supports can assist them in parenting their child, and help him or her participate in family life and community activities.

A family-directed assessment of their concerns, priorities, and resources related to parenting a child with special needs is an ongoing process. As a relationship with a new baby develops over time, parents gain insight and experience about what they want for their child. As a child grows and develops, or as family circumstances vary, their concerns, priorities, and resources may change. Events or markers that may prompt a family to alter their perspective include:

- birthday celebrations;

- developmental milestones such as when a child typically learns to sit up, talk, and use the toilet;
- family trips and vacations to a new environment with unfamiliar people and surroundings;
- moving to a different apartment/house with a new physical layout;
- a child's six month and annual IFSP review; and
- a child's upcoming transition from early intervention at 3 years of age.

A planning discussion should also include understanding a family's daily routines and activity settings, and the settings/activities in which they would like their child to participate. Examples of open-ended questions to prompt families to consider their daily and desired activities include:

- What are your family's hopes for (child)?
- What is (child) interested in? What does (child) like?
- Who does (child) spend time with during the day?
- Where does (child) spend time throughout the week?
- What kinds of things does your family do that you would like (child) to be part of?
- What questions do you have about how (child) is doing, or what you would like (child) to do?

d. Using self-report instruments in conjunction with personal interviews to help families identify their concerns, priorities and resources

Self-report instruments- such as surveys and questionnaires about child-related family resources and priorities-may be helpful for family members to review during a personal interview, or may be left with family members to look over later. Some people find that completing a written questionnaire helps them think about their family routines and resources, and others prefer to talk about them (Sexton, D., & Snyder, P., Rheams, T., Barron-Sharp, B. & Perez, J., 1991). Family members often rate written instruments as more useful and user-friendly than do service providers (Bailey and Blascoe, 1990). This may be because such surveys tend to be brief, and provide clear boundaries for information sharing.

When self-report instruments are used to supplement a personal interview, a variety of measures should be available. Each family member should be provided with an individual copy. Family members also should have the option of deciding how the information will be shared (e.g., return completed surveys to the interim service coordinator, or keep responses only for family use for further discussion with early intervention providers).

The following self-report instruments can be found in Appendix A of this material:

The Family's Assessment Focus (Project Dakota).

Preassessment Planning: The setting (Project Dakota)

Family Support Scale (Dunst, Jenkins & Trivette)

Family Needs Scale (Dunst, Cooper, Weeldreyer, Snyder & Chase).

Family Needs Survey, revised (Bailey and Simeonsson).

A "Snapshot" and "Developing" picture (Kramer).

e. Influences on a family's decision to talk about their concerns, priorities, and resources

There are many factors that can influence a family's decision to discuss their concerns, priorities and resources including:

- Cultural mores about family life and raising children. Family members and early intervention providers are each part of a unique cultural and family group that has developed specific perspectives and rules governing interactions and behavior among group members (as well as outsiders). Understanding these cultural variations among families is dependent on the ability of early intervention providers to recognize the cultural influences on their own behavior. These influences include:
  - age
  - gender
  - sexual preference
  - religion
  - ethnic/racial background
  - socioeconomic status
  - education (informal and formal)
  - geography (urban vs. rural, region of country)
  - communication (verbal and nonverbal, including professional jargon).

  How parents organize their family life and raise children is highly influenced by their childhood experiences in their family of origin as well as their cultural background.

  Shelley grew up as the only girl in a family with four boys, and learned to stand up for herself. With their first two sons, Shelley and her husband continued her parents' practice of letting the kids work things out for themselves. Their third son was an observant boy who loved to paint and had significant language delays. Shelley was uncomfortable with the speech-language pathologist's recommendations to structure his interactions and elicit speech from him, especially while playing with his brothers. She talked with the SLP about not wanting to over structure his play time at home, and together they identified other settings to encourage his language use.

Likewise, the expectations of early interventions providers about family life and parenting are drawn from their own family of origin, personal experiences raising children, and professional training (Barber, Turnbull, Behr & Kerns, 1989).

Fran's father was injured early in her life, and used a wheelchair to get around outside their home. She had many positive memories about her father doing "wheelies" and giving her and her friends rides in his chair. Remembering this, she was surprised by the strong negative reaction a father had to her recommendation that they use an adapted stroller, or rent a child's wheelchair, for their 2 year old daughter during their next vacation. Fran wanted the family to move around without carrying their daughter everywhere, and the father felt that this meant that his daughter probably would not walk.

It is helpful, when encountering unfamiliar behaviors/traditions or surprising reactions, to ask oneself the following questions:

To whom is this behavior/tradition/reaction unfamiliar or surprising?

What do I see/hear another person do and say?

What assumptions, if any, am I making about what this peronssays/does?

How do these assumptions affect my behavior and interactions with this person?

Having attended a pacifist church his whole life, Sam, an early childhood special educator, was disturbed by one father's interest in letting his young son learn about his hunting gun. Aware that he considered this inappropriate parenting, Sam asked his supervisor to help him understand his reaction, and review his interaction with this father.

- Perspectives about the nature of developmental delay/disability. A family member's cultural background may influence his/her understanding of a child's behavior and diagnosis, and whether or not a child may need assistance to participate in family and community activities. Most parents develop an "explanatory model," usually unspoken, about a child's personality, behavior, strengths and challenges. Part of this explanation is based on a parent's understanding of a child's identified diagnosis or developmental delay, its severity and impact on daily life, cause for any delay, and what would be helpful (Kleinman, 1988).

  Ravi's father believes his son's delayed development is due to his own past misdeeds, and does not think that early intervention can change his son's predetermined path. Ravi's therapist misinterprets his lack of interest in her visit as an indicator of his attachment to his son.

  Ping marries an American and brings her son, Luo, to the United States for treatment of his autism. She enrolls her son in the local infants and toddler program, and two private programs with very different philosophies because she hopes western medicine will

prompt her son's development. She works with Luo whenever he is awake, and doesn't understand his teacher's encouragement to "play" with him.

- Past experiences obtaining services and interacting with personnel in medical facilities, and agencies such as public health and social services. Previous interactions with professionals such as doctors, nurses, and social workers create expectations for family members about interacting with early intervention providers. Every cultural group has developed mores about giving and receiving professional care for dependent members who are very young, fragile, ill, or at the end of their lives. Each person develops culturally based attitudes about dependency, gaining and losing autonomy, and receiving help from others. It is useful for early intervention providers to ask:

  Are our current early intervention policies, customs and practices helpful?
  If so, to whom are they helpful? Families? Children? Providers?, All groups? (Johnston, 1980).

  Mybinh's parents are recent immigrants and speak limited English. In their experience, family and friends were born at home, with assistance from the village "midwife". When Mybinh was born prematurely, they consider her stay in the NICU an intrusion on their family life, and don't understand most of the medical procedures recommended by doctors.

  Kirsten's mother is a medical librarian, and is comfortable looking up and using medical terms. She reads all the research studies about her daughter's diagnosis, and asks many questions, thinking at least she can educate herself about what to expect. Angela, a new therapist, misinterprets this mother's questions as a sign of mistrust.

- Ability of early intervention providers to build rapport with families from various cultural and socioeconomic groups. Families have suggested that one of the best strategies for developing rapport is to learn to listen like a friend, and provide empathy and support for a family's situation (McBride, Brotherson, Joaning, Whiddon, & Demmitt, 1993).

  In addition to cultural and religious factors, the age/gender match between early intervention providers and family members may influence how comfortable family members feel discussing their priorities, resources and concerns. For example:

  - Some young mothers may not be ready to share personal information with an early intervention service provider who is close in age to their own mother. Other young parents, however, might find this situation very natural.

  - Women in some cultures may not be willing to speak directly to a male early intervention provider unless a male family member is present. Early intervention providers may find themselves talking to fathers who have very little to do with caring for very young children.

f. Strategies to help families feel comfortable discussing their concerns, priorities, and resources

The following suggestions may provide a foundation for establishing a rapport with families by demonstrating respect for their traditions and culture:

- Elicit family information in a personal interview, supplemented by written surveys (which can be completed at a later date, if desired).

- Ask family members how they prefer to be addressed, e.g. using a formal salutation such as Mr. or Mrs., or informal first names.

- Find out what language a family is most comfortable conversing in. This includes preferences for sign language for family members who are hearing impaired. Try to match families with interim service coordinators who speak their language, and consider when and how to use interpreters or solicit family members to interpret.

- Avoid professional jargon, and define terms when they cannot be avoided. Be particularly aware of abbreviations and common words familiar to providers but not to family members. Examples include Part C, Part B, MITP, transition, IFSP, IEP, and outcomes. Do not expect families to remember these terms even after an explanation; provide a written list or pamphlet that discusses these terms.

- Describe how family information will be used to guide services/supports and who will have access to such information;.

- Understand that eliciting family information is a process that will unfold as a relationship develops between early intervention service providers and family members.

- Acknowledge that family members have different perspectives to share, and create an opportunity to solicit their input. If some family members are silent, ask, “Would you like to add anything to what we have been talking about?”

- If key family members are absent during a planning discussion, consider the following strategies:

    Ask the family members present what activities the other(s) might say are important for a child to participate in.

    Leave copies of self-report surveys for other family members to look over

    Suggest that future visits could be scheduled at more convenient times, and be willing to converse by phone with family members who cannot change schedules to participate.

- Practice active listening by assuming a relaxed posture, and pace questions and prompts. Learn to be comfortable with silences and lulls in conversation. Give family members an opportunity to ask questions and reflect before answering questions. Try to sit in a position that enables all family members present to be part of the conversation.

- Answer family questions promptly, or identify who can. Follow a parent's lead, and be willing to adjust the discussion as appropriate.

- Summarize key points at the end of each visit, particularly next steps to be taken by whom (e.g., "I'll look up more information for you about… and you'll ask your doctor for a copy of Jani's immunizations").

g. Issues related to planning a child's evaluation and assessment

Two things should take place during a planning conversation for evaluation and assessment. First, specific issues about the evaluation and assessment need to be discussed. Second, based on this conversation, decisions need to be made about how to structure the evaluation so that family/provider questions are answered in a comfortable, supportive environment.

The following issues should be discussed with families as part of the planning conversation for evaluation and assessment:

- **Family preferences for mode of communication**
- **Child's participation (current and desired) in his/her daily settings and key family routines/activities**
- **Behavioral characteristics of the child**
- **Child's medical history**
- **What an eligibility evaluation and assessment looks like**
- **How a child will be determined to be eligible**
- **When and how evaluation and assessment results will be shared with a family**

- **Family preferences for mode of communication**, including a child and family's native language. Do not assume that a child understands your language even when a parent does, or vice versa. Also, find out if an interpreter is needed, or whether a child/parent is hearing impaired, and what kind of communication they use.

  Sylvia, a family service coordinator, learned serveral important communication tips from talking with a parent using a sign language translator. The most important was to stop talking when she gave printed information to a parent who needed to look at the translator, and not the brochure, in order to understand her message.

- **Child's participation (current and desired) in his/her daily settings and key family routines/activities**. Explore with a family how a child's (strengths and challenges) affects his or her participation in daily activities. For example, if a parent expresses concern that a child is not sitting up, explore the situations in which the parent would like to see the child sit and participate (e.g., playing with a brother, petting the family cat, sitting in a high chair at meal times with the family).

  Also, clarify any referral concerns and questions that parents may have, including areas of development about which the family would like to have more information. Frequently, family members notice that their child is not talking or walking like other children of similar age, or there may be concerns due to a child's medical status or health issues. If these questions/information requests cannot be answered during an initial planning conversation, be sure they are relayed to the appropriate early intervention providers.

  > Katarina, a family service coordinator, listened to a mother express concerns about whether her daughter's hearing was actually assessed while in the NICU. She relayed the mother's concerns to the evaluators who would review the child's medical reports.

- **Behavioral characteristics of a child** that might influence evaluation and assessment results, such as time of day when a child is most alert, or his or her responsiveness to strangers. Ask about having comfort objects available, such as a special stuffed animal or pacifier. Obviously, family members will provide the most comfort for a child who is wary or fatigued by unfamiliar people and materials.

  > Tyler's mother described how hard it was to calm him since he had dropped his beloved teddy bear at a yard sale, and it was actually sold to an unsuspecting neighbor. Ceila agreed wholeheartedly with the mother that the bear should be back in hand by the time of Tyler's eligibility evaluation,

- **Child's medical history**, including diagnosis and reports from previous assessments, if the family chooses to share this information. Explain how medical and developmental information can be used to streamline a child's evaluation for eligibility since it is not necessary to repeat evaluations if results are still valid. Federal and Maryland laws guarantee eligibility by virtue of having a condition that is associated with a high probability of developmental delay, such as a chromosomal disorder or prematurity less than 1200 grams at birth.

- **What an eligibility evaluation and assessment looks like**, so that families have an idea of what will happen. Include in your description:

  - Names and roles of providers who will participate in the evaluation/assessment, if known (if not, provide this information as soon as possible);

- Description of the five developmental areas (communication, language, physical including hearing and vision, social/emotional and adaptive), which must be assessed according to federal/state law. It is often helpful to give simple examples of the five areas, so that families can understand what the evaluation team will be looking for.

- **How a child will be determined eligible** for the early intervention program. It is helpful to review with families that the purpose of the Part C early intervention program in Maryland, as defined by federal and state law, is to provide support/services to families when a child meets the following criteria:

  - Is 25% delayed in one of five developmental areas (cognitive, physical including vision and hearing, communication, social/emotional; adaptive); or

  - Demonstrates atypical development or behavior in one of the five areas that interferes with current development, and is likely to result in a subsequent delay (even when diagnostic instruments and procedures do not document a 25% delay); or

  - Has a diagnosed physical or mental condition that has a high probability of resulting in developmental delay.

- **When and how results of evaluation and assessment will be shared with the family**. Families should receive immediate verbal feedback about any evaluation and assessment on the same day that these procedures are conducted. They should also have the opportunity to ask questions and share their observations about their child's performance. Information about when written reports will be completed should also be discussed.

h. Deciding how to structure a child's evaluation and assessment

Decisions that need to be made by parents, the interim service coordinator and early intervention providers about a child's eligibility evaluation and assessment include:

- **What information to collect about a child**
- **Collecting information in a family-friendly manner**
- **Who should conduct the child's eligibility evaluation and assessment**
- **Role of family in a child's evaluation and assessment**
- **Family preferences for location, time, and dates**

Two instruments that suggest considerations to discuss with families are included in Appendix A. The Family's Assessment Focus and Preassessment planning: The Setting (Link to each instrument in Appendix A) can guide the discussion about planning for a child's assessment.

Families can choose to review the topics/questions during the planning conversation with early intervention providers verbally, or submit their responses in writing.

What information to collect about a child. If a child is not automatically eligible for early intervention due to his or her medical condition, an eligibility evaluation must be conducted to determine the child's status in each of five developmental areas

Once a child is eligible for early intervention, assessment begins, and is ongoing throughout a child's participation in an early intervention program. Assessment is the process of identifying, with families, a child's unique strengths and needs, as well as the services appropriate to support a family in meeting those needs. A family's priorities and concerns about a child always form the basis for assessment.

- **Collecting information about a child in a family friendly manner**. A child's evaluation and assessment can include administering a specific test, and should always include observation of the child in a familiar setting. Decisions must be made with families about when and where to observe a child, and what to look for.

- **Who should conduct a child's eligibility evaluation and assessment**, if needed? Qualified personnel will determine if a child is eligible for early intervention due to a diagnosed condition. They will evaluate a child's status in each of five developmental areas. Personnel who have the expertise to address family questions about a child's development and participation in daily activities should conduct the eligibility evaluation and begin assessment.

- **Role of family in a child's evaluation and assessment**. Family preferences for involvement and who may be present during a child's evaluation and assessment. A family member should always be present at a child's evaluation/assessment, at the very least to observe and comment on how a child interacts with the evaluation team and the materials/items presented. Family members may also present test items, as appropriate to standardized test procedures, when a child does not want to interact with unfamiliar testers. Family members may also describe a child's performance in specific situations, such as what happens when a child wakes up in the morning and is hungry, or tries to open a bag to retrieve a snack.

  Plans should be made among evaluators to keep brothers and sisters involved, if appropriate. For example, bring a puzzle, or crayons and paper for a preschooler who may be interested in the "new" toys that have just appeared in their home. Suggesting that parents arrange for alternative childcare for their other children during evaluation and assessment conveys the message that early intervention is only about the referred child.

- Simone was intent on listening to Rachel's mother talk about what a fighter her daughter was. Little attention was paid to Rachel's older brother, Jacob, until he entered the living room, looking like a ghost, with an entire container of preemie Enfamil formula dumped on his head. Later, Simone talked with her colleagues about being sure to include activities for a 4 year old during Rachel's assessment. **Family preferences for location, time, and dates** to conduct evaluation and assessment procedures. When selecting location(s) and time(s), discuss the advantages and disadvantages of various environments for conducting specific procedures. Find out when a child is most alert during the day, and when nap and mealtimes are generally observed, and try to schedule around these times. Alternatively, if a child's eating behavior is a concern, try to schedule the evaluation and assessment during a mealtime, or at least discuss having desirable snack food on hand.

i. Why identify a child's activity settings and how they influence evaluation and assessment

Federal and Maryland regulations mandate that early intervention services be provided in natural environments - settings that are natural or normal for a child's peers who do not have a disability. The term "natural environments" does not refer solely to the places, or locations, where a child/family spends time during the course of their day. It also includes the participatory experiences that occur in those places, i.e., the typical actions and interactions that occur between a child, family members and peers throughout the day.

The planning process for evaluation and assessment should focus on clarifying, for all partners, what ***participatory experiences*** are desirable for a child, not just the location where a child spends time each day. These participatory experiences are called activity settings, and provide the context for individualized learning opportunities for each child (Roberts, Rule and Innocenti, 1998; Bruder & Dunst, 2000; Dunst, Bruder, Trivette, Hamby, Raab, & McLean, 2001).

An activity setting is one of many participatory experiences in a specific location that provide the context for a child's learning. Activity settings are composed of:

- the people involved, their values and beliefs, purposes and motives;
- what the involved people would like to do, and how they will go about doing it;
- relationships and interactions among participants.

Examples include:

Location	Activity setting
Home - kitchen	eating family dinner
Neighborhood	going for a walk
Child care center	playing with friends
Home - bedroom	reading a book before bedtime

A **natural learning opportunity** is a planned or spontaneous situation within an activity setting that presents a chance for a child to use/learn/practice skills or behaviors in order to successfully participate in an activity. Examples include: driving a toy truck along a road with a friend at childcare, or pointing to specific objects while reading a book.

Location	Activity setting	Learning Opportunity
Home - kitchen	eating family dinner	using both hands to hold a glass
Neighborhood	going for a walk	looking for, and saying "dog" while walking outside
Child care center	playing with friends	pushing a toy truck along a wiggly "road"
Home - bedroom	reading a book with a parent before bedtime	pointing to specific objects while reading a book.

Numerous learning opportunities are available within the many activity settings a child participates in within a specific location. The focal point for evaluation and assessment is to begin to figure out how to facilitate a child's participation in family-desired home, neighborhood and community activity settings. This process will continue with the ongoing assessment that is an integral part of the services/support provided to families once a child is eligible for early intervention.

j. Questions a family may have about evaluation and assessment

The following are typical concerns families voice related to evaluation and assessment:

- I don't want my child labeled
- I just want my child to learn to walk and talk like other children
- I/we want more information about what is happening with our child, understanding what his/her diagnosis means, how to help our child, what early intervention services/supports are available for our family
- What will happen during my child's evaluation? What will the early intervention evaluator's find out?
- What will this cost, and is it covered by any health plan I may have?
- How soon can we schedule the evaluation and assessment, and will I/we have to miss work?
- Will my/our other children be welcome during the evaluation and assessment?
- How soon will I/we find out if my child qualifies for early intervention?
- Will I/we get a written report, and who else will see this information?
- What if my child doesn't qualify for early intervention?

Family concerns and questions about the evaluation and assessment process vary according to their:

- **Familiarity with the Part C early intervention program**. Some families may have a friend, neighbor or family member with a child who participates in an infants and toddlers program. Sometimes referrals come from child care providers who are already caring for a child in the program, or who work in coordinating agencies such as Early Head Start or a local pediatrician's office. If a family has participated in early intervention with another child, it is helpful to find out where, and how the evaluation and assessment process was conducted.

  During a planning conversation with Yusef's mother, Mayra learned that his 8 year old brother, Ahmed, had received early intervention in another state. Since the parents were familiar with early intervention, Mayra concentrated on explaining the family supports and services available in Maryland.

- **Level of concern about a child's functioning**. Parents who are worried about their child may react in varying ways. Some parents may have many questions, and will want to know exactly when, where and how the evaluation and assessment will take place. Other parents may be so involved caring for their child that they just want to know what the next step is in order to start early intervention. Some families, particularly if encouraged by someone else to make the referral contact, may not recognize a child has delayed development, or that a particular diagnosis may result in delays, and therefore have very few questions, or may be guarded about agreeing to an evaluation/assessment. Whatever a family's level of concern appears to be during initial conversations with early intervention providers, keep in mind the typical concerns identified above that other families have expressed.

k. Informed consent needed from families for evaluation and assessment

All information about a child/family, and any information desired by a family, must be collected in a non-intrusive manner, with informed consent from parents/guardians. Informed consent means that family members have had an opportunity to discuss relevant issues in order to give consent to begin evaluation and assessment, and have taken part in joint decision making with the service coordinator (or interim) and other early intervention providers. Consent must be given in writing for both a child's evaluation and assessment and the specific medical records that may be released to the local early intervention program. Families need to understand that their consent is voluntary, and may be revoked at any time. If written consent is not given by parents, reasonable efforts must be made to ensure that the parent understands why the evaluation is needed, and that neither the evaluation nor early intervention services can be provided without it.

Keep in mind that identifying, with families, their priorities, resources, and concerns is a voluntary process, related to identifying the supports and services that will help family members

meet the developmental needs of their child. Consent for identifying, with families, their priorities, resources, and concerns should also be secured near the beginning of a planning conversation, after a family has heard some information about the Maryland Infants and Toddlers program.

l. How previous medical and developmental information affect planning for evaluation and assessment

It is imperative to ask parents for their consent to obtain copies of a child's medical/health records, because that information may help determine a child's eligibility for Part C early intervention services in one of two ways:

- A diagnosis already made may indicate that a child has a physical or mental condition which has a high probability of resulting in developmental

- An evaluation and assessment may have recently been completed indicating that a child has at least a 25% delay in one of five developmental areas (cognitive, physical including vision and hearing, communication, social/emotional; adaptive). Qualified personnel should use informed clinical opinion to decide whether a previous evaluation still accurately reflects a child's current developmental status. (link to source: www.nectac.org/pubs/pdfs/nnotes10.pdf))

In either instance, this information, when received in writing, can be used by qualified personnel to make the determination that a child is eligible for Part C early intervention services. Keep in mind that the legal requirement for a multidisciplinary evaluation (involvement of two or more disciplines) must still be met.

If a child's diagnosis automatically qualifies him or her for early intervention supports/services, or a previous multidisciplinary evaluation has addressed a child's status in each of five developmental areas, then the early intervention team can address the state and federal requirements for assessment. This means beginning the process of identifying a child's unique strengths/needs in each of five developmental areas, as well as the services and supports appropriate to assisting a family to meet those needs.

Planning with Families
Application Activity
Appreciating Cultural Beliefs and Practices

Consider your experience interacting with a family from a cultural group different from your own, or interview someone from a cultural group that you are likely to come in contact with in your community/work environment. Keep in mind the various dimensions of culture when choosing a family to think about during this activity.

Compare this family's daily life activities to your own in the following categories:

Category	My family	Family 1	Family 2
Typical foods for breakfast, lunch and dinner			
Childbirth and parenting practices			
Childhood toys and games			
Symbols of good luck feared events objects/animals			
Typical children's names and names for parents/grandparents			
Special holidays and their significance			
Health care for typical and serious childhood illnesses			

Reflect on the following:

1. How are your own family's routines and rituals similar or different from the family you know or interviewed, or the families introduced by colleagues?

2. How would your personal expectations and/or professional training help/hinder your interactions with members of this cultural group? As a friend? As an early intervention service provider?

3. How would this family's beliefs and traditions affect their participation in early intervention evaluation and assessment? For their child? For themselves? What can

you do to support family members so that evaluation and assessment is a positive experience?

4. For family members who participate in this application activity: What have been your evaluation and assessment experiences interacting with early intervention providers who are from a cultural group different from your own? What did you (or could you) do to help early intervention providers understand your traditions and beliefs?

Planning with Families
Application Activity
Understanding Informal and Formal Family Resources and Supports

As an orientation to assisting families to consider a wide range of informal and formal resources and supports*,the Family Resource and Support Survey provides an opportunity to explore resources that an individual might use when encountering typical and unusual family/personal situations.

1. **Look over the ordinary and extraordinary life situations** described in the Family Resource and Support Survey, and note the people and/or agencies/organizations you would contact in the following two categories:

    a. Informal supports: friends, family, neighbors and community contacts that include members of social networks (e.g., co-workers, religious groups, baby sitters, carpool partners) and community groups and programs that address a broad segment of the community (e.g., YMCA, service clubs, sports leagues, libraries, schools, community)

    b. Formal supports: professionals and professionally oriented agencies/organizations, usually with specific functions and missions (e.g., public health clinics, mental health programs, transportation services, family preservation programs, social services)

2. **Review the informal vs. formal contacts you identified**. Were there any surprises?

3. **Discuss how to assist one family** that you currently work with to identify and use informal and formal supports as resources in helping their child participate in daily family and community activities. Consider how you might introduce family surveys and questionnaires (1, 2, 3, and 4) as prompts to help family members discuss, in writing or verbally, their child's needs during a planning conversation.

4. **How can early intervention service providers collaborate** with informal sources of family support?

** For further reading:* Trivette, C., Dunst, C., & Deal, A. (1997). Resource-based approach to early intervention. InK. Thurman, J. Cornwell, & S. Gottwald (Eds), *Contexts of early intervention* (pp. 73-92). Baltimore, MD: Paul H. Brookes.

Planning with Families
Application Activity
Addressing Possible Family Concerns about Evaluation and Assessment

Reflect on the following concerns (often unspoken) families may have and draft possible responses that families might find helpful. Review any information sheets or Frequently Asked Questions for families that may be available in your Infants and Toddlers program. **It is recommended that family members, early intervention providers and administrators work together** to draft responses that are family-friendly and reflect program policies. Use this opportunity to ask family members, advocates, and family support coordinators about other concerns families may have, and draft responses to these questions also.

Concerns families may have:

- I don't want my child labeled
- I just want my child to learn to walk and talk like other children
- I/we want more information about what is happening with our child, understanding what his/her diagnosis means, how to help our child, what early intervention services/supports are available for our family
- What will happen during my child's evaluation? What will the early intervention evaluator's find out?
- What will this cost, and is it covered by any health plan I may have?
- How soon can we schedule the evaluation and assessment, and will I/we have to miss work?
- Will my/our other children be welcome during the evaluation and assessment?
- How soon will I/we find out if my child qualifies for early intervention?
- Will I/we get a written report, and who else will see this information?
- What if my child doesn't qualify for early intervention?

Planning with Families
Application Activity
Tracking Evaluation and Assessment Planning with Families

Spend about one month reviewing your planning discussions with 2-3 families. Use the Self-Assessment Inventory: Planning with Families for Evaluation and Assessment to guide your reflections.

*If you are not involved in planning discussions with a family, consider interviewing family members or early intervention providers who have participated in them.

After completing the inventory, reflect (preferably with colleagues and families) on the following:

1. How do I/we plan with families for evaluation and assessment?

2. What is the outcome of my/our planning for individual families, and our early intervention program?

3. Are planning discussions taking place consistently in all regions of our Infants and Toddlers Program?

4. Do we need to schedule professional development activities on this topic? If so, what specifically would be helpful?

Planning with Families
Application Activity
Using a Child's Medical /Developmental Information to Plan Evaluation and Assessment

Consider the following scenarios related to using a child's medical and developmental history in their evaluation and assessment, and reflect on the questions accompanying each vignette.

Easton Family

Kate Easton has just returned home to her parents and her older brother after spending her first three months in a NICU. Kate was born 12 weeks premature and weighed just 1100 grams. She is a fighter, and survived many ups and downs during her NICU stay. She is now 4 months old and weighs 4.6 lbs.

Mrs. Easton called the local Infants and Toddlers Program to ask for assistance. You followed up with an initial visit to talk about your EI program and find out more about how to help Kate and her family. Her parents are most concerned about Kate's weight gain. It takes Kate a very long time to drink her bottle, and she must be fed every 3-4 hours, day and night. The Eastons also have questions about what to expect regarding how soon she will "catch up" with other children, and sit up by herself.

1. **How will you explain early intervention to Mr. & Mrs. Easton?**

   Core considerations: The Easton's experience with medical professionals has been in a neonatal intensive care setting. What information can you share with this family about early intervention, particularly informal and formal family supports, to help them understand what your program offers in comparison to a medical facility?

   What do the Eastons need to know about your program so that they can give their informed consent for evaluation and assessment?

2. **What previous medical and developmental evaluations would you expect to have been completed for Kate, and how will you use this information?**

   Core consideration: Is Kate eligible for Part C early intervention services due to having a condition which can result in developmental delay?

3. **What issues should the Eastons and early intervention service providers discuss in order to plan Kate's evaluation and assessment? What decisions need to be made together?**

Core considerations:

- issues to discuss with families;
- decisions to make with families

4. How can the Easton's priorities, resources and concerns related to Kate be discussed in a family-friendly manner?

Core consideration: Review family surveys and consider strategies to help families feel comfortable when discussing their personal information.

Lee family

Cheng Lee and his parents, two sisters and grandmother immigrated to Maryland from Cambodia 4 months ago. Cheng is 2 ½ years old, and has been diagnosed with epilepsy. Cheng's family does not believe that medication will stabilize his frequent grand mal seizures. In this family's culture, Cheng's seizures are viewed as a symptom that an evil spirit has robbed him of his identity. Mr. & Mrs. Lee have given permission to their social worker to refer Cheng to your EI program. The parents speak Hmong and will need an interpreter, although Mr. Lee understands some English.

1. How will you explain early intervention to the Lees?

Core considerations: The Lees experience with professional caregivers in the United States has been in a medical setting e.g., physicians offices and pediatric intensive care units and outpatient hospital departments.

- How will you communicate with the Lees?
- How does this family's culture explain their view of Cheng's diagnosis and what intervention they may believe will be successful in helping him?
- What information can you share with the family about early intervention, particularly informal and formal family supports, to help them understand what your program can offer, and ensure that they give their informed consent for evaluation and assessment?

2. What previous medical and developmental evaluations would you expect to have been completed for Cheng, and how will you use this information?

Core consideration: Is Cheng eligible for Part C early intervention services due to having a condition which can result in developmental delay?

3. What issues do the Lees and early intervention service providers need to discuss in order to plan Cheng's evaluation and assessment? What decisions can early intervention providers assist the Cheng's in making?

Core considerations:

- issues to discuss with families;
- decisions to make with families

4. How can the Lee's priorities, resources and concerns related to Cheng be discussed in a family-friendly manner?

Core considerations:

- Review the discussion about assisting families to identify their priorities, resources and concerns;
- Reflect on this family's cultural background as you think about the Lee's priorities, resources and concerns;
- Consider strategies to help families feel comfortable discussing their personal information; and
- Will any family surveys be helpful to the Lees?

Note: For those interested in reading a nonfiction narrative about a family story this vignette is based on, see the abstract for The Spirit Catches You and You Fall Down (Recommended Reading).

Recommended Reading

Dunst, C. J., Bruder, M. B., Trivette, C. M., Hamby, D. W., Raab, M., & McLean, M. (2001). Characteristics and consequences of everyday natural learning opportunities. *Topics in Early Childhood Special Education*, 68-92.

This research study provides a wealth of sources emphasizing the importance of everyday natural learning opportunities for changing child behavior and performance. Any one physical location provides many different activity settings or situations for learning how to interact, move and communicate. These natural learning opportunities provide the building blocks for early intervention services.

Fadiman, A. (1997). *The spirit catches you and you fall down*. New York: Farrar, Straus and Giroux.

Annie Fadiman, a medical anthropologist, tells the story of Lia Lee, born in the San Joaquin Valley in California to Hmong refugees. When she was 3 months old, Lia showed signs of having what the Hmong know as quag dab peg (the spirit catches you and you fall down), a condition diagnosed by Western doctors as epilepsy. Fadiman traces the clash of western treatment by medication with the introduction by Lia's family of folk remedies to coax her wandering soul back to her body. She expertly identifies the profound cultural differences and linguistic miscommunication that ensues, and highlights issues for early intervention providers to consider in their interactions with cross cultural groups.

Hanft, B., & Pilkington, K. (2000). Therapy in natural environments: The means or end goal for early intervention? *Infants and Young Children*, 12(4), 1-13.

The authors emphasize that how therapy is provided in natural environments is just as important as where it is provided. They explore how working in natural environments reinforces family-centered care, discuss the benefits for all parties when therapy is provided within a child's daily routines and settings and describe a team decision-making process for selecting learning opportunities (outcomes) and intervention models.

Krauss, M. (2000). Family assessment within early intervention programs. In Shonkoff and S. Meisels (eds), *Handbook of early childhood intervention* (pp. 290 -308, second edition). New York: Cambridge University Press.

This chapter explores the context and processes of assessing, with families, their priorities, concerns and resources within early intervention. Topics include the legal and programmatic frameworks for family assessment, theoretical bases, challenges to doing such assessments, and informal and formal strategies. A summary of research studies on available family instruments is included.

Lynch, E., & Hanson, M. (Ed) (1998). *Developing cross-cultural competence* (second ed). Brookes Publishing: Baltimore, MD.

This book provides practical information for early intervention providers who work with children and families from diverse cultures and linguistic backgrounds. Topics include the influence of

culture on a person's beliefs, values, and behaviors; descriptions of the challenges a family may face when adapting to a different culture; and strategies that promote respectful and effective interactions.

Maryland Infants and Toddlers Program. (2013). *Maryland Individualized Family Service Plan process and document*. Baltimore, MD: Maryland State Department of Education.

The Maryland individualized family service plan process and document provides guidelines for building family and professional partnerships that enable families to make informed choices about the early intervention services they want for their children. The IFSP process provides a framework for discussion and planning between families and early intervention service providers; the IFSP form is a working document that reflects the continually changing needs of very young children.

Especially for families:

Jung, L. (2003). More is better: Maximizing natural learning opportunities. *Young Exceptional Children*, 6(3), 21-26.

The most effective way to maximize intervention for young children is not by providing more one-one services from providers, but by supporting a family's ability to maximize natural learning opportunities and embedding intervention into their own activities and routines.

Self-Assessment Inventory
Planning with Families for Evaluation and Assessment

Name:_____ **Date:** _____

Review your competency in preassessment planning with families by checking the appropriate column for each item identified below, using the following scale:

Awareness	I am aware of this but don't apply it in my work/interactions.
Knowledge	I understand it, & sometimes apply it in my work/interactions.
Application	I understand this and apply it consistently in my work/interactions.
Mastery	I understand and apply this well enough to teach/mentor others.

This self-assessment inventory can help identify areas for continued professional development for individuals and teams, and identify individuals who can mentor/coach others. It is designed as a reflection tool, not an evaluation of individual competencies.

Have I discussed with families:	**Aware but don't apply**	**Sometimes apply**	**Consistent application**	**Can teach & coach others**
1. Preferences for how to communicate with family members/child				
2. Child's participation (current and desired) in his/her daily settings and key family routines/activities				
3. Child's health, development (abilities and challenges), and behavior				
4. Child's previous evaluations and medical information, including vision and hearing				
5. Priorities for child and resources (supports/services)				
6. What will happen during an evaluation/assessment				
7. Eligibility criteria in Maryland				
8. Early intervention supports/services available to eligible families in a child's daily settings/activities				
9. Roles of service coordinator and qualified providers who will facilitate evaluation and assessment				

How have I assisted families in making decisions about:	Aware but don't apply	Sometimes apply	Consistent application	Can teach & coach others
10. What information is needed to determine a child's eligibility (or progress)				
11. How best to collect evaluation/assessment information				
12. Preferences for their level of involvement in evaluation/assessment				
13. Location, time and dates of evaluation/ assessment				
14. When and how results will be shared with parents				

How well do I build rapport with families?	Aware but don't apply	Sometimes apply	Consistent application	Can teach & coach others
15. Solicit family perspectives re: child's performance & desired supports/service				
16. Demonstrate respect for family culture, routines and parental role				
17. Use active listening skills (including eye contact, paraphrasing, summarizing, clarifying);				
18. Answer questions immediately, or suggest how questions can be answered				
19. Share positive comments with family about a child's development & their parenting				

Comments:

Planning with Families
Appendix A

Instruments for assisting families to identify their priorities, resources and concerns.

The Family's Assessment Focus (Project Dakota). A guide for eliciting family members' observations of child behavior and progress as a basis for planning a child's evaluation and assessment.

> Source: Kjerland, L. & Kovach, J. (1990). Family-staff collaboration for tailored infant assessment. In E. Gibbs & D. Teti (Eds), Interdisciplinary assessment of infants (pp. 287 - 298). Baltimore, MD: Paul H. Brookes Publishing Co.

Preassessment Planning: The setting (Project Dakota). A guide for eliciting suggestions and preferences from family members about where, when and how to conduct a child's evaluation and assessment.

> Source: Kjerland, L. & Kovach, J. (1990). Family-staff collaboration for tailored infant assessment. In E. Gibbs & D. Teti (Eds), Interdisciplinary assessment of infants (pp. 287 - 298). Baltimore, MD: Paul H. Brookes Publishing Co.

Family Support Scale (Dunst, Jenkins & Trivette, 1988). This survey assists families in identifying informal and formal resources within their family, neighborhood and community. Each resource can be assigned a rating on a five point scale ranging from "not at all' to "very helpful" with regards to raising children. Eighteen items include relatives, friends, co-workers, childcare and pediatricians.

> Source: Dunst, C., Trivette, C, & Deal, A. (1988). Enabling and empowering families: Principles and guidelines for practice. Cambridge, MA: Brookline Books.

Family Needs Scale (Dunst, Cooper, Weeldreyer, Snyder & Chase).

> Source: Dunst, C., Trivette, C, & Deal, A. (1988). Enabling and empowering families: Principles and guidelines for practice. Cambridge, MA: Brookline Books.

Family Needs Survey, revised (Bailey and Simeonsson, 1990).

> Source: Frank Porter Graham Child development Center, CB # 8180, University of North Carolina, chapel Hill, NC 27599

A "Snapshot" and "Developing" picture (Kramer, 1989).

> Source: Project Dakota Outreach, 680 O'Neill Dr., Eagan, Minnesota, 55121

Planning with Families
Appendix B

Roles family members may assume during evaluation and assessment

Observer	Narrator	Coach	Reflector
Watches child perform task or test items with evaluators; may **hold** an infant or toddler while specialist presents test items or plays with child.	Presents a portrait of the child by **describing and elaborating** on the child's behavior and performance; may **identify** emerging skills for more in-depth assessment.	Assists in **eliciting** optimal performance by **suggesting** modifications in presented tasks and toys or the child's position; may **speak to, touch, or move** the child to focus his or her attention on the task at hand.	**Comments** on child's performance and provides **guidance** to team members about whether performance is representative of behavior typically demonstrated

Planning with Families
Appendix C
Description of five developmental domains

Area of development	Description	Examples (for two ages)
Cognitive	Thinking Learning Making decisions	4-6 months: Explores with hands/mouth 2- 2½ years: Understands using a light switch
Communication	Expressive: Making sounds/gestures and talking Receptive: Understanding sounds, words & gestures	4-6 months: Coos to others Looks for sounds/voices 2- 2½ years: Points to most body parts Uses two words together
Social-emotional	Interacting with others Expressing feelings/emotions Self awareness	4-6 months: Smiles frequently at others 2- 2½ years: Wants to do things "my way"
Adaptive	Feeding/eating Dressing Sleeping Self-care (washing, brushing teeth)	4-6 months: Naps 2-3 times per day 2-2½ years: Puts on/takes off socks
Motor	Gross Motor: Moving & using large muscles Fine Motor: Using hands and fingers	4-6 months: Rolls over to reach for a toy 2-2½ years: Takes the lid off a jar

Planning with Families
Appendix D
Family Resource & Support Survey

Please read the following statements regarding personal/family situations and identify the informal or formal supports you would contact to help you with each situation.

> **Informal supports**: friends, family, neighbors and community contacts that include members of social networks (e.g., co-workers, religious groups, baby sitters, carpool partners) and community groups and programs that address a broad segment of the community (e.g., YMCA, service clubs, sports leagues, libraries, schools, community)
>
> **Formal supports**: professionals and professionally oriented agencies/organizations, usually with specific functions and missions (e.g., public health clinics, mental health programs, specialized transportation services, family preservation programs, social services)

Situation	Informal support	Formal support
1. My child is going to be thrown out of childcare due to his behavior.		
2. I ran out of gas and I'm by myself on the highway.		
3. I'm unable to pay my bills this month.		
4. We can't go away for the weekend because one child has the chicken pox.		
5. I'd like to change jobs/find a job/continue my education.		
6. I can't take my child to the grocery store because he has a temper tantrum if we stay too long.		
7. My child needs a special type of formula that is very expensive.		
8. My mother/father is seriously ill.		
9. My car was struck by a large tree limb during yesterday's storm.		
10. My child is 2 ½ years old and just took his first step.		

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