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Chapter 1: Principles of Part C Early Intervention

- Early intervention supports and services are available to all eligible infants and toddlers and their families through the Infant & Toddler Connection of Virginia regardless of the family's ability to pay.
- The purpose and focus of Part C supports and services are to increase the child's participation in family and community activities identified by the family and to support the family in identifying learning opportunities and enhancing their child's development.
- Consideration of family routines, activities and natural settings occurs throughout the early intervention process from child find, assessment, and delivery of entitled services on through transition from services.
- Supports and services occur in the context of and are integrated into the normal daily activities, routines and environments of each child and family. Supports and services fit into the family's life and build effectively on the resources and supports already in place.
- Parents already do things to teach their children everyday – they are the primary agent of change in their child's development and the experts on their child and family. Part C providers add their specialized skills and knowledge and work as a team with the parents and other caregivers to identify and use existing learning opportunities and create new ones as needed to address the outcomes that the family and Part C providers have developed together.
- Individualized outcomes are relevant for the family, focus on the child's participation in activity settings that are important to the family, and focus on the whole child rather than specific developmental skills.
- Service delivery options, including specific supports and services, service providers, and locations of service delivery are determined *after* the desired outcomes and potential learning opportunities have been identified. Providers partner with families to make an individualized determination about the supports and services that are necessary to support the child's ability to participate in family and community activities.
- Service providers use multiple methods, including accommodations, adaptations, coaching with parents/caregivers, and expanding activity settings, to accomplish outcomes.
- Effective Part C early intervention requires an active parent-provider partnership that includes involvement by the family/caregiver in each early intervention session. The focus is on expanding the parents'/caregivers' confidence and competence to help the child learn during everyday activities.
- The State Lead Agency for the Infant & Toddler Connection of Virginia monitors local system status on statewide performance and compliance standards to promote timely and effective Part C early intervention services for all eligible infants, toddlers and families.

Chapter 2: State Infrastructure



Infant & Toddler
Connection of Virginia

**INFANT & TODDLER CONNECTION OF VIRGINIA
PART C EARLY INTERVENTION SYSTEM
Infrastructure**

Governor, Commonwealth of Virginia
(Designates State Lead Agency)

**Secretary of Health and Human Resources
Secretary of Education**
(Promote Interagency Planning and Resolve Interagency Disputes)

State Lead Agency

- Promulgates Regulations
- Establishes State Part C Budget
- Contracts with Local Lead Agencies
- Certifies Part C Providers
- Provides Monitoring, Supervision and Technical Assistance

Virginia Interagency Coordinating Council (VICC)
(Provides Advice and Assistance to State Lead Agency)

Local Interagency Coordinating Councils
(Provide Advice and Assistance to Local Lead Agency)

Local Lead Agencies
(Administer local systems of Part C Services in Compliance with State and Federal Regulations)

Service Providers, including Service Coordinators
(Plan and Implement IFSP Services as Team Members)

Chapter 3: Referral

An effective referral process ensures early identification of eligible children, timely supports and services for eligible children and families, and a strong base of referral sources who understand what is available through the Infant & Toddler Connection system and can rely on early intervention providers to partner with them in supporting the child and family they have referred. Referral is the first point of contact between the Infant & Toddler Connection system and the family. It is also a critical point of contact between the Infant & Toddler Connection system and the primary referral source. All referrals must receive a timely, professional and family-centered response.

Public Awareness and Child Find

Local Lead Agency Responsibilities:

- Use statewide materials and ensure that any local public awareness materials that are developed to use in addition to the statewide materials are consistent with the statewide public awareness materials and reflect the diversity of the local community.
- Coordinate local activities with planned statewide public awareness activities (e.g., airing of public service announcements, dissemination of materials).
- Provide notice throughout the community before any major child find activity takes place.
- Disseminate materials to local agencies and places of business. The following agencies/businesses may be targeted for dissemination of information:
 - Pediatricians'/general practitioners' offices;
 - Hospitals, including NICUs and NICU follow-up and other outpatient clinics;
 - WIC clinics;
 - Well-baby/immunizations clinics and mobile vans;
 - Community and migrant health centers;
 - Head Start and Early Head Start programs;
 - Family support programs;
 - Child day care centers and family day care homes;
 - Visiting public health nurse programs;
 - Local social service departments;
 - Programs that serve families affected by substance abuse;
 - Mental health clinics;
 - Civic groups;
 - Ethnic/community centers;
 - Homeless family shelters;
 - Family planning organizations;
 - Businesses (e.g., banks, utility companies, grocery stores, Laundromats, beauty parlors, etc.);
 - Places of worship;
 - Professional associations;
 - Advocacy associations;
 - Private providers;
 - Public schools;
 - Adoption agencies;
 - Parent support groups; and
 - Other local points of contact with families and young children.

- Develop and implement local public awareness and child find procedures that include the following:
 - The methods to be used for planning and distributing public awareness information;
 - The roles of agencies and individuals in the community involved in public awareness activities, including, but not limited to:
 - a. Public agencies (e.g., local school systems, Head Start and Early Head Start, health agencies, social service departments);
 - b. Private entities (e.g., pediatricians);
 - c. Lay groups (e.g., Chambers of Commerce, service organizations, neighborhood associations, faith based organizations, major employers, advocacy groups); and
 - d. Agencies and individuals who represent underserved groups, including minority, low-income, homeless and rural families and children, and children with disabilities who are wards of the State.
- Involve primary referral sources, especially hospitals and physicians, in the child find system.
- Inform primary referral sources, especially hospitals and physicians, about procedures to assist families in accessing the local Infant & Toddler Connection system.
- Work with physicians and other local agencies/providers to use a variety of mechanisms that may include, but are not limited to, mass general screenings, well baby checks, individual child screens, medical records/chart review, documentation of needs by primary referral sources, and parent observation and report to identify infants and toddlers potentially eligible for Part C.
- Determine the required single point of entry for the local Infant & Toddler Connection system.
- Collect and enter data into ITOTS for every child referred to the local Infant & Toddler Connection system in accordance with the most current terms of the *Contract for Continuing Participation in Part C Early Intervention for Infants and Toddlers with Disabilities and Their Families*.
- Use available data, including ITOTS data, regarding which children are receiving supports and services to evaluate the effectiveness of local public awareness and child find efforts on an ongoing basis and to determine the need to revise interagency agreements and other efforts related to child find and public awareness.

Receiving and Processing a Referral

General:

- Each local Infant & Toddler Connection system must designate a single point of entry for receiving referrals.
- Referrals may be made by phone, fax, in writing or in person to the local single point of entry.
- It is not necessary to have parent consent in order to make a referral to the local Infant & Toddler Connection system. It is recommended that the referral source inform the family prior to making the referral. However, the local system must still accept a referral even if the referral source has not informed the family.
- The date of referral to the local Infant & Toddler Connection system is day one of the 45-day timeline for development of the initial IFSP.

- If a referral is received when the office is closed (e.g., for the weekend or on a State or federal holiday), then the referral is processed on the next business day. That next business day, when the staff member hears the message on the answering machine or reads the fax, email or written referral received through the mail, is considered the date of the referral. The local system must ensure timely processing of referrals through sufficient staffing of the single point of entry with back-up available when an individual is ill or on vacation. If the office is closed for an extended period, such as during a week-long spring break or winter holiday break, then there must be a mechanism for processing referrals during that period.
- If a family or referral source calls the single point of entry just to ask a question about child development or to get other general information, then this is not considered a referral.
- The date of referral for a child referred from another local early intervention system (from either in or out of state) is the date the child is available (i.e., has moved into the area served by the local system) or the date of referral, whichever comes last.
- Information received by the local Infant & Toddler Connection system in a referral is considered confidential under the Family Educational Rights and Privacy Act (FERPA).
 - If the local Infant & Toddler Connection system is unable to contact the family (e.g., depending on the contact information provided by the referral source, this may mean attempting to contact the family by phone, by letter and/or by stopping by the address), the single point of entry should contact the referral source to inform them that the family has not been contacted and to request additional contact information.
 - Once the family has been contacted, information about the referral (beyond acknowledging receipt of the referral) may not be given to the referral source without a signed consent for release of information. If the referral source wants to know the outcome of its referral, the referral source should seek consent from the family and provide a copy of a signed consent for release of information to the single point of entry at the time of referral. [Link to physician referral form; non-physician referral form] Information about referrals may also be given to the referral source if the parent provides consent using a local Infant & Toddler Connection system release form or the referral source later obtains parent consent and provides a copy of that signed release form to the local lead agency.
- If the single point of entry is unable to contact a family after requesting additional contact information from the referral source or the family repeatedly fails to respond, then the dates of attempted contact must be documented in the child's record. Attempts to contact the family may be made by phone, mail, visiting the address provided by the referral source, and/or other means based on the contact information available. It is recommended that no more than 15 – 20 calendar days pass during this process of attempting to contact the family. Prior to closing the referral, a letter should be mailed to the family stating that the child's referral record will be closed if contact is not made within a given number of calendar days from the date on the letter. The letter mailed to the family must include information about how the family can re-establish contact with the local Infant & Toddler Connection system if they wish to and must include a copy of the *Notice of Child and Family Safeguards in the Infant & Toddler Connection of*

Virginia Part C Early Intervention System. If the single point of entry is never able to contact the family, the single point of entry should inform the referral source that the family could not be contacted.

Single Point of Entry Responsibilities:

- Provide general information to families and/or other interested persons who have questions regarding child development and accessing Part C supports and services and/or other available resources.
- Collect the following information from the referral source, if available:
 - Child's full name
 - Parent(s)' name(s)
 - Address
 - Phone number(s)
 - Date of birth
 - City/County of Residence
 - Gender
 - Reason(s) for referral
 - Whether developmental screening and/or assessment have occurred
 - Name and contact number(s) for referral source
- If screening and/or assessment information is available, request a copy.
- Verify that the child is age eligible for Part C and lives in the area served by the local Infant & Toddler Connection system. If it is clear at the time of referral that the child is past his third birthday or lives outside the area served by the local system, then inform the referral source and provide information about where and how to make an appropriate referral. If it is determined after contact with the family that the child is three or older or lives outside the area served by the local system, then facilitate a referral to the appropriate program or services, with parent consent.
- Inform referred families whose children are close to the age of eligibility for early childhood special education services through the local school division (under Part B) that they have the option to be referred to Part B instead of or simultaneously with referral to Part C.
- Begin the child's Part C early intervention record (see Chapter 9).
- Acknowledge receipt of referral by sending the *Acknowledgement Letter to Referral Source* to the referral source. This is an optional step in the process but is strongly encouraged since it conveys a professional response that promotes further referrals from this referral source. This correspondence is only for the purpose of acknowledging receipt of the referral and is intended for use with professional referral sources (e.g., physicians, social workers, school system, etc.) rather than families or neighbors. The acknowledgement letter is electronically generated by ITOTS.
- Determine the need for a surrogate parent in accordance with Virginia Part C regulations. [Link to regulations] The *Surrogate Parent Identification of Need* form is an optional form that may be used in determining and/or documenting the need for a surrogate parent. If a surrogate parent is needed, then:
 - Appoint a surrogate parent in accordance with local procedures; and
 - Notify (1) the surrogate parent-appointee using the *Surrogate Parent Appointment Letter*, and (2) the person charged with responsibility for the child or the public agency and/or other participating agency/provider charged with responsibility for the child when the child is a ward of Virginia.

The *Surrogate Parent Identification of Need* form also may be used in determining and/or documenting when a surrogate parent is no longer needed. When the surrogate parent's role ends, he/she is notified using the *Surrogate Parent Termination letter*.

- Assign a service coordinator.
- Ensure phone contact with the family to share basic information about the Infant & Toddler Connection system and to schedule an intake appointment with the service coordinator. This contact may be made by the single point of entry or by the service coordinator or there may be phone contact by both. The amount of information covered will depend on the family, including how much time they have available during the initial phone call and how much information they want and can receive at one time. It is expected that the information outlined in the box on the next page will be discussed with families early in their experience with the local Infant & Toddler Connection system. This information may be shared during a single phone call with the family, through more than one phone conversation, or through a combination of an initial phone call(s) and the intake visit.

Early Conversations with Families:

This list is intended to guide conversations and should not be read to families

- Be sure to introduce yourself and let the family know your role in the local system (e.g., service coordinator or staff at the single point of entry)
- Let the family know how you got their name and their child's name.
- Find out whether they knew their child was going to be referred.
- Confirm the information you received from the referral source, e.g., child's name, date of birth, address, phone number
- Ask whether the family has heard of the early intervention program before and, if so, what they have heard. This may allow you to skip some of the basic information you would typically share with a newly-referred family or give you the opportunity to address any misperceptions.
- Remember to spend some of the conversation listening to the family. Ask the family about their child, how he/she is doing, etc.
- Briefly explain the state definition of eligibility.
- Discuss the process of eligibility determination, explaining that information already available from the child's physician or other providers will be used to help determine eligibility, along with your observations, any developmental screening information, and information from the family. Share with the family that if existing information is not enough to determine eligibility, then additional assessment will be conducted with their consent.
- Explain what will happen during the first face-to-face visit with the family.
- Ask if the family has any medical or developmental records that they are willing to share about their child, and if so, to please have those available at the intake visit. Otherwise, explain that you will be asking at that visit for their permission to request those records.
- Inform the family that the eligibility determination and development of an Individualized Family Service Plan will occur within 45 calendar days unless the family prefers to extend that timeline.
- Introduce the rights and safeguards the family has and the need for parental consent in order to proceed with Part C early intervention activities, including screening and/or eligibility determination. If you will be mailing notice and consent forms prior to the intake visit, then fully explain the family's rights and safeguards associated with screening and eligibility determination as detailed in Chapter 4.
- Explain that some services are available at no cost to families (eligibility determination, assessment for service planning, IFSP development, service coordination). Let the family know that they may meet the cost of remaining services through use of Medicaid or private insurance or by monthly payment of a fee that is determined based on their family size, income and extra expenses. Emphasize that no family will be denied services because of an inability to pay.

- Ensure entry of referral data into ITOTS. (See ITOTS Data Entry section at the end of this chapter)
- If, upon initial contact, the family declines an intake visit or any further service, provide an explanation of and then mail a *Declining Early Intervention Services* form and *Notice of Child and Family Safeguards in the Infant & Toddler Connection of Virginia Part C Early Intervention System* to the family.
 - Make reasonable efforts to ensure the family understands the screening and eligibility determination services that are available, that these services must be provided at no cost to the family, and that these services cannot be provided without parental consent.
 - Offer to make referrals to other appropriate resources/services based on child and family needs and preferences, with parent consent.
 - Using the bottom half of the *Declining Early Intervention Services* form, mark the first line (that they understand that eligibility determination may be conducted) and the last line indicating that they do not choose to have their child receive an eligibility determination. Explain to the family how they can contact the local Infant & Toddler Connection system in the future using the phone number provided at the bottom of the form if they have concerns about their child's development.
 - If the child is close to being age eligible for early childhood special education services through the local school division (under Part B), explain how to access Part B services through the local school division.
 - Attempt to obtain parent consent to communicate with the primary care physician and the primary referral source, if not already provided. It is also acceptable to give the family the option to notify their physician themselves.

Talking with the Family About Notifying the Physician:

Consider using the following language in seeking parent permission to notify the physician: "It's important to let your physician know that your child will not be receiving early intervention services so he/she can continue to keep an eye on your child's development. We can do that if you'll give us written consent (which we can do by mail). If not, we would ask that you let your physician know yourself."

- Ensure that copies and explanations of the *Declining Early Intervention Services* form and *Notice of Child and Family Safeguards in the Infant & Toddler Connection of Virginia Part C Early Intervention System* are provided in the family's native language or other mode of communication unless clearly not feasible to do so.

ITOTS Data Entry – Referral [Link to ITOTS Manual]

The local system manager ensures that the following data is entered into ITOTS:

- Child's full name
- Social security number, if available
- Date of birth

- City/County of residence
- Gender
- Local case number (optional)
- Service coordinator (optional)
- Referral source
- Date of referral

Local Monitoring and Supervision Associated with Referral

The local system manager provides the supervision and monitoring necessary to ensure the following:

- Appropriate use and explanation of procedural safeguards forms
- Consistent and accurate information to the family and referral source at the point of referral
- Consistent and accurate information to the family during the phone call(s) to share basic information about the Infant & Toddler Connection system
- Timely and accurate entry of ITOTS data

Chapter 4: Intake

The intake process includes the initial face-to-face visit with the family and the start of information gathering for eligibility determination. This initial visit between the service coordinator and the family provides the opportunity to welcome and get to know the family, further describe the Infant & Toddler Connection system (which was introduced in the phone call with the family to schedule the visit), and discuss the options and opportunities available to them through the system. At the point of intake, the local Infant & Toddler Connection system is already beginning to provide supports and services to the family by sharing tips and information on child development and/or parenting and by providing referrals to other resources, as appropriate and with parent consent.

The Intake Visit (The Initial Face-to-Face Visit):

Service Coordinator Responsibilities:

- Meet with the family in order to share information about the Infant & Toddler Connection system. All families receive consistent information about the Infant & Toddler Connection system using the outline of topics in the box on the next page.

Topics to discuss with Families During the Intake Visit:

This list is intended to guide conversations and should not be read to families

- Introduce yourself and explain that you, as their service coordinator, will assist the family during the intake and eligibility process. Let the family know that if their child is found eligible, they will always have a service coordinator who will help them obtain the services and assistance they need.
- Explain the purpose of your visit. For example, you might say, “I am here today to talk with you about the Infant & Toddler Connection of _____, to answer any questions which you might have, and to learn about your child and his/her development, your family, your activities, and to discuss what information may be needed to proceed with determining your child’s eligibility for services.”
- Explain or briefly review (if introduced in a previous conversation or through written materials) the state definition of eligibility, and explain that two providers from two different disciplines participate in the determination of eligibility. Explain that the eligibility team will be using medical record information, the results of developmental screening (if needed), and the information the family shares about their child’s activities, what is going well or not going well, to determine whether their child is eligible. Share with the family that if the existing information is not enough to determine eligibility, then additional assessment will be conducted to determine eligibility. If the family should ask you if you think their child is eligible, then reflect on the information that you have gathered and how that relates to Virginia’s definition of eligibility. Explain that you cannot make a definitive statement at this time.
- Explain that if their child is eligible, an Individualized Family Service Plan, which is called an IFSP for short, will be developed. Let the family know that the IFSP will list the supports and services necessary to support the family in enhancing their child’s development through everyday activities.
- Remind the family that the eligibility determination and development of an Individualized Family Service Plan will occur within 45 calendar days of the day they were referred unless the family prefers to extend that timeline.
- Explain that parents and/or other caregivers are involved in each step of the process and, if their child is eligible, in each early intervention session.
- Explain that some services are available at no cost to families (eligibility determination, assessment for service planning, IFSP development, service coordination). Let the family know that they may meet the cost of remaining services through use of Medicaid or private insurance or by monthly payment of a fee that is determined based on their family size, income and extra expenses. Emphasize that no family will be denied services because of an inability to pay.
- Let the family know that all information they share with you about their child and family is kept confidential. Specifically share that any information that has been received from the referral source and the information that you are gathering today is protected by confidentiality requirements.
- Give the family the opportunity to ask questions and to share with you information that they feel is important.

- Fully inform the family about their rights, responsibilities and procedural safeguards under Part C and complete necessary paperwork (if not already addressed during phone or other contact prior to the intake visit). Emphasize the rights and safeguards applicable to the screening and eligibility determination steps in the early intervention process.
 - Ensure that copies and explanations of procedural safeguard forms are provided in the family's native language or other mode of communication unless clearly not feasible to do so.
 - Provide a copy and explanation of *Notice of Child and Family Safeguards in the Infant and Toddler Connection of Virginia Part C Early Intervention System* and *Strengthening Partnerships: A Guide to Family Safeguards in the Infant & Toddler Connection of Virginia Part C Early Intervention System*.
 - Explain the policies and procedures related to storage, disclosure to third parties, retention, and destruction of personally identifiable information, pointing out where this information is included in the *Notice of Child and Family Safeguards in the Infant and Toddler Connection of Virginia Part C Early Intervention System*. Discuss the family's rights and safeguards associated with inspecting and reviewing records and correcting information in the record that the family believes to be inaccurate, misleading or in violation of privacy or other rights.
 - Obtain informed, written parental consent to proceed to screening (if needed) using the *Notice and Consent for Screening* form. If screening is not needed, obtain informed, written parental consent to proceed to eligibility determination using the *Notice and Consent for Eligibility Determination* form. The *Notice and Consent for Eligibility Determination* form may be explained and signed at the same time as the *Notice and Consent for Screening* form or following the screening, depending on the preferences of the family. In some situations, it also will be appropriate to obtain informed written consent to proceed to assessment for service planning using the *Notice and Consent for Assessment for Service Planning* form. Situations in which this might be appropriate are further described later in this chapter.

Can screening occur during the intake visit even if the family signs the *Notice and Consent for Screening* form during the intake visit? If the service coordinator is trained to conduct the screening(s), then all or parts of the Virginia hearing and vision screenings and the developmental screening may be completed during the intake visit, with parent consent. Prior to requesting parent consent to conduct the hearing, vision and/or developmental screening at the intake visit, the service coordinator must fully explain the screening activities and discuss with the family the advantages and disadvantages of proceeding with the screening on the same day versus doing so at a separate visit. Only with fully informed parent consent, indicated by initialing the Optional statement in the lower right corner of the notice and consent form, may the screening be conducted on the same day the consent form is signed.

Consider using the following language in explaining the advantages and disadvantages of completing the screening on the same day: "I am required to give you at least 5 days notice before we plan to conduct the screening. You have the option, though, to move forward immediately if you prefer. Some families like to take some time to review the activities proposed, ask questions, or talk with other family members or individuals who offer guidance and support to them before making a decision to proceed. Others feel like they understand what's being proposed and want to move ahead quickly. You should feel free to decide based on what you think is best for your family."

- Obtain parent signature on release of information forms in order to obtain existing screening, medical, or other information to assist in determination of eligibility.
- Obtain parent consent to contact the referring agency/provider and the child's primary medical care provider to inform them of the child's status in the Part C system, if consent was not already obtained by the referral source and/or primary medical care provider.
- Ask the family about the child's race/ethnicity using the federally-required 2-part question:
 1. Is your child Hispanic/Latino?
 2. Is your child from one of the following racial groups – American Indian or Alaska Native; Asian; Black or African American; Native American or Other Pacific Islander; or White?Document the family's response for entry into ITOTS.
- Gather information about the child's development, his health history and his medical home information.
 - Begin a conversation with the family which lets you get to know the child and his family and their activities, and which will be used for the purpose of eligibility determination. Conversation starters may include, but are not limited to, the following:
 - Tell me about your family-who is in your family.
 - Who are the other caregivers for Johnny, e.g., extended family, child care providers, etc.
 - Tell me about the places your child and family spend time.
 - What is a typical day like for your child and family?
 - Tell me about your routines/activities. Which routines/activities are going well and which are not?

- What other activities would you like your child and family to participate in?
- What activities really interest your child, and which ones interest you to do with your child?

This list of suggested conversation starters is not presented in any particular order, and there is no requirement that they be worded as written.

- Ensure the following screenings have been or are conducted:
 - Hearing and vision screening, with the Virginia Part C Hearing Screening and Virginia Part C Vision Screening forms completed [Link to Virginia Part C Hearing and Vision forms and instructions].
 1. Parent consent for hearing and vision screening may be documented on the *Notice and Consent for Screening* form or on the *Notice and Consent for Assessment for Service Planning* form depending on the timing of the hearing and vision screening and whether the child will require developmental screening.
 2. The Virginia Part C Hearing Screening and Virginia Part C Vision Screening may be conducted by any practitioner, including service coordinators, trained to conduct the screening.
 3. If the child has a diagnosed condition or an obvious delay or atypical development that will make the child eligible, then it is not necessary to complete the hearing and vision screening prior to eligibility determination. Under these circumstances, the hearing and vision screening may be completed as part of the assessment for service planning instead.
 4. No child may be found ineligible for Part C without having the hearing and vision screenings completed.
 - A developmental screening using a tool unless there is (1) a diagnosed physical or mental condition with a high probability of resulting in developmental delay, (2) documented developmental delay or atypical development, or (3) the child has already received a developmental assessment or screening prior to referral. {Add list of approved screening tools once determined}
 1. Developmental screening may be conducted by practitioners certified as early intervention specialists and by those certified as early intervention assistants or early intervention service coordinators who have been trained to conduct screening.
 2. For those children who must receive a developmental screening using a tool (those who do not fall into one of the three exceptions listed above), it is acceptable to first screen in the area of the suspected delay. If screening in that area(s) indicates the child will be eligible for Part C, then it is not necessary to screen in the remaining areas of development.

3. No child may be found ineligible for Part C without having a developmental screening completed in all areas of development.
 - Document, in a contact note(s) or through other written means, the information shared by the family and gathered through screening and observation so this information can be shared with other team members during eligibility determination, assessment for service planning and IFSP development. This promotes timely and accurate communication and minimizes the number of times the family needs to share the same information.
 - If the referral was not from the child's primary medical care provider, then request the name of that provider from the family. If the child does not have a primary medical care provider, then offer assistance to the family in obtaining a primary care provider for their child. For example, assistance can be provided by giving the family a listing of area physicians and their phone numbers.
 - Arrange to assist the family in completion of a Medicaid application or applications for other programs and supports, as needed.
- Let the family know when their child's eligibility determination will be made and how the information provided by the family is used in that determination.
 - Local systems have the option to invite the family to participate further in the eligibility determination process by phone, in writing or through a meeting, depending on how the eligibility process works in the local system and what makes sense for this specific child and family.
 - If the family will not participate in the eligibility discussion then explain that you will call them following the determination to inform them of the decision.
 - If the referral information or information gathered during intake indicates the child has a diagnosed condition that meets Virginia's eligibility criteria (see Chapter 5), explain to the family that they may want to combine the eligibility determination and assessment for service planning steps since eligibility can be quickly confirmed by the review of existing documentation at the same time assessment is conducted. Be sure to explain the purpose of both steps in the process and obtain parent consent for both eligibility determination and assessment for service planning.
- If the family declines screening or the family decides not to proceed to eligibility determination:
 - Provide a copy and explanation of the *Declining Early Intervention Services* form and the *Notice of Child and Family Safeguards in the Infant & Toddler Connection of Virginia Part C Early Intervention System*.
 - Make reasonable efforts to ensure the family understands the screening and eligibility determination services that are available, that these services must be provided at no cost to the family, and that these services cannot be provided without parental consent.
 - Using the bottom half of the *Declining Early Intervention Services* form, the family is asked to mark the first line (that they understand that eligibility determination may be conducted) and then to read and mark the last line indicating that they do not choose to have their child receive an eligibility determination.

- In explaining the *Notice of Child and Family Safeguards in the Infant & Toddler Connection of Virginia Part C Early Intervention System*, review and explain the complaint procedures.
- Explain how to access Part C services in the future, pointing out the contact number provided at the bottom of the *Declining Early Intervention Services* form.
- If the child is close to being age eligible for early childhood special education services through the local school division (under Part B), explain how to access Part B services through the local school division.
- Obtain parent consent to make referrals to other appropriate resources/services based on child and family needs and preferences.
- Obtain parent consent to communicate with the primary care physician and the primary referral source, if not already provided.

Other Intake Activities Following the Intake Visit:

Service Coordinator Responsibilities:

- Request existing screening, medical and other information to assist in eligibility determination, if not already requested.
 - Medical information requested should be specific to eligibility determination and service planning (e.g., diagnostic information and developmental screening and assessment results). A full medical record is generally not necessary or appropriate.
 - Service coordinators are expected to make every effort to obtain physician and other appropriate records prior to eligibility determination, following up on initial requests with actions such as phone calls to request a fax of the needed records, going to the physician's office to pick up copies, or collecting the information via a telephone call with a hard copy received later for inclusion in the child's record.

ITOTS Data Entry – Intake: [Link to ITOTS manual]

The local system manager ensures the following data is entered into ITOTS:

- Verify that the family-identified race for their child matches with the race entered into ITOTS at referral; correct in ITOTS if necessary.
- If the family declines to proceed to eligibility determination, then mark Child Evaluated as No and mark the appropriate box for the reason (Unable to contact, deceased, declined screening, declined eligibility determination)

Local Monitoring and Supervision Associated with Intake:

The local system manager provides the supervision and monitoring necessary to ensure the following:

- Appropriate use and explanation of procedural safeguards forms
- Consistent and accurate information to the family during the intake visit
- Timely request and follow-up to receive medical and other records for eligibility determination
- Use of qualified personnel and approved screening tools in conducting developmental, hearing and vision screening
- Timely and accurate entry of ITOTS data

Chapter 5: Eligibility Determination

Eligibility determination is the process by which a multidisciplinary team reviews medical reports, developmental screening results, parent report, observation summaries, and assessment reports, if available, to determine whether or not a child meets the Infant & Toddler Connection of Virginia eligibility criteria as specified in Virginia's Part C regulations. Assessments are conducted as part of the eligibility determination process only if a child's eligibility is uncertain based on existing information.

Virginia Part C Eligibility Criteria

Infants and toddlers, birth to three years old, and their families are eligible for early intervention supports and services through the Infant & Toddler Connection of Virginia if the multidisciplinary team determines, through the practices described in this chapter, that the child meets one or more of the following criteria:

- Developmental Delay – Children who are functioning at least 25% below their chronological or adjusted age in one or more of the following areas:
 - Cognitive development;
 - Physical development, including fine motor and gross motor;
 - Communication development;
 - Social or emotional development; or
 - Adaptive development.

For children born prematurely (gestation < 37 weeks), the child's adjusted age is used to determine developmental status. Chronological age is used once the child is 18 months old.

- Atypical development – Children who manifest atypical development or behavior, which is demonstrated by one or more of the following criteria (even in the absence of a 25% developmental delay):
 - Atypical or questionable sensory-motor responses (listed in ITOTS as “Abnormal or questionable sensory-motor responses”), such as:
 - a. Abnormal muscle tone;
 - b. Limitations in joint range of motion;
 - c. Abnormal reflex or postural reactions;
 - d. Poor quality of movement patterns or quality of skill performance;
 - e. Oral-motor skills dysfunction, including feeding difficulties.
 - Atypical or questionable social-emotional development (Listed in ITOTS as “Identified Affective Disorders”), such as:
 - a. Delay or abnormality in achieving expected emotional milestones;
 - b. Persistent failure to initiate or respond to most social interactions;
 - c. Fearfulness or other distress that does not respond to comforting by caregivers.
 - Atypical or questionable behaviors that interfere with the acquisition of developmental skills (Listed in ITOTS as “Behavioral disorders that interfere with acquisition of developmental skills”).
 - Impairment in social interaction and communication skills along with restricted and repetitive behaviors.
- Children with a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay. These conditions include, but are not limited to the following:
 - seizures with significant encephalopathy;
 - significant central nervous system anomaly;

- severe Grade 3 intraventricular hemorrhage with hydrocephalus or Grade 4 intraventricular hemorrhage;
- symptomatic congenital infection;
- effects of toxic exposure including fetal alcohol syndrome, drug withdrawal and exposure to chronic maternal use of anticonvulsants, antineoplastics, and anticoagulants;
- myelodysplasia;
- congenital or acquired hearing loss;
- visual disabilities;
- chromosomal abnormalities, including Down syndrome;
- brain or spinal cord trauma, with abnormal neurologic exam at discharge;
- inborn errors of metabolism;
- microcephaly;
- severe attachment disorders;
- failure to thrive;
- autism spectrum disorder;
- endocrine disorders with a high probability of resulting in developmental delay;
- hemoglobinopathies with a high probability of resulting in developmental delay;
- cleft lip or palate; or
- other physical or mental conditions at the multidisciplinary team members' discretion.

Additional explanation of the eligibility categories is provided at the end of this chapter.

Planning and Preparation for Eligibility Determination

Service Coordinator Responsibilities:

- Assemble documentation that will be used in eligibility determination, including results of any screenings completed, medical information, parent report, formal/informal observation and written assessment reports if available.
- Facilitate identification of the multidisciplinary team that will determine eligibility and coordinate scheduling of the eligibility determination meeting, if needed.
 - The multidisciplinary team must be comprised of professionals from at least 2 different disciplines and the service coordinator. There is no requirement that the disciplines on the team match the areas of concern for the child.
 - It is possible that one or more disciplines were involved in conducting screening and/or assessment prior to referral that may be used for eligibility determination. A written report by this individual is enough to count towards the requirement for 2 disciplines to participate if (1) the report or cover letter states that this individual believes the child is eligible for Part C based on _____ (developmental delay, atypical development or diagnosed condition as evidenced by ____); or (2) the report states the child's level of development or percent of delay, gives the diagnosed condition, or states the presence of atypical development; or (3) the report gives enough specific data about the child's skills that the other team member can determine that the child has at least a 25% delay in one or more areas of development or atypical development.
 - The service coordinator may only serve as one of the disciplines if he or she is also a qualified practitioner in a discipline other than service

coordinator (e.g., the service coordinator is also a speech-language pathologist who is certified as an Early Intervention Specialist). In that situation, the service coordinator may participate on the multidisciplinary team in the dual function as one discipline and as the service coordinator.

- Eligibility determination may take place as a face-to-face meeting, phone call or video conference.
- All families participate in the eligibility determination process by sharing information during intake that is reviewed by the multidisciplinary team and used in determining eligibility. The family may be invited to participate further in the process by phone, in writing or through a meeting, depending on how the eligibility process works in the local system and what makes sense for this specific child and family.

Determining Eligibility

General:

- During eligibility determination, it is not necessary to determine the child's specific age level in each area of development. The multidisciplinary team must only be able to state whether the child has a developmental delay (at least 25% in one or more areas of development), atypical development or a diagnosed condition that meets Virginia's eligibility criteria. Eligible children will move on to assessment for service planning, and that assessment information combined with the information used to determine eligibility will allow the team to describe on the IFSP the child's status (current level of functioning) in each area of development. The current level of functioning required on the IFSP does not have to be an age level or range but may be a description of the child's functional skills in that area of development.
- A child referred from another local Infant & Toddler Connection system within Virginia who has already been determined eligible does not need to be found eligible again and may move directly to assessment for service planning, IFSP development or IFSP implementation (with an IFSP review) depending on how far into the process the family was with the sending local system.
- For children referred with an eligibility determination and/or an IFSP from another state, eligibility must be established in Virginia prior to proceeding to IFSP development and implementation. Existing information, such as medical records, developmental screening results, parent report, observation and available assessment results, will be used for eligibility determination. If there is insufficient medical and developmental information from within the past 6 months to determine eligibility, then new developmental screening may be conducted. The results of that developmental screening, along with parent report and observation may then be used for eligibility determination. The service coordinator will ask the family for consent to request the early intervention records from the sending state.
- If a child is found eligible and the family declines to proceed to an assessment for service planning but later the child is referred again, then unless the eligibility was based on a diagnosed condition a multidisciplinary team must again review existing information to make a new determination of eligibility. Depending on the length of time since the child left the system, information used previously to determine eligibility may be used again as long as it still reflects the child's current developmental status.
- The annual IFSP meeting includes confirmation of ongoing eligibility. The determination of ongoing eligibility is made based on the progress reports of

team members, not through formal testing. The progress report may be written or may be a verbal report based on contact notes. The child's eligibility status at the time of the annual IFSP is documented on the *Determination of Eligibility* form. Further information on the annual determination of eligibility is provided in the Annual IFSP section of Chapter 8.

Multidisciplinary Team Responsibilities:

- Review available documentation to determine whether the child has a diagnosed condition that meets the criteria in Virginia's Part C regulations for a physical or mental condition with a high probability of resulting in developmental delay. In order for a child to be determined eligible based on a diagnosed physical or mental condition which has a high probability of resulting in a developmental delay, there must be documentation that the condition has been diagnosed by a professional qualified to make the diagnosis. Remember that endocrine disorders and hemoglobinopathies make the child eligible under Part C in Virginia only if the multidisciplinary team determines that the diagnosis has a high probability of resulting in developmental delay for this specific child.
 - When referral information or information gathered at intake indicates the child has a diagnosed condition that meets Virginia eligibility criteria, it makes sense to combine eligibility determination with assessment for service planning, with parent consent.
- If the child does not have a diagnosed condition that meets the criteria in Virginia's Part C regulations, determine whether the child is eligible based on a developmental delay or atypical development as defined in Virginia's Part C regulations.
 - Review pertinent records less than six (6) months old from the primary care physician and other sources related to the child's current health status, physical development (including vision and hearing), and medical history, or arrange for participation by the primary health care provider(s). Other records pertinent to eligibility determination, such as birth records, newborn screening results and early medical history, shall also be reviewed by the team (with parent consent), even if those records are more than six (6) months old. Document in the child's early intervention record if the parent(s) chose not to consent to a review of records or if requested records were not received in time for review for eligibility determination, despite a timely request and follow-up.
 - Consider the results of any developmental screening completed, parent report, formal/informal observation, and any available written assessment reports.
 - Use informed clinical opinion – Informed clinical opinion is the result of synthesizing medical and developmental information (based on a tool, observation, parent report, medical records, etc.) with professional expertise and experience to make a determination regarding a child's developmental status and/or eligibility. Informed clinical opinion may be the basis upon which the eligibility determination is made. This does not violate the requirement (below) that no single procedure be the sole criterion for determining a child's eligibility since the informed clinical opinion would be based on multiple procedures and sources of information. Informed clinical opinion may be used to establish a child's eligibility even when screening or assessment instruments or other information does not establish that eligibility. However, informed clinical

- opinion cannot be used to negate eligibility established through the use of appropriate assessment instruments or procedures.
- Ensure that no single procedure is used as the sole criterion for determining a child's eligibility – By looking at the multiple sources of information available for eligibility determination (e.g., medical records, developmental screening results, information from formal/informal observation, parent report, etc.) the multidisciplinary team ensures that the eligibility determination is based on more than one procedure.
 - If existing information is insufficient to determine the child's eligibility under Part C, then determine the appropriate provider(s) to carry out any assessment activities necessary for eligibility determination.
 - In this situation, it is recommended that any assessment needed to determine eligibility be combined with assessment for service planning, with parent consent. It is not necessary for the multidisciplinary team to meet again, as a separate activity, to determine eligibility before proceeding to assessment for service planning.
 - In combining the assessment for eligibility determination and assessment for service planning, the multidisciplinary team is expected to consider how the assessment can proceed in such a way that, if it becomes clear that the child does not meet eligibility criteria, then a full assessment for service planning is not completed. For example, if the area of concern (based on referral information, screening, observation and parent report) is language then begin the assessment by focusing on that area of development.
 - Complete the *Determination of Eligibility* form.

Service Coordinator Responsibilities:

- Participate in the determination of eligibility by sharing information from the family and from any screening and/or observation completed by the service coordinator. This information may be shared in writing or verbally (based on contact notes). This may occur face-to-face with other team members, by phone, or in writing.
- Share results of the eligibility determination process with the family, including a copy of the completed *Determination of Eligibility* form. This information may be shared with the family in person or by phone (with the form faxed, mailed or handed to the family at the next contact).
- If the child is eligible, then schedule a visit or phone contact(s) with the family, as needed, to discuss and plan for assessment for service planning and the IFSP meeting.
- If the child is eligible but the parents decline to proceed, then
 - Provide a copy and explanation of the *Declining Early Intervention Services* form and the *Notice of Child and Family Safeguards in the Infant & Toddler Connection of Virginia Part C Early Intervention System*.
 - a. Using the bottom half of the *Declining Early Intervention Services* form, the family is asked to mark the second line (that they understand that an IFSP can be developed for their child/family) and then to read and mark the last line indicating that they do not choose to have their child receive an IFSP. Explain to the family how they can contact the local Infant & Toddler Connection system in the future using the phone number provided at the bottom of the form if they have concerns about their child's development.

- b. In explaining the *Notice of Child and Family Safeguards in the Infant & Toddler Connection of Virginia Part C Early Intervention System*, review and explain the complaint procedures.
- o Explain how to access early childhood special education services through the local school division (under Part B) if the child is close to being age eligible for Part B services.
- o Obtain parent consent to make referrals to other appropriate resources/services based on child and family needs and preferences.
- o Attempt to obtain parent consent to communicate with the primary care physician and primary referral source, if not already provided. It is also acceptable to give the family the option to notify their physician themselves.

Talking with the Family About Notifying the Physician:

Consider using the following language in seeking parent permission to notify the physician: "It's important to let your physician know that your child will not be receiving early intervention services so he/she can continue to keep an eye on your child's development. We can do that if you'll give us written consent (which we can do by mail). If not, we would ask that you let your physician know yourself."

- If the child is ineligible:
 - o Provide the parents with a copy and explanation of the *Parental Prior Notice* form (indicating "Your child is not eligible for Infant & Toddler Connection of Virginia") and the *Notice of Child and Family Safeguards in the Infant & Toddler Connection of Virginia Part C Early Intervention System*. On the *Parental Prior Notice* form, identify the information used to make the determination that the child is not eligible. In explaining the *Notice of Child and Family Safeguards*, the service coordinator reviews and explains the complaint procedures.
 - o Facilitate an opportunity for the family to talk with the eligibility determination team if the family has questions or disagrees with the eligibility finding and if desired by the family
 - o Obtain parent consent to make referrals to other appropriate resources/services based on child and family needs and preferences.
- Ensure that copies and explanations of procedural safeguard forms are provided in the family's native language or other mode of communication unless clearly not feasible to do so.
- Document in the child's early intervention record any and all circumstances that result in a delay in eligibility determination.

Interim IFSP

General:

- An interim IFSP may be developed and implemented for an eligible child in those exceptional circumstances where there is an obvious and immediate need for services to begin before the team has completed the assessment for service planning and developed the IFSP. These situations should be the exception rather than the rule.

- The use of an interim IFSP does not negate the requirement to develop an initial IFSP within 45 calendar days of referral. Rather, the interim IFSP allows essential services to begin while the team completes the remaining steps for developing the initial IFSP.
- If there are exceptional circumstances that make it impossible to complete assessment for service planning and IFSP development within the 45-day timeline, then these circumstances must be documented in the child's record. An interim IFSP may be used for an eligible child in this situation, as appropriate to address immediate needs. One situation in which an interim IFSP may be appropriate would involve an eligible child who is medically fragile or experiencing a medical crisis who is currently unable to undergo necessary assessment or whose family is unable to participate in an IFSP meeting but for whom there is an immediate need for early intervention services. The use of an interim IFSP in this situation allows for needed services to begin while also allowing the child and family to wait until a more appropriate time to complete the assessment for service planning and IFSP development.

Service Coordinator Responsibilities:

- Ensure the eligibility determination process is completed and the child found eligible prior to development of an interim IFSP.
- Develop the interim IFSP jointly with the family and with input from the multidisciplinary team. Input from the multidisciplinary team members may be provided in person, by phone or other electronic means or in writing. The interim IFSP must include:
 - The name of the service coordinator who is responsible for implementation of the interim IFSP and coordination with other agencies and persons;
 - The early intervention supports and services that are needed immediately by the child and the child's family; and
 - Signatures of both the service coordinator and the parent(s).
- Ensure that assessment for service planning and development of the initial IFSP still occur within 45-calendar days of referral and that any circumstances resulting in a delay in development of the IFSP are fully documented in the child's record.

ITOTS Data Entry – Eligibility Determination:

Following eligibility determination, if the child is found ineligible or if the family declines to proceed in the early intervention process, the local system manager ensures that the following data is entered into ITOTS:

- Child evaluated (for eligibility determination)? Yes or No
 - If no, reason not evaluated
 - If yes, date of eligibility determination
- Result of evaluation

Local Monitoring and Supervision Associated with Eligibility Determination

The local system manager provides the supervision and monitoring necessary to ensure the following:

- There is timely request for and follow-up to receive existing records for use in eligibility determination.
- Assessment is carried out for eligibility determination only if the multidisciplinary team finds that existing information is insufficient to determine eligibility.

- Determination for eligibility occurs quickly enough after referral to allow time for assessment for service planning and IFSP development to occur within the 45-day timeline.
- There is timely and accurate entry of ITOTS data.

Interpretation of Eligibility Criteria for Part C

The following information is designed to provide interpretation of the criteria used in determining eligibility for Virginia's Part C Program.

Developmental Delay:

>25% deficit based on adjusted age: adjusted age is determined by subtracting actual gestational age (weeks) at birth as determined by expected date of confinement (EDC, i.e., due date) or Dubowitz (or Ballard, a modification of the Dubowitz exam) from 40 weeks (normal term gestation). This value is then added to the actual birth date to determine the adjusted birth date. For example, an infant born at 36 weeks is 4 weeks early. If the birth date is 1/12/96, the adjusted birth date would be 4 weeks from the date, or February 8, 1996.

Cognitive development refers to intellectual development

Fine motor refers to use of the hands, and hand-eye coordination

Gross motor refers to locomotion, and the ability to move and support oneself (sit, roll, walk)

Speech and language refer to the development of both expressive and receptive speech

Social-emotional includes behavioral responses, interpersonal skills

Adaptive includes the ability to care for oneself

Atypical development: Refers to patterns of development that are clearly abnormal but do not necessarily result in a developmental deficit of 25%.

Diagnosed Conditions with High Probability of Resulting in Delay:

Seizures with significant encephalopathy: Seizures must be accompanied by evidence of alterations in brain function that impair normal mentation and responses to stimulation such as coma, hallucinations.

Significant CNS anomaly: This refers to an anatomical abnormality that is known to be associated with future developmental abnormalities such as agenesis of the corpus callosum, hydrocephalus, encephalocele.

Grade III IVH with hydrocephalus: Grade III intraventricular hemorrhage is defined as blood in the ventricles with evidence of ventriculomegaly. Hydrocephalus refers to enlargement of the ventricles that develops as a complication of the bleed and is felt to be due to abnormal reabsorption of cerebrospinal fluid. The hydrocephalus may be static or may increase requiring intervention.

Grade IV IVH: A grade IV bleed is defined as both a bleed into the ventricles and a bleed into the parenchyma of the brain itself. These may or may not be associated with hydrocephalus. The area of intra parenchymal bleed normally results in necrosis of brain cells and will ultimately be a porencephalic cyst or empty space.

Congenital infection, symptomatic: This refers to an infection that developed in utero and may manifest at birth, in infancy, or in childhood. The most common diseases in the category are the TORCHS infections; toxoplasmosis, rubella, CMV, herpes, syphilis. The word symptomatic means that there are stigmata of the infections on exam which may include growth retardation, abnormal blood studies and/or organ involvement.

Toxic exposure, in utero to include fetal alcohol syndrome, drug withdrawal, and others (anticonvulsants, anticoagulants): In these cases there must be evidence of an abnormality in the infant that is a direct result of the toxic exposure.

Meningomyelocele: This term is synonymous with spina bifida.

Hearing loss: The definition does not define the degree of hearing loss that meets the criteria for referral. Hearing loss must be diagnosed by a licensed audiologist.

Visual disabilities: The diagnosis of visual impairment must be made by an ophthalmologist.

Chromosomal abnormality: This includes any diagnosed abnormality of chromosome number or length.

Brain/spinal cord trauma with abnormal exam at discharge: Trauma to these areas could include such diagnoses as hemorrhage, swelling. In this instance there must be continued evidence of neurologic dysfunction at the time of discharge to qualify.

Inborn error of metabolism: These diseases are rare and are diagnosed with special tests, including those conducted through the Virginia Newborn Screening Services program. These include:

- Argininosuccinic acidemia (ASA);
- Beta-Ketothiolase deficiency (β KT);
- Biotinidase deficiency (BIOT);
- Carnitine uptake defect (CUD);
- Citrullinemia (CIT);
- Congenital adrenal hyperplasia (CAH);
- Congenital hypothyroidism (CH);
- Cystic fibrosis (CF);
- Galactosemia (GALT);
- Glutaric acidemia type I (GA I);
- Hemoglobin Sickle/Beta-thalassemia (Hb S/ β Th);
- Hemoglobin Sickle/C disease (Hb S/C);
- Homocystinuria (HCY);
- Isovaleric acidemia (IVA);
- Long chain hydroxyacyl-CoA dehydrogenase deficiency (LCHAD);
- Maple syrup urine disease (MSUD);
- Medium-chain acyl-CoA dehydrogenase deficiency (MCAD);
- Methylmalonic acidemia (mutase deficiency) (MUT);
- Methylmalonic acidemia (Cbl A,B);
- Multiple carboxylase deficiency (MCD);
- Phenylketonuria (PKU);
- Propionic acidemia (PROP);
- Tyrosinemia type I (TYR I);
- Trifunctional protein deficiency (TFP);
- Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD);
- 3-hydroxy 3-methyl glutaric aciduria (HMG), and

- 3-Methylcrotonyl-CoA carboxylase deficiency (3MCC).

Other diagnostic tests may include the urine for metabolic screen and/or the urine for organic acids.

Microcephaly: This is defined as a head circumference that is less than the 10th percentile for gestational age.

Severe attachment disorder: This refers to a mental and emotional condition occurring in the first two years of life that causes a child not to bond or to trust his primary caretaker.

Failure to thrive: This is defined as a failure to achieve expected growth for age. The causes are multiple with the most common being psycho-social.

Autism Spectrum Disorder: This refers to impairment in social interaction, an impairment in communication skills, and a restricted and repetitive repertoire of activities and interests. Includes the diagnosis of Autism, Pervasive Developmental Disorder (PDD), Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS), Asperger's Disorder, Rett's Syndrome, and Childhood Disintegrative Disorder

Hemoglobinopathies: Sickle cell anemia (Hb SS disease) (Hb SS).

“Other” Diagnosed Conditions With A High Probability Of Resulting in Developmental Delay

The category of eligibility called “diagnosed physical or mental conditions with a high probability of resulting in developmental delay” is a limited one with some specific parameters. While IFSP teams are given discretion to identify “other” conditions under this category of eligibility, these “other” conditions must still meet the criteria that the condition has a high probability of resulting in developmental delay. Many chronic conditions and genetic disorders are more appropriately considered risk factors rather than diagnosed conditions that meet Virginia’s definition of eligibility. Some children with these risk factors will be eligible for Part C services because of a developmental delay or atypical development.

“Other” conditions are discussed below under several headings which describe how they actually should fit in the determination of Part C eligibility. However, please note that with any situation in which discretion is left to the IFSP team and only limited information is available to analyze, it is very difficult to state absolutes (e.g. this condition always goes here or never goes there). What follows is a summary related to where each of the listed “other” conditions would **usually** or **probably** fall:

- 1. Conditions that are often listed as “Other” but actually belong in one of the conditions already listed in Virginia’s definition of eligibility:**
- | | |
|--|--|
| <ul style="list-style-type: none"> ▲ Significant Central Nervous System Anomaly <ul style="list-style-type: none"> ▪ Agenesis of the Corpus Callosum ▪ CMV ▪ Dandy-Walker Syndrome ▪ Delayed myelinization ▪ Fetal Stroke ▪ Hydrocephaly ▪ Left Arachnoid Cyst ▪ Lissencephaly ▪ Mobius Syndrome ▪ Significant Central Nervous System Anomaly ▪ Sturge-Weber Syndrome ▪ Symptomatic Congenital Infection ▪ Toxoplasmosis ▲ Inborn Error of Metabolism <ul style="list-style-type: none"> ▪ Krabbe’s Disease ▲ Seizures/Significant Encephalopathy <ul style="list-style-type: none"> ▪ Infantile Spasms ▪ Leucoencephalomalacia ▲ Visual Disabilities <ul style="list-style-type: none"> ▪ Albinism | <ul style="list-style-type: none"> ▲ Chromosomal Abnormalities <ul style="list-style-type: none"> ▪ 18P Syndrome ▪ 2-P Syndrome ▪ Apert’s Syndrome ▪ Chondrodysplasia ▪ Crouzon’s Syndrome ▪ Ehlers-Danlos Syndrome ▪ Marden Walker Syndrome ▪ Osteogenesis Imperfecta ▪ Otopalatodigital Syndrome, Type II ▪ Prader Willi Syndrome ▪ Saethre-Chozen Syndrome ▪ Trisomy 2 with Mosaics ▪ Tuberous Sclerosis ▪ Turners Syndrome ▪ Williams Syndrome ▪ Wolf-Hirschorn Syndrome ▲ Brain or Spinal Cord Trauma <ul style="list-style-type: none"> ▪ Erb’s Palsy/Brachial Plexus Injury ▪ Left parietal infarct with small subdural hygroma |
|--|--|

2. Conditions reported as “other” that are most likely listed correctly and qualify the child as eligible under Part C.

- | | |
|--|--|
| ▲ Amniotic Band syndrome | ▲ Congenital myotonic dystrophy |
| ▲ Arthrogryposis | ▲ Muscular dystrophy |
| ▲ Caudal Regression Syndrome | ▲ Poland Syndactyly |
| ▲ Congenital amputee | ▲ Spinal muscular atrophy/ Werdnig-Hoffman |
| ▲ Congenital muscle fiber disproportion type | |

3. “Other” conditions which actually fit under developmental delay or atypical development categories

- ▲ Hypotonia -- atypical development
- ▲ Vocal Cord Paralysis -- speech/language development; atypical development

4. “Other” conditions which are considered risk factors rather than diagnosed conditions with a high probability of resulting in developmental delay -- The following would be listed under risk factors on the child data form and would not, by themselves, make a child automatically eligible for Part C services in the absence of developmental delay or atypical development. Please note that some of the following may be symptoms of a qualifying diagnosed condition.

- | | |
|--|---|
| ▲ Bronchopulmonary dysplasia (BPD) | ▲ Most tumors -- (e.g. cystic hygroma, lymphangioma, nephroblastoma, non-Hodgkins lymphoma) |
| ▲ Burns | ▲ Oculoauricular Vertebral Syndrome (may be eligible under congenital or acquired hearing loss if that is present) |
| ▲ Chronic eczematoid rash | ▲ One Lung |
| ▲ Chronic Lung Disease | ▲ Periventricular leukomalacia (PVL)/periventricular cysts |
| ▲ Congenital Diaphragmatic Hernia | ▲ Pseudo Obstruction Syndrome |
| ▲ Congenital Hip Dysplasia | ▲ Reflux Disorder/Gastroesophageal reflux |
| ▲ Diabetes Insipidus | ▲ Renal Disease, end stage |
| ▲ DiGeorge Syndrome | ▲ Scoliosis |
| ▲ Dwarfism/achondroplasia | ▲ Shaken Baby Syndrome (could be a diagnosed disabling condition if it has resulted in a visual disability or brain or spinal cord trauma with abnormal neurologic exam at discharge) |
| ▲ Eating difficulties | ▲ Short Gut Syndrome |
| ▲ Esophageal atresia | ▲ Subglottic Stenosis |
| ▲ Heart Defect/Cardiac Condition | ▲ Torticollis |
| ▲ Hirshprung’s Disease | ▲ Total anomalous pulmonary venous return |
| ▲ Hyperthyroidism | ▲ Tracheo-esophageal fistula |
| ▲ Hypoplastic Lungs | ▲ VACTERL Association (Vertebral, Anal, Cardiac, Tracheoesophageal fistula, Renal/Radical, Limb Association) |
| ▲ Hypoxia | |
| ▲ Infantile botulism | |
| ▲ IUGR (intrauterine growth retardation) | |
| ▲ Laryngomalacia | |
| ▲ Leukemia/Acute Lymphocytic Leukemia | |
| ▲ Liver Failure | |
| ▲ Macrocephaly | |
| ▲ Meconium Aspiration | |
| ▲ Meningitis | |

5. "Other" conditions, where it just depends...

- ⤴ Bihemispheric hematomas -- Could be a diagnosed disabling condition under Brain or Spinal Cord Trauma if there is abnormal neurologic exam at discharge or could be a risk factor under Brain/Spinal Cord Trauma if there is normal exam at discharge
- ⤴ Cranial Calcification -- this is generally a symptom of some other disease or trauma. Depending upon the cause, this could be listed as a diagnosed condition under brain/spinal cord trauma, symptomatic congenital infection, or other.
- ⤴ Midline cerebellar epidural hematoma -- same as above
- ⤴ Right Arm AVM (Arterial Veinous Malformation) with hypertrophy -- depends on the degree of hypertrophy

An excellent reference book regarding diagnoses, symptoms and outcomes (which may assist local teams in determining whether and how a medical condition fits within the diagnosed condition category) is available from W.B. Saunders Publishing: Smith's Recognizable Patterns of Human Malformation (5th edition, edited by Kenneth Jones, ISBN #0-7216-6115-7, the cost is about \$100).

Chapter 6: Assessment for Service Planning

Assessment for service planning includes several steps in the early intervention process. The required activities will occur through a combination of phone contact and/or a visit(s) with the family. The number of visits and phone calls needed to accomplish these activities will be individualized to meet each family's need for information, time to consider options and other family scheduling preferences. This step in the early intervention process includes the identification of the resources, priorities and concerns of the family through a family-directed family assessment. A multidisciplinary team reviews existing medical and developmental information and conducts observation and assessment of the eligible child to assist the IFSP team in identifying the early intervention supports and services necessary to meet the child's unique needs in all areas of development. An assessment tool(s) will be used at this point as an objective anchor for the comprehensive assessment of the child's functional skills in comparison to same age peers for determination of the child's entry status on the OSEP child indicators. Planning and preparation for the IFSP meeting begin and family cost share paperwork is completed.

Service Coordinator Responsibilities:

- When notifying the family that their child is eligible, share information about the process for child and family assessment and IFSP planning. Explain the family's role in these steps of the early intervention process, the other people who will be involved, and the service coordinator's role in coordinating the activities and supporting their active participation. Discuss the notice and consent requirements related to assessment for service planning and determine with the family whether they would like to proceed to assessment or would prefer more time to consider their options. This may be accomplished by phone contact(s) or a visit with the family, depending on the needs and preferences of the family.
- Provide a copy and explanation of the procedural safeguards forms associated with assessment for service planning:
 - Provide a copy and explanation of the *Notice and Consent for Assessment* form and the *Notice of Child and Family Safeguards in the Infant & Toddler Connection of Virginia Part C Early Intervention System* prior to conducting any assessment activities. The form and rights document may be mailed to the family after discussion by phone or may be handled during a visit with the family depending on family preferences. Depending on the child and family circumstances, this paperwork may have been completed during intake.
 - Individual families and participating family members must be informed before any formal or informal process to identify family resources, priorities and concerns begins, that participation in such family assessment activities is strictly voluntary on the part of the family, that the process shall be family directed, and that a family's decision not to participate in the assessment of the family's resources, priorities and concerns will not affect the child's eligibility for early intervention supports and services.
 - Ensure that copies and explanations of procedural safeguard forms are provided in the family's native language or other mode of communication unless clearly not feasible to do so.
 - Ensure the following occur if the family declines to proceed to assessment for service planning:

- Provide a copy and explanation of the *Declining Early Intervention Services* form and the *Notice of Child and Family Safeguards in the Infant & Toddler Connection of Virginia Part C Early Intervention System* related to declining services.
 1. Using the bottom half of the *Declining Early Intervention Services* form, the family is asked to mark the second line (that they understand that an IFSP can be developed for their child/family) and then to read and mark the last line indicating that they do not choose to have their child receive an IFSP. Explain to the family how they can contact the local Infant & Toddler Connection system in the future using the phone number provided at the bottom of the form if they have concerns about their child's development
 2. In explaining the *Notice of Child and Family Safeguards in the Infant & Toddler Connection of Virginia Part C Early Intervention System*, the service coordinator reviews and explains the complaint procedures.
- Explain how to access Part C services in the future. If the child is close to being age eligible for early childhood special education services through the local school division (under Part B), explain how to access Part B services through the local school system.
- Obtain parent consent to make referrals to other appropriate resources/services based on child and family needs and preferences.
- Obtain parent consent to communicate with the primary care physician and primary referral source, if not already provided.
- Ensure that copies and explanations of procedural safeguard forms are provided in the family's native language or other mode of communication unless clearly not feasible to do so.
- Support the family in assessing their resources, priorities and concerns. This includes identifying natural environments and gathering other family input for IFSP development.
 - The method of obtaining information from the family must be directed by the family, meaning that the family decides what information they want to share and how they want to share it. Methods may include, but are not limited to, a conversation, a checklist or other written options and address daily family routines and activities and the family's perceptions of their child's abilities and needs in the context of daily activities. No one method is recommended for all families.
 - Each family should be offered multiple and continuing opportunities to identify their own resources, priorities and concerns in those areas of family life that the family feels are relevant to their ability to enhance the child's development.
 - The information gathered from the family during intake to assist in determining eligibility may be re-visited or expanded upon as part of the family assessment.
- Coordinate the multidisciplinary assessment of the child for service planning. The assessment for service planning includes reviewing available pertinent records that relate to the child's current health status and medical history and conducting personal observation and assessment of the child in order to identify

the child's unique strengths and needs, including an identification of the child's level of functioning in each area of development (cognitive development; physical development, including vision and hearing; communication development; social or emotional development; and adaptive development) based on objective criteria, which must include informed clinical opinion. The assessment information is also used to determine entry ratings for the three child indicators (positive social relationships, acquiring and using knowledge and skills, and taking appropriate action to meet needs) for all eligible children new to early intervention who are 30 months or younger. The determination of entry ratings on the three indicators may occur at the assessment for service planning or the IFSP meeting if those two activities occur on different days (please see the last bullet under "The Initial IFSP Meeting" in Chapter 7 for instructions on determining entry ratings).

- Ensure that one of the following comprehensive assessment tools is used as the foundation of the child assessment: {Add list approved assessment tools}. Discipline-specific assessment tools may be used in addition to the comprehensive assessment, if needed for an individual child.
- Ensure two or more different disciplines are involved in the assessment for service planning. Please note that a physical therapist must have a physician referral (order) to conduct an assessment. It is possible that one or more disciplines were involved in assessment activities prior to or since referral that may be used for service planning. These assessors count towards the requirement for 2 disciplines to participate as long as there is a written report from that discipline.
- Participate in any assessment activities that occur after referral, supporting the family as an active participant in the assessment.
- Complete the following steps in those rare instances where the child was found eligible by the multidisciplinary team based on a review of available documentation (including results of any screenings completed, medical information, parent report, formal/informal observation and written assessment reports if available) but is no longer eligible based on the information gathered during the assessment for service planning:
 - Congratulate the family on the good news that their child's development now appears to be closer to or at age level or more typical than it first appeared.
 - Provide the parents with a copy and explanation of the *Parental Prior Notice* form (indicating "Your child is not eligible for Infant & Toddler Connection of Virginia") and the *Notice of Child and Family Safeguards in the Infant & Toddler Connection of Virginia Part C Early Intervention System*. On the *Parental Prior Notice* form, identify the information used to make the determination that the child is not eligible. In explaining the *Notice of Child and Family Safeguards*, review and explain the complaint procedures.
 - Obtain parent consent to make referrals to other appropriate resources/services based on child and family needs and preferences.
- Document any and all circumstances that result in required assessments not being completed within the required timelines.
- Review family cost share practices with the family. These should have been introduced during referral and intake. The service coordinator is also responsible

- for ensuring the Family Cost Share Agreement form is completed in accordance with the procedures specified in Chapter 11.
- Identify an ongoing service coordinator.
 - Work with the family to identify the composition of the IFSP team. Required team members include the following:
 - The parent(s) of the child;
 - Other family members, as requested by the parent, if feasible;
 - An advocate or person outside the family if requested by the parent;
 - The service coordinator who has been working with the family since referral and/or the ongoing service coordinator;
 - People involved in eligibility determination and/or assessments; and
 - As appropriate, individuals who may be providing supports and services to the child and family.
 - Determine with the family whether a foreign language translator or sign language interpreter will be needed for the IFSP meeting. If so, identify a translator or sign language interpreter in accordance with the following:
 - A professional foreign language translator is not required. An IFSP team member may be able to translate or there may be an extended family member, neighbor, clergyman, or other family friend who would be willing and able to translate (if the family agreed). The local Infant & Toddler Connection system may wish to collaborate with the local school system(s) in finding translators since Part B has the same requirements related to native language.
 - When sign language interpreters are needed during IFSP meetings in order to meet the requirement related to family's mode of communication, these interpreters must meet professional licensure requirements. To locate qualified sign language interpreters, contact the Virginia Department for the Deaf and Hard of Hearing (1-800-552-7917) or access their website, www.vddhh.org, for a directory of qualified interpreters. If a licensed sign language interpreter is not available in the area served by the local system, then document efforts to locate a licensed sign language interpreter and use a family member, family friend or other informal resource to provide the needed interpreting.
 - Plan and schedule the IFSP meeting.
 - Provide the family with a copy and explanation of the *Parental Prior Notice* form (with check marks by "Your child is eligible for Infant & Toddler Connection of Virginia" and "A meeting to develop the initial IFSP is needed"), *Confirmation of the Individualized Family Service Plan (IFSP) Schedule* form, and *Notice of Child and Family Safeguards in the Infant & Toddler Connection of Virginia Part C Early Intervention System*. Emphasize those safeguards applicable to IFSP development.
 - Schedule the IFSP meeting at a time convenient for team members with preference being given to times that are best for the family. While development of the IFSP is a separate step in the process, the IFSP meeting may occur on the same day as the assessment for service planning if that is the family's preference. Families may need time to review and consider the assessment information, do research or ask questions in understanding and preparing for the IFSP development process. Parents may want to talk with other family members or individuals who offer guidance and support to them before participating in the IFSP meeting. A decision to combine the assessment and IFSP

meeting activities on the same date must be made by a fully informed family and cannot be required by the local system.

Talking with Families About Conducting the Assessment for Service Planning and the IFSP Meeting on the Same Day:

Consider using the following language in explaining the advantages and disadvantages of completing the assessment for service planning and the IFSP meeting on the same day: “Some families prefer to move straight from the assessment for service planning into the IFSP meeting. This can mean fewer visits/meetings, getting started sooner on services and has the advantage that the assessment information is fresh in your mind. On the other hand, some families prefer to wait and hold the IFSP meeting on a different date. Combining it all on one day can be a lot ... it can take a couple of hours. Families may find it helpful to wait because they want time to review and consider the assessment information, do research or ask questions in understanding and preparing for the IFSP development process. You may want to talk with other family members or individuals who offer guidance and support to you before participating in the IFSP meeting. You should feel free to decide based on what you think is best for your family.”

- Arrange IFSP meetings in the setting and language that facilitates a family's ability to participate.
- Notify all participants in writing of the date, time and location for the IFSP meeting using the *Confirmation of Individualized Family Service Plan (IFSP) Schedule* form.
- Ensure that IFSP team members who are not able to meet at times convenient for the family are given other options for IFSP participation, such as telephone consultations or providing written information.
- Assist the family in preparing for the IFSP meeting by providing a blank copy of the statewide IFSP form and reviewing each section of the form, discussing the kind of information included and the role the family can play in providing that information. Encourage families to make notes of their input and questions in each section of the blank form and to bring that to the IFSP meeting as a reminder for the family during the meeting. The level of support that each family will want and need in preparing for the IFSP meeting will vary and preparation should be individualized for each family.
- Ensure the following occur if the family declines to proceed to IFSP development:
 - Ensure that the family's signature is obtained on the *Declining Early Intervention Services* form and that the family receives further explanation of sections of the *Notice of Child and Family Safeguards in the Infant & Toddler Connection of Virginia Part C Early Intervention System* related to declining services.

1. Using the bottom half of the *Declining Early Intervention Services* form, the family is asked to mark the second line (that they understand that an IFSP can be developed for their child/family) and then to read and mark the last line indicating that they do not choose to have their child receive an IFSP.
2. Explain to the family how they can contact the local Infant & Toddler Connection system in the future using the phone number provided at the bottom of the form if they have concerns about their child's development.
3. In explaining the Notice of Child and Family Safeguards, review and explain the complaint procedures.
 - If the child is close to being age eligible for early childhood special education services through the local school division (under Part B), explain how to access Part B services through the local school system.
 - Obtain parent consent to make referrals to other appropriate resources/services based on child and family needs and preferences.
 - Obtain parent consent to communicate with the primary care physician and primary referral source, if not already provided.
 - Ensure that copies and explanations of procedural safeguard forms are provided in the family's native language or other mode of communication unless clearly not feasible to do so.

Responsibilities of Other Providers:

- Focus on gathering information through the assessment that is important for the IFSP team to use in service planning (e.g., functional skills, developmental strengths, areas of concern). The providers conducting the assessment are not recommending specific services, only providing information (e.g. functional skills the child has, areas of concern, skills not observed, etc.) for the IFSP team to use in identifying desired outcomes and the necessary supports and services.
- Review any assessment information less than six (6) months old to determine if they are appropriate for consideration in service planning in order to prevent children and families from undergoing unnecessary assessment and duplication of already existing assessment information. However, given the rapid changes in growth and development in infancy, it is important that all information used in service planning accurately reflects a child's current status.
- Check in with the family during the assessment to determine whether the skills and behaviors observed are representative of what the family sees at other times and in other places or situations.
- Limit the use of jargon and acronyms and explain words or concepts that may be unfamiliar to the family.

ITOTS Data Entry – Assessment: [Link to ITOTS Manual]

No further data can be entered into ITOTS until the IFSP is signed or the child is discharged (e.g., lost to contact or family declines to proceed).

Local Monitoring and Supervision Associated with Assessment for Service Planning

The local system manager provides the supervision and monitoring necessary to ensure the following:

- Appropriate use and explanation of procedural safeguards forms
- Assessment for service planning occurs in a timely manner so that the initial IFSP meeting can be held within the 45-day timeline. Any circumstances that result in a delay in the assessment for service planning are fully documented in the child's record.
- Assessment documentation is sufficient to support child indicator rating decisions.