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Chapter 5: Eligibility Determination

Eligibility determination is the process by which a multidisciplinary team reviews medical reports, results from a developmental screening tool, 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. Assessments are conducted as part of the eligibility determination process only if a child's eligibility is uncertain based on existing information, and those assessments then become part of the information used by the multidisciplinary team to determine eligibility.

Infant & Toddler Connection of Virginia 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, based on medical or other records (using the practices described in Chapter 4) or through the practices described in this chapter, that the child meets one or more of the following criteria:

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

2. 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):
 - a. Atypical or questionable sensory-motor responses (listed in ITOTS as “Abnormal or questionable sensory-motor responses”), such as:
 - Abnormal muscle tone;
 - Limitations in joint range of motion;
 - Abnormal reflex or postural reactions;
 - Poor quality of movement patterns or quality of skill performance;

- Oral-motor skills dysfunction, including feeding difficulties.
 - b. Atypical or questionable social-emotional development (Listed in ITOTS as “Identified Affective Disorders”), such as:
 - Delay or abnormality in achieving expected emotional milestones;
 - Persistent failure to initiate or respond to most social interactions;
 - Fearfulness or other distress that does not respond to comforting by caregivers.
 - c. 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”).
 - d. Impairment in social interaction and communication skills along with restricted and repetitive behaviors.
3. 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:
- a. seizures with significant encephalopathy;
 - b. significant central nervous system anomaly;
 - c. severe Grade 3 intraventricular hemorrhage with hydrocephalus or Grade 4 intraventricular hemorrhage;
 - d. symptomatic congenital infection;
 - e. effects of toxic exposure including fetal alcohol syndrome, drug withdrawal and exposure to chronic maternal use of anticonvulsants, antineoplastics, and anticoagulants;
 - f. meningomyelocele;
 - g. congenital or acquired hearing loss;
 - h. visual disabilities;
 - i. chromosomal abnormalities, including Down syndrome;
 - j. brain or spinal cord trauma, with abnormal neurologic exam at discharge;
 - k. inborn errors of metabolism;
 - l. microcephaly;
 - m. severe attachment disorders;
 - n. failure to thrive;
 - o. autism spectrum disorder;
 - p. endocrine disorders with a high probability of resulting in developmental delay;
 - q. hemoglobinopathies with a high probability of resulting in developmental delay;
 - r. cleft lip or palate;
 - s. periventricular leukomalacia;
 - t. neonatal factors that make developmental delay highly probable:
 - Gestational age \leq 28 weeks, or
 - NICU stay \geq 28 days; or
 - u. other physical or mental conditions at the multidisciplinary team members' discretion.

Children may not receive services on or after their third birthday.

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

Planning and Preparation for Eligibility Determination

Service Coordinator Responsibilities:

1. Use the procedures described in Chapter 4 if eligibility can be established by medical or other records. Otherwise, follow the procedures described below to determine eligibility.
2. Assemble documentation that will be used in eligibility determination, including results from a developmental screening tool, medical information, parent report, formal/informal observation and written assessment reports if available.
3. Facilitate identification of the multidisciplinary team that will determine eligibility and coordinate scheduling of the eligibility determination meeting, if needed.
 - a. The multidisciplinary team must be comprised of the service coordinator and one or more professionals representing at least 2 different disciplines (other than service coordination). There is no requirement that the disciplines on the team match the areas of concern for the child. When considering the use of one professional who is qualified in more than one discipline (other than service coordination) to serve as the multidisciplinary “team” for eligibility determination, consider the following:
 - The individual’s experience and skills in evaluating a child’s level of functioning across all developmental domains, including his or her ability to identify atypical development in all developmental areas;
 - The amount of existing information available to use in eligibility determination and whether eligibility seems to be pretty clear or more borderline; and
 - Whether it is an initial determination of eligibility or an annual confirmation of the child’s continuing eligibility and whether this impacts the individual’s level of confidence in a making an eligibility determination decision without input from an additional team member(s).
 - b. 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 Professional). In that situation, the service coordinator may participate on the multidisciplinary team in the dual function as one discipline and as the service coordinator
 - c. Eligibility determination team members may communicate through a face-to-face meeting, phone call, email, fax, video conference, or other electronic means. Face-to-face meetings may take place in office settings, in a family’s home or in other locations as determined by the team. Although eligibility determination does not require a face-to-face meeting, it must be planned ahead of time to allow team members adequate opportunity to review available information.
 - d. 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:

1. Eligibility determination must include determining the child's level of functioning in each area of development. This does not mean that a specific age level must be identified in each area.
2. 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 early intervention process the family was with the sending local system.
3. If a child was previously enrolled in the Infant & Toddler Connection system but has been out of services for 6 months or longer or is currently enrolled but has been lost to contact for 6 months or more, then the local system must conduct a new eligibility determination and assessment for service planning, establish new entry ratings on the child indicators (if the child is still 30 months old or younger), and establish a new IFSP before resuming services. If a child has been out of services for less than 6 months, then it is only necessary to conduct a new eligibility determination if there is an indication of a significant change in the child's developmental status.
4. 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 a developmental screening tool may be used to collect developmental information. The results from that tool, along with medical records, 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.
5. The annual IFSP meeting includes confirmation of ongoing eligibility. The process for conducting the annual eligibility determination varies, as follows:
 - a. If the child was initially found eligible based on a diagnosed condition, then at the annual IFSP the service coordinator will complete the Eligibility Determination form indicating that eligibility was established by records.
 - b. If contact notes are enough to establish the child's ongoing eligibility, then one individual who is certified as an Early Intervention Professional may review those notes and complete the Eligibility Determination form indicating that eligibility was established by records. The individual determining eligibility based on the contact notes may be the same individual who wrote the contact notes as long as that person is an Early Intervention Professional.
 - c. If neither of the above conditions is met, then the determination of ongoing eligibility is made by two disciplines (either two individuals from different disciplines or one individual qualified in two different disciplines) and is based on the progress reports of team members and/or review of contact notes and other records. Formal testing is neither required nor recommended. The progress report may be written or may be a verbal

report based on contact notes. The child's eligibility status is then documented on the *Eligibility Determination Form*.

Further information on the annual determination of eligibility, including procedural safeguards requirements associated with this step, is provided in the "Annual IFSP" section of Chapter 8.

6. If, prior to the annual IFSP meeting, the family or another IFSP team member(s) believes the child has reached age level in all areas of development and shows no sign of atypical development (and does not have a diagnosed condition), then an IFSP review is held to determine ongoing eligibility. Eligibility determination can occur during the IFSP review meeting (as long as either eligibility can be determined based on contact notes by one Early Intervention Professional or one or more individuals representing two disciplines other than service coordinator participate in the IFSP review). Details on determining eligibility in this situation are provided in the "IFSP Reviews" section of Chapter 8.

Multidisciplinary Team Responsibilities:

1. Focus solely on whether or not the child meets Virginia's eligibility criteria. The assessment for service planning team will gather the information necessary to determine what supports and services an eligible child needs.
2. If the child has an endocrine disorder or hemoglobinopathy and eligibility was not established by records, review available documentation to determine whether that diagnosis has a high probability of resulting in developmental delay for this specific child since not all disorders within these categories have a high probability of resulting in developmental delay for all children.
3. Determine whether the child is eligible based on a developmental delay or atypical development as defined earlier in this chapter.
 - a. 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, also should 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.
 - Eligibility determination should not be delayed to wait for medical records unless other information gathered through intake or through intake plus assessment for eligibility is insufficient to determine and document the child's eligibility.
 - b. Consider the results from a developmental screening tool, parent report, formal/informal observation, and any available written assessment reports.
 - c. 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.
 - d. 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, results from a developmental screening tool, information from formal/informal observation, parent report, etc.) the multidisciplinary team ensures that the eligibility determination is based on more than one procedure.

4. If existing information is insufficient to determine the child's eligibility for early intervention services, then determine the appropriate provider(s) to carry out any assessment activities necessary for eligibility determination.
 - a. 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.
 - b. 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.
5. Complete the *Eligibility Determination Form*.
 - a. Complete the information at the top of the form: Date of Eligibility Determination, Child's Name, Date of Birth, Age, Adjusted Age, Parent's Name, and Service Coordinator's Name. When recording the date of eligibility determination, use the date that eligibility was determined, even if that occurred on the same date as the assessment for service planning (Medicaid will still reimburse for the assessment for service planning in this situation).
 - b. Mark whether this is an initial, annual, or interim eligibility determination.
 - c. Mark whether the child was determined eligible or not eligible
 - d. If the child is eligible, check off all criteria on which that eligibility was based (e.g., developmental delay and/or atypical development and/or diagnosed condition). If the child has a diagnosed condition(s), mark the specific condition(s) in the next section of the form. Note: The *Eligibility Determination Form* should reflect only those reasons for eligibility identified as of the date of eligibility determination. Additional reasons for eligibility may be discovered during the assessment for service planning, and these will be documented elsewhere, not on this form.
 - e. Use the Methods and Documents section of the form to check off all of the methods and documents that were used and reviewed in making the eligibility determination. If a comprehensive developmental screening tool was used, identify the tool used and the person who completed it.
 - f. Complete the Eligibility Narrative. The information provided in this section should be detailed enough that someone who was not a member of the team could read the form and understand why the child was found eligible/not eligible. The Eligibility Narrative section will automatically expand onto the next page when the form is completed electronically. When completing the form by hand, it may be necessary to continue on the back of the page or on an attached page.
 - g. Identify the members of the eligibility determination team and their method of participation. Typed names or electronic signatures are permitted in lieu of handwritten signatures. Use the appropriate check box to indicate each provider's discipline.
 - h. Although age levels or ranges are not required in order to determine eligibility, these may be recorded on the *Eligibility Determination Form*, in contact notes, and/or on screening or assessment instruments that are maintained in the child's record if age levels or ranges were identified for some or all areas of development.

Service Coordinator Responsibilities:

1. Participate in the determination of eligibility by sharing information from the family and from any screening tool used 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 other electronic means, or in writing.
2. Share results of the eligibility determination process with the family, including a copy of the completed *Eligibility Determination Form* (at no cost to the family). 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). Facilitate an opportunity for the family to talk with the eligibility determination team if the family has questions about the eligibility finding and if desired by the family.
3. 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. Remind the family that the eligibility determination team's job was to determine whether there was any delay, atypical development or diagnosed condition that would make their child eligible. Explain that the assessment for service planning will help to identify whether there are any other areas of concern beyond those identified during eligibility determination, as well as highlighting their child's areas of strength and interest and their child's functioning in the areas of positive social-emotional skills and social relationships, acquiring and using new knowledge and skills, and getting his or her needs met.
4. If the child is eligible but the parents decline to proceed, then
 - a. Provide a copy and explanation of the *Declining Early Intervention Services* form and the *Notice of Child and Family Rights and Safeguards Including Facts About Family Cost Share*.
 - 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 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.
 - In explaining the *Notice of Child and Family Rights and Safeguards Including Facts About Family Cost Share*, review and explain the complaint procedures. Even if the family has already received a copy of the Notice of Child and Family Rights and Safeguards document, another copy must be offered. If the family has previously received a copy of the rights document and states that they do not want another copy, it is not necessary to leave another copy. A contact note must be used to document that another copy of the document was offered and that the family declined.
 - b. 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.
 - c. Obtain parent consent to make referrals to other appropriate resources/services based on child and family needs and preferences.

- d. 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."

- e. Document in ITOTS, within 10 business days of the family declining services, that eligibility determination was completed and that either the child was eligible/declined services or eligible/chose other services. Enter the exit date (the date the family declined to proceed).
5. If the child is ineligible:
- a. 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 Rights and Safeguards Including Facts About Family Cost Share*. 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 Rights and Safeguards*, the service coordinator reviews and explains the complaint procedures. Even if the family has already received a copy of the *Notice of Child and Family Rights and Safeguards* document, another copy must be offered. If the family has previously received a copy of the rights document and states that they do not want another copy, it is not necessary to leave another copy. A contact note must be used to document that another copy of the document was offered and that the family declined.
 - b. For Medicaid/FAMIS recipients only: Complete and provide the family with the *Early Intervention Services – Notice of Action* letter and explain to the family their right to appeal under Medicaid if they disagree with the multidisciplinary team's determination that their child is not eligible for early intervention services. Point out where additional information about the appeal process is located in the *Notice of Child and Family Rights and Safeguards Including Facts About Family Cost Share*.
 - c. 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.
 - d. Obtain parent consent to make referrals to other appropriate resources/services based on child and family needs and preferences.
 - e. Document in ITOTS, within 10 business days of completing eligibility determination, that eligibility determination was completed and that the child is not EI eligible. Enter the exit date (the date the child was found ineligible).

6. 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.
7. Document in the child's early intervention record any and all circumstances that result in a delay in eligibility determination.

Interim IFSP

General:

1. 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. When an interim IFSP is needed, its purpose is to document those services that are needed immediately, as well as the parent's consent for those services to begin.
2. 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.
3. 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:

1. Ensure that either the child is found eligible based on medical or other records or the eligibility determination process is completed and the child found eligible prior to development of an interim IFSP.
2. 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:
 - a. The name of the service coordinator who is responsible for implementation of the interim IFSP and coordination with other agencies and persons;
 - b. The early intervention supports and services that are needed immediately by the child and the child's family. Specify the frequency, length, intensity (individual or group), location, method, and potential payment source(s) for each service; and
 - c. Signatures of both the service coordinator and the parent(s).There is no requirement to use pages or sections from the statewide IFSP form in developing an interim IFSP.
3. Facilitate the timely start of services identified on the interim IFSP. Although the services must begin within 30 calendar days of the date the family signs the interim IFSP, because services on an interim IFSP have been identified based on an immediate need these services should begin right away and certainly in much fewer than 30 days.
4. 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, the local system manager ensures that the following data is entered into ITOTS within 10 business days of the eligibility determination:

1. Eligibility determination completed? Yes or No
 - a. If no, reason not completed
 - b. If yes, date of eligibility determination
2. EI Eligible? Yes or No
3. Result of eligibility determination. This data element must be completed after the IFSP meeting is held unless the child exits the Infant & Toddler Connection system prior to the IFSP meeting.
4. Exit Date if eligibility determination is not completed, child is lost to contact, child is ineligible, or result of eligibility is something other than "Eligible will receive services." The Exit Date is the date the family declined to proceed, the date the child was found ineligible, etc.

[Complete ITOTS instructions are available at

<http://www.infantva.org/documents/forms/INST1117eR.pdf>]

Local Monitoring and Supervision Associated with Eligibility Determination

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

1. There is timely request for and follow-up to receive existing records for use in eligibility determination.

2. Assessment is carried out for eligibility determination only if the multidisciplinary team finds that existing information is insufficient to determine eligibility.
3. Determination of eligibility occurs quickly enough after referral to allow time for assessment for service planning and IFSP development to occur within the 45-day timeline.
4. Eligibility determination is completed by a multidisciplinary team representing at least 2 different disciplines and the service coordinator.
5. Providers participating in eligibility determination have a complete and accurate understanding of Virginia's eligibility criteria.
6. The *Eligibility Determination Form* is accurately completed and reflects the necessary information to support the decision of the individuals determining eligibility (i.e., all sections of the form are completed, including the signatures/names of team members, and the narrative is detailed enough that someone who was not a member of the team could read the form and understand why the child was found eligible/not eligible).
7. There is timely and accurate entry of ITOTS data.

Interpretation of Eligibility Criteria for the Infant & Toddler Connection of Virginia

The following information is designed to provide interpretation of the criteria used in determining eligibility for the Infant & Toddler Connection of Virginia.

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%.

Atypical or questionable sensory-motor responses (listed in ITOTS as “Abnormal or questionable sensory-motor responses”), such as abnormal muscle tone; limitations in joint range of motion; abnormal reflex or postural reactions; poor quality of movement patterns or quality of skill performance; atypical articulation*; or oral-motor skills dysfunction, including feeding difficulties.

Atypical or questionable social-emotional development (Listed in ITOTS as “Identified Affective Disorders”), such as delay or abnormality in achieving expected emotional milestones; persistent failure to initiate or respond to most social interactions; or 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

* A note about articulation issues: A review of journal articles indicates that articulation issues may be considered atypical development or a delay in language development. Therefore, using either category of eligibility is acceptable. The eligibility determination team should use their informed clinical opinion to determine whether a child’s articulation issues fall into atypical development or developmental delay. If the child is determined eligible due to atypical development, then articulation falls into the sensory-motor category.

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: Any degree of hearing loss (unilateral, bilateral, mild, moderate, severe) makes the child eligible. 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/βTh);
- 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, 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).

Periventricular Leukomalacia

Gestational Age ≤ 28 weeks

NICU Stay ≥ 28 days

Cleft lip or palate

“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 early intervention 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 eligibility for early intervention services. 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:**
- ▲ Significant Central Nervous System Anomaly
 - 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
 - Krabbe’s Disease
 - ▲ Seizures/Significant Encephalopathy
 - Infantile Spasms
 - Leucoencephalomalacia
 - ▲ Visual Disabilities
 - Albinism
 - ▲ Chromosomal Abnormalities
 - 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-Chatzen Syndrome
 - Trisomy 2 with Mosaics
 - Tuberous Sclerosis
 - Turners Syndrome
 - Williams Syndrome
 - Wolf-Hirschorn Syndrome
 - ▲ Brain or Spinal Cord Trauma
 - 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 for early intervention services.

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

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 early intervention 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)
- ▲ Burns
- ▲ Chronic eczematoid rash
- ▲ Chronic Lung Disease
- ▲ Congenital Diaphragmatic Hernia
- ▲ Congenital Hip Dysplasia
- ▲ Diabetes Insipidus
- ▲ DiGeorge Syndrome
- ▲ Dwarfism/achondroplasia
- ▲ Eating difficulties
- ▲ Esophageal atresia
- ▲ Heart Defect/Cardiac Condition
- ▲ Hirshprung’s Disease
- ▲ Hyperthyroidism
- ▲ Hypoplastic Lungs
- ▲ Hypoxia
- ▲ Infantile botulism
- ▲ IUGR (intrauterine growth retardation)
- ▲ Laryngomalacia
- ▲ Leukemia/Acute Lymphocytic Leukemia
- ▲ Liver Failure
- ▲ Macrocephaly
- ▲ Meconium Aspiration
- ▲ Meningitis
- ▲ Most tumors -- (e.g. cystic hygroma, lymphangioma, nephroblastoma, non-Hodgkins lymphoma)
- ▲ Oculoauricular Vertebral Syndrome (may be eligible under congenital or acquired hearing loss if that is present)
- ▲ One Lung
- ▲ Pseudo Obstruction Syndrome
- ▲ Reflux Disorder/Gastroesophageal reflux
- ▲ Renal Disease, end stage
- ▲ Scoliosis
- ▲ 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)
- ▲ Short Gut Syndrome
- ▲ Subglottic Stenosis
- ▲ Torticollis
- ▲ Total anomalous pulmonary venus return
- ▲ Tracheo-esophageal fistula
- ▲ VACETRL Association (Vertebral, Anal, Cardiac, Tracheoesophageal fistula, Renal/Radical, Limb Association)

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).

Newborn Screen & Development: Facts about Genetic Diseases

(Developed in 2006 by Alexandra Iwashyna, Medical Intern)

Effective March 2006, the Virginia Newborn Screening Services program, through the Virginia Department of Health, was expanded to include testing for 28 heritable disorders and genetic diseases. Infants under 6 months of age who are born in Virginia will be screened for the following disorders and diseases, which are identified through newborn dried blood-spot screening tests. Any infant whose parent or guardian objects on the grounds that the tests conflict with his religious practices or tenets will not be required to receive the newborn dried blood-spot screening tests. All of these disorders and conditions are considered diagnosed conditions with a high probability of resulting in developmental delay. Therefore, these infants will be eligible for early intervention services in Virginia.

1) Argininosuccinic acidemia (ASA)

- a) Incidence: ~1 in 70,000
- b) Deficiency in an enzyme of the urea cycle leading to hyperammonemia
- c) May appear normal at birth
- d) Without treatment: symptoms of lethargy, vomiting, poor appetite, seizures, hypotonia and muscle weakness, breathing problems, coma and death
- e) Treatment: low protein diet and a special medical formula
- f) With early treatment (before symptoms occur): may develop normally, however, more often children have some mental retardation despite treatment
- g) Autosomal recessive

2) Beta-Ketothiolase deficiency (β KT)

- a) Unknown incidence
- b) Deficiency mitochondrial acetoacetyl-CoA thiolase leading to build up in isoleucine
- c) May appear normal at birth (symptoms occur 6-24 mo)
- d) Without treatment: vomiting, dehydration, trouble breathing, extreme tiredness, occasionally convulsions, and can sometimes lead to coma or mental retardation
- e) NOTE: some with BKT never have symptoms
- f) Treatment: L-Carnitine & possibly low protein diet
- g) With early treatment (before symptoms): probable normal growth and intelligence, however, even with treatment, some children still have symptoms (metabolic crises) which can cause brain damage leading to learning disabilities, mental retardation or other problems (although after age 10 symptoms/crises are rare)
- h) Autosomal recessive

3) Carnitine uptake defect (CUD)

- a) Unknown incidence
- b) Deficiency of carnitine uptake leads to in the tissues impaired ability to use fats to produce energy and ketone bodies.
- c) Without treatment: cardiomyopathy, muscle weakness, hypotonia and with repeat episodes brain damage leading to learning disabilities and mental retardation, heart failure, death.

- d) NOTE: some children never have symptoms
- e) Treatment: supplementation with carnitine & frequent feedings
- f) Treatment before symptoms or early: typical growth and development
- g) Treatment with continuing symptoms: repeat metabolic episodes can cause neurological damage over time leading to learning disabilities and mental retardation
- h) Autosomal recessive

4) Citrullinemia (CIT)

- a) Incidence: ~1 in 57,000
- b) Deficiency in an enzyme of the urea cycle leading to hyperammonemia
- c) Without treatment: symptoms of lethargy, vomiting, poor appetite, seizures, hypotonia and muscle weakness, breathing problems, cerebral edema, coma and death
- d) Treatment: Dietary restriction of protein & oral dosage of sodium phenylbutyrate and arginine
- e) With early treatment (before symptoms occur): may develop normally, however, some children may have some neurological impairment despite treatment
- f) Possibility of brain damage leading to learning disabilities and mental retardation correlates to severity of initial presentation and amount of recurrent episodes
- g) Recurrent episodes often occur with illnesses (e.g., common cold)
- h) Autosomal recessive

5) Glutaric acidemia type I (GA I)

- a) Incidence: ~1 in 30,000/40,000
- b) Deficiency in Glutaryl-coenzyme A dehydrogenase leading to excessive levels of amino acids and their intermediate breakdown products
- c) Without treatment: brain damage (particularly the basal ganglia which are helps control movement) leading to hypotonia, spasticity, involuntary movement disorder, delays in motor skills, speech problems and mental retardation
- d) Treatment: Prompt treatment of catabolic events and prevention of fasting during illnesses; diet modifications
- e) With treatment (even early treatment): up to 35% will have neurological insult and disability
- f) Autosomal recessive

6) Isovaleric Acidemia

- a) Incidence: ~1 in 100,000 live births
- b) Enzyme deficiency in isovaleryl-CoA dehydrogenase, involved in catabolism of Leu
- c) Without treatment: vomiting, lethargy, severe metabolic ketoacidosis progressing to coma and death (50% with the acute neonatal form will die during their first episode); some may have neurological damage though several make complete recoveries. The majority of patients are developmentally normal.
- d) Treatment: protein-restricted diet, special formula and carnitine supplementation
- e) With treatment: Most will have normal development (especially with early treatment)
- f) Autosomal recessive

7) Long chain hydroxyacyl-CoA dehydrogenase deficiency (LCHAD)

- a) Incidence: ~1 in 75,000 births

- b) Enzyme defect that prevents the body from breaking down fatty acids into an energy source
- c) Without treatment: lethargy, hypoglycemia, hypotonia, liver dysfunction, cardiomyopathy. Acute symptoms may be difficult to manage and resistant to therapeutic attempts (with high mortality) because the presentations may involve a lethal acute liver failure, a rapidly evolving cardiomyopathy, or hypoketotic hypoglycemic encephalopathy
- d) Treatment: avoid fasting, high carbohydrate and low fat diet supplemented with MCT oil
- e) With treatment: Normal development and learning abilities (if no damage from crises). Peripheral neuropathy, if present, may not improve and prevention of ophthalmological changes (pigmentary retinopathy*) may not occur with treatment.
- f) Autosomal recessive

8) Methylmalonic acidemia (mutase deficiency) (MUT)

- a) Incidence: ~1 in 50,000-100,000
- b) Deficiency of the adenosylcobalamin-dependent enzyme methylmalonyl-CoA mutase leading to an inability to process certain proteins and fats properly
- c) Without treatment: lethargy, failure to thrive, recurrent vomiting, profound metabolic acidosis, respiratory distress, hypotonia, and later on renal failure. Complications of these episodes can include metabolic stroke, extrapyramidal signs, dystonia and brain damage leading to neurological damage.
- d) NOTE: Disease varies from fatal neonatal disease to asymptomatic & age of onset of symptoms can help prognosticate – those with later onset tend to have a more benign course.
- e) Treatment: Protein-restricted diet and special formula diet, OH-Cbl injections, carnitine supplementation, may need other medications
- f) With treatment: most serious of the methylmalonic acidemias up to 60% of patients die within the first year of life and of those that survive, 40% are developmentally impaired
- g) Autosomal recessive

9) Methylmalonic acidemia (Cbl A,B)

- a) Incidence: ~1 in 50,000-100,000
- b) Defect in intracellular cobalamin metabolism leading to an inability to process certain proteins and fats properly
- c) Without treatment: Episodic ketoacidosis with vomiting, lethargy and coma which can lead to death. Survivors can have developmental delays, growth retardation, spastic quadriplegia, dystonia and seizures, neutropenia, thrombocytopenia and osteoporosis
- d) Treatment: Protein-restricted diet, OH-Cbl injections, Vitamin B12
- e) With treatment: Children who respond to vitamin B12 treatment tend to do very well as long as treatment is continued. Cb1A has a far better prognosis than Cb1B. Cb1B has ~33% of patients with neurologic impairment.
- f) Autosomal recessive

10) Multiple carboxylase deficiency (MCD)

- a) Incidence: ~1 in 87,000

* Loss of night vision and peripheral vision in varying degrees

- b) Defect in cellular biotin transport or metabolism leading to impaired activity of three enzymes that are dependent on the vitamin biotin: propionyl CoA carboxylase, beta-methylcrotonyl CoA carboxylase, and pyruvate carboxylase
- c) Mimics biotinidase deficiency

11) Propionic acidemia (PROP)

- a) Incidence: ~1 in 100,000
- b) Deficiency of propionyl CoA carboxylase leading to acidosis and hyperammonia
- c) Without treatment: tachypnea, vomiting, lethargy, irritability, shock, coma, and death. Death is very likely if symptomatic in infancy. Repeated episodes leading to mental retardation
- d) Treatment: Diet modifications with special formulas without specific amino acids that make propionyl CoA
- e) With treatment: If had symptoms before treatment (or difficulty maintaining treatment), high probability of brain damage leading to developmental delay. Also optic nerve atrophy may occur.
- f) Autosomal Recessive

12) Tyrosinemia type I (TYR I)

- a) Incidence: ~1 in 100,000
- b) Deficient enzyme in catabolism of tyrosine
- c) Without treatment: Symptom onset as early as 2-6 wks with FTT, chronic liver disease (liver disease can start prenatally)
- d) Treatment: special formula restricted in specific amino acids, the medication Orfadin, and typically liver transplant
- e) With treatment: Risks with liver transplant including infections or rejection
- f) Autosomal recessive

13) Trifunctional protein deficiency (TFP)

- a) Unknown incidence
- b) See LCHAD (mimics disease)
- c) Autosomal recessive

14) Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD)

- a) Unknown incidence
- b) Defect in very long-chain acyl-CoA dehydrogenase leading to problems breaking down fats to energy
- c) Without treatment: variable, from recurrent episodes of hypoglycemia to cardiomyopathy and liver problems and can progress to coma, cardiac arrest, brain damage, or even death (especially in children who are not eating well)
- d) Treatment: eating frequently and avoiding fasting, and sometimes medication (carnitine)
- e) With treatment: not much data but it looks like resolution of cardiomyopathy and normal development and learning abilities especially for later-onset disease
- f) Autosomal Recessive

15) 3-hydroxy 3-methyl glutaric aciduria (HMG)

- a) Unknown incidence
- b) A defect in HMG lyase leading to problems breaking down an amino acid (leucine)

- c) Without treatment: vomiting, dehydration, extreme tiredness, seizures, hypoglycemia, metabolic acidosis, and coma
- d) Treatment: a special diet (low leucine), including medical foods and formula, possible medications (carnitine)
- e) With treatment: good chance to have typical growth and development. However, even with treatment, some children still have repeated bouts of hypoglycemia or metabolic crises which may cause brain damage leading to learning problems or mental retardation
- f) Autosomal recessive

16) 3-Methylcrotonyl-CoA carboxylase deficiency (3MCC)

- a) Rare
- b) A deficiency in 3-methylcrotonyl CoA carboxylase (3MCC) is leading to problems breaking down an amino acid (leucine)
- c) Without treatment: vomiting, dehydration, extreme tiredness, seizures, hypoglycemia, metabolic acidosis, and coma
- d) Treatment: a special diet (low leucine), including medical foods and formula, possible medications (carnitine)
- e) With treatment: good chance to have typical growth and development. However, even with treatment, some children still have repeated bouts of metabolic crisis which may cause brain damage leading to learning problems or mental retardation
- f) Autosomal recessive