

Virginia Best Practice Protocol for Hospitals Referring to Early Intervention

Introduction

Virginia regulations require timely and appropriate screenings and referrals for children who are suspected of having a developmental delay or are at risk for a developmental disability. In Virginia, the Early Intervention (EI) program is administered by the Infant and Toddler Connection of Virginia (I&TC). The Virginia Hospital Research and Education Foundation (VHREF) has been awarded funding from the Virginia Board for People with Disabilities to convene participating hospitals in a learning collaborative entitled, *The Virginia Neonatal Intensive Care Unit Early Intervention Collaborative* (the Collaborative). Within this body of work, VHREF has partnered with 33 Virginia hospital Neonatal Intensive Care Units (NICUs) and the I&TC to enhance linkages between Virginia hospitals and local Early Intervention lead agencies, with the goal of improving the quantity and quality of referrals to Early Intervention for at-risk children.

Newborns and infants admitted to NICUs may need support services after their hospital stay. Early Intervention supports families of infants and toddlers, age birth to three years, with developmental delays and disabilities. Children learn best with people they know and in the places they spend most of their time. Early Intervention professionals help families build on the things they do every day to support their child's learning and development in order to reach their goals for their child.

This Best Practice Protocol serves as a model referral protocol by providing a review of Virginia laws and regulations, and a recommended referral practice for implementation by all Virginia hospitals. The purpose of the protocol is to a) provide guidance and clarification regarding procedures to be followed by hospital staff as primary referral sources to Early Intervention Local Lead Agencies, b) to promote timely and appropriate referrals of children to Early Intervention, and c) establish coordination of care among care partners in the referral and intake process. It is intended to help hospital staff navigate the system while partnering with families to ensure that all children are appropriately screened and referred to services. Hospital staff are encouraged to partner with families and the Early Intervention Local Lead Agencies within their community to enhance care coordination for former hospital patients.

How to use this Best Practice Protocol

This protocol has been divided into four content sections:

[Who makes referrals to Early Intervention and by when?](#)

[What tools should be used in the referral process?](#)

[How can providers partner with parents and families?](#)

[What training is recommended?](#)

Each section includes applicable Virginia laws and regulations, as well as summarized best practice recommendations. Regulations as set forth by Virginia Administrative Code (V.A.C.) can be accessed [here](#) (Title 12. Health. Agency 35. Department of Behavioral Health and Developmental Services. Chapter 225. Requirements for Virginia Early Intervention System). Virginia statutes regarding the Early Intervention System can be found [here](#) (Code of Virginia. Title 2.2. Administration of Government. Chapter 53. Early Intervention Services System).

Acknowledgments

VHREF has partnered with several agencies to coordinate this work on behalf of Virginia's NICU patients. We would like to acknowledge the following organizations for their financial and resource support:

The Virginia Board for People with Disabilities (VBPD)
Virginia NICU EI Collaborative participating hospitals
The Virginia NICU EI Collaborative Advisory Council
The Infant and Toddler Connection of Virginia
The Arc of Virginia's New Path
Kelly Walsh-Hill, PT, VA NICU EI Collaborative Consultant

About the Funder: VBPD serves as Virginia's Developmental Disabilities (DD) Council. DD Councils are in every state and territory of the United States. They work for the benefit of individuals with DD and their families to identify needs and help develop policies, programs and services that will meet these needs in a manner that respects dignity and independence. Seventy-five percent of the funding for this project was provided by the Virginia Board for People with Disabilities under the federal Developmental Disabilities and Bill of Rights Act. For more information on VBPD, please call (800) 846-4464, email info@vbpd.virginia.gov, visit VBPD's website at www.vaboard.org, or send mail to the Washington Office Building at 1100 Bank Street, 7th Floor, Richmond, VA 23219.

Who makes referrals to Early Intervention and by when?

REFERRAL BEST PRACTICE RECOMMENDATIONS:

- **ESTABLISH A HOSPITAL-WIDE PROCESS FOR MAKING A REFERRAL**
- **USE THE REFERRAL GUIDANCE FORM (SEE ATTACHMENT A)**
- **BEGIN DISCUSSING EARLY INTERVENTION WITH FAMILIES AS SOON AS AN INFANT IS IDENTIFIED AS NEEDING A REFERRAL, WITH CONTINUED DISCUSSIONS DURING THE DISCHARGE PROCESS**
- **IDENTIFY WHICH HOSPITAL STAFF ARE RESPONSIBLE FOR MAKING A REFERRAL**
- **DESIGNATE A KEY STAFF MEMBER (CHAMPION) TO OVERSEE REFERRAL COORDINATION, PARTNERSHIP WITH EARLY INTERVENTION LOCAL SYSTEM MANAGER, AND PROVIDE FOLLOW UP WHEN NECESSARY**
- **PROVIDE INFORMATION TO THE PATIENT'S PRIMARY CARE PHYSICIAN WHEN POSSIBLE**

Virginia Law

Virginia regulation defines primary referral sources as those agencies, providers, entities, and persons who refer children and their families to the Early Intervention system and includes hospitals, prenatal and postnatal care facilities; physicians; parents; public health facilities; other public health or social service agencies; and other clinics and health care providers, among others (12 V.A.C. 35-225-20).

The Infant & Toddler Connection requires primary referral sources to complete timely screening and referrals for children within two categories:

- Infants and toddlers suspected of having a developmental delay in one or more areas;
- Infants and toddlers suspected of having a disability

Virginia regulation requires primary referral sources to refer infants or toddlers potentially eligible for Early Intervention services as soon as possible, but in *no case more than seven days after the child has been identified as potentially eligible* (12 V.A.C. 35-225-50(B)).

State regulation requires the local Early Intervention agency to follow up on a referral within 45 days of receiving the referral, with the first day counted as the day on which the referral was received (12 V.A.C. 35-225-80(C)). Once a referral is made, the Early Intervention Service Coordinator will begin a record for the child, and assist the family with intake, eligibility determination, and if eligible, assessment for service planning and development of an Individualized Family Service Plan (IFSP).

Parental consent is not required to make a referral to the local Early Intervention system. The local system accepts a referral even if the referral source has not informed the family of the referral (12 V.A.C. 35-225-50(F)). When making a referral, the referral source shall provide, at minimum, the child's or a family member's name and one method of contacting the family (12 V.A.C. 35-225-50(H)). If a family verbally declines the referral, the referral should not be sent. The family should be provided the contact information for the Early Intervention Agency where they reside as a resource.

A referral from a primary referral source does not automatically qualify an infant or toddler for services unless the primary referral source submits documentation in the medical record that (a) identifies the child

as having a diagnosis with a high probability of having a delay or disability, or (b) identifies the child as having a delay in one or more developmental areas (12 V.A.C. 35-225-80(A)). If medical record documentation is not available or does not support the criteria stated above, then, with parent consent, the referral initiates the request for a multidisciplinary assessment, performed by the local Early Intervention service providers, who then determine eligibility for services for the child.

"Multidisciplinary" means the involvement of two or more separate disciplines or professions (12 V.A.C. 35-225-20).

As primary referral sources, hospital providers, including personnel caring for patients in the NICU, are required to refer children suspected of having or at risk of a developmental delay or disability to the local Early Intervention system (12 V.A.C. 35-225-50(B)).

Recommended Best Practices:

Children admitted to NICUs may be more likely to meet eligibility requirements than other infants. Each Virginia hospital unit has a unique staffing structure. As a best practice, each hospital should identify which care team members will serve as referral sources on behalf of the hospital. It is *not recommended* that hospitals designate one staff member as the sole referral source on behalf of the hospital, nor should this be confined to only one care discipline, such as Physical Therapy, Occupational Therapy, or Speech Therapy. Limiting the primary referral source to one person or one profession may lead the hospital to overlook a child that would otherwise need a referral. Therefore, it is recommended that the hospital design a referral procedure, whereby any member of the patient's multidisciplinary care team can and should make a referral.

Referrals may be based on developmental screening results, diagnostic procedures, direct observation, and clinical assessment of a child's developmental progress, or identification of factors placing the child at risk for a developmental delay or disability. The [Infant & Toddler Connection of Virginia Early Intervention Referral Guidance and Form](#) (also known as the Referral Guidance Form, provided in Attachment A) provides a list of common admission diagnoses and congenital or acquired diagnoses that are associated with developmental delays and/or disabilities. The full listing of other eligible conditions can be accessed in the [Infant & Toddler Connection Practice Manual](#).

Hospital staff completing referrals should communicate early and often with parents and families regarding findings that may make an infant eligible for Early Intervention. As soon as a screening test or diagnosis indicates that a child may need a referral, hospital staff should begin working with the parents to explain Early Intervention, its benefits to the child and family, and next steps in referring the child. The referring staff should discuss Early Intervention again with the families during the discharge process. By having continual conversations with the family, a continuum of care is established that engages the family at the time their baby is admitted to the NICU, increases their participation and knowledge during their baby's hospital stay, and prepares them for the transition to Early Intervention after discharge. If hospital staff wait until the discharge process to discuss early intervention for the first time, families may be too overwhelmed to fully process or utilize the information.

In addition to the multidisciplinary care team completing referrals, each hospital should designate a staff member to oversee the process and follow up on referrals. This referral champion should not be the sole party making referrals on behalf of the hospital, but instead should oversee the process, follow up on individual cases as needed, and collaborate with local Early Intervention Service Coordinators. The

champion should serve as the liaison between the patient's family, primary care provider, hospital provider, and Early Intervention Service Coordinator. The champion should serve as the expert on the referral procedure, communicating with the family, and training hospital staff on the benefits of Early Intervention. In many hospitals, this champion is a Case Manager or Care Coordinator. During the referral process, the champion should coordinate referral data, including necessary discharge summaries, completed Referral Guidance Form, and initial and discharge therapy assessments (physical therapy, occupational therapy, hearing and speech). The champion should work with hospital staff to ensure that the family has been informed of Early Intervention as early as possible and coordinate communication to prepare the family for discharge and post-discharge. The champion should obtain parental signature on the Referral Guidance Form when possible.

Parental signature allows the Early Intervention Service Coordinator to contact the referring party in follow up to a referral, in the event that the parent or family member cannot be reached or in other circumstances where the Early Intervention Service Coordinator would want or need to communicate directly with the referral source. The absence of the signature does not mean the child is not referred. It means that the Early Intervention system cannot share information regarding the status of the referral with the pediatrician or primary health care provider, nor with the referral source. When the signature is included, if the Service Coordinator has difficulty contacting the parent, the signature allows the Service Coordinator to work with the referral source to reestablish contact with the family. If a parent declines the initial referral, hospital staff should provide parents with contact information to the Early Intervention Local Lead Agency as a resource should they have concerns in the future.

What tools should be used in the referral process?

BEST PRACTICE TOOLS AND RESOURCES

- **INCLUDE ALL REQUIRED INFORMATION WHEN COMPLETING A REFERRAL**
- **USE THE INFANT & TODDLER CONNECTION REFERRAL GUIDANCE AND FORM (SEE ATTACHMENT A), AND ATTACH PATIENT DISCHARGE SUMMARY, THERAPY ASSESSMENTS, AND SIGNED CONSENT TO RELEASE PROTECTED HEALTH INFORMATION**
- **PARTNER WITH THE PARENT IN COMPLETING THE REFERRAL, OBTAINING PARENT SIGNATURE WHEN POSSIBLE**
- **ACCESS THE INFANT & TODDLER CONNECTION CENTRAL POINT OF ENTRY LISTING (SEE ATTACHMENT B), AND CREATE AN EASILY ACCESSIBLE FILE CONTAINING CONTACT INFORMATION FOR THE EARLY INTERVENTION LOCAL LEAD AGENCY SERVING PATIENTS IN YOUR COMMUNITY**
- **CREATE A PROCESS FOR TRACKING THE NUMBER AND TYPE OF REFERRALS COMPLETED PER UNIT, USING GUIDANCE IN THE ENCYCLOPEDIA OF MEASURES (SEE ATTACHMENT C)**

Virginia Law

When making a referral, the referral source shall provide, at minimum, the child's or a family member's name and one method of contacting the family (12 V.A.C. 35-225-50(H)).

Requested Documentation:

Providing comprehensive information when completing a referral will ensure the Early Intervention coordinator can begin working with the infant and family as soon as possible. Although only a child or parent name and one method of contact is required, the Infant & Toddler Connection of Virginia Practice Manual (see [Chapter 3](#)) suggests the following information be included for a referral:

- Child's name, gender, and date of birth
- Name, address, and telephone number of the parent or legal guardian
- Reason for referral (child has suspected or confirmed developmental delay or disability)
- Health and physical information, including vision and hearing, results of any neurological or developmental evaluations and any other information pertinent to the child's physical and developmental status and needs
- The referring parties' name and telephone number

Referrals to the local single point of entry may be made by phone, fax, mail, email, web-based system, in writing, or in person.

Recommended Best Practices:

The Collaborative, in partnership with Virginia hospital and Early Intervention local system representatives, developed revised standardized referral forms to be used once a child is identified as needing a referral for services. The [Infant & Toddler Connection of Virginia Early Intervention Referral Guidance and Form](#) (also known as the Referral Guidance Form, provided in Attachment A) provides instructions for healthcare workers to complete a referral for an identified child. In checklist format, the form clearly identifies

conditions which require a referral for Early Intervention services and establish automatic eligibility. The Referral Form contains links to the specific listing of local [Early Intervention points of entry](#) in Virginia, which are also provided in Attachment B, as well as a link to the [I&TC website](#).

To ensure the Early Intervention system receives comprehensive referral information, hospitals should use the newly developed Referral Guidance Form. However, use of the Collaborative-developed Referral Guidance Form is not required to make a referral.

Hospitals should include discharge summaries, completed Referral Guidance Form, Therapy Assessments, and signed consent to release protected health information when submitting a referral to the local Lead Agency. Though not required, including alternate contact information for the parent/guardian, and providing the name of the child's primary care physician can help Early Intervention Service Coordinators establish a connection with the family after discharge and ensure a smooth transition.

The Referral Guidance Form and assessment documentation serve several purposes:

1. Increase staff awareness for which patients may need a referral;
2. Begin the conversation with the family about Early Intervention services prior to discharge and help inform them about the next steps involving the transition from hospital to Early Intervention;
3. Provide more complete information to Early Intervention. This enhances their understanding of the child's starting place by including discharge summary, NICU therapy assessments, etc.;
4. The parent's signature provides evidence that a conversation about Early Intervention has begun.

In Virginia, referrals can be made by contacting the I&TC's "[central point of entry](#)" (see Attachment B) for the locality in which the child resides, by calling the state toll free number: 1-800-234-1448, or by clicking on "Central Directory" at www.infantva.org. Primary referral sources may make the referral for the family, as well as provide specific contact information to the family.

Data collection is an essential component to improving the quality and increasing the quantity of referrals to Early Intervention. Collecting referral data enables hospitals to determine if they have referred all potentially eligible children and provides evidence that the practices they've implemented have resulted in an improvement. The Collaborative developed an Encyclopedia of Measures (provided herein as Attachment C), whereby data measures were created to better identify the number of referrals completed by each NICU, the number of children with diagnosed conditions that meet or are likely to meet eligibility criteria, and infants with diagnoses related to substance exposure. Prior to this work, many hospitals were not tracking the number of referrals.

For the reasons stated above, hospital units are encouraged to create a process for collecting referral data, using guidance in the Encyclopedia of Measures in Attachment C. Data collection should include which hospital unit completed the referral, who was the referring party, patient demographics including diagnoses/conditions which triggered the referral, and date of referral. Hospitals using the Referral Guidance Form will have all these data points on one page. Because many hospitals are completing referrals in an Electronic Medical Record, then faxing the referral, it is recommended that the referral champion retain a copy of the Referral Guidance Form for all referrals made during the month. A unit secretary and/or Referral Champion should review the number of referrals monthly and enter these data points into a simple data tracking spreadsheet. For hospitals participating in the Collaborative, this data will be requested each quarter until September 2020.

How can providers partner with parents and families?

FAMILY ENGAGEMENT BEST PRACTICE RECOMMENDATIONS:

- **ENGAGE THE FAMILY IN THE CHILD’S CARE AS EARLY AS POSSIBLE**
- **BE CLEAR, CONSISTENT, AND DIRECT WHEN COMMUNICATING WITH FAMILIES ABOUT DEVELOPMENTAL SCREENINGS AND FINDINGS**
- **USE THE REFERRAL GUIDANCE FORMS IN ATTACHMENT A AS A GUIDE IN COMMUNICATING WITH THE FAMILY**
- **DESCRIBE WHAT THE FAMILY CAN EXPECT BEFORE, DURING, AND AFTER A REFERRAL IS MADE, AND WHO WILL BE HELPING THEM AS PARTNERS IN CARE**
- **PROVIDE EASY TO UNDERSTAND BROCHURES AND WATCH THE “WHAT IS EARLY INTERVENTION IN VIRGINIA” VIDEO WITH THE FAMILY**
- **USE THE ON YOUR WAY TOOL IN ATTACHMENT D TO COACH PARENTS AND FAMILIES TO ENHANCE SKILL BUILDING**

Virginia Law

Parental consent is not required to make a referral to the system, and the Early Intervention system will accept a referral even if the referral source has not informed the family of the referral (12 V.A.C. 35-225-50(F)). Additionally, no child is denied services because of their inability to pay (12 V.A.C. 35-225-230(C)).

Recommended Best Practices

The Virginia NICU EI Collaborative team has developed several resources to support families and children during and after their hospital stay. Many of the resources, including a video explaining the benefits of Early Intervention, can be found on the [publicly-facing Collaborative website](#).

Communicating effectively with parents and families when screening for a developmental disability or delay helps to establish a partnership between medical providers and the child’s caregivers. Having a child admitted to the hospital can be an overwhelming experience for the parent and family. If a child has a condition that prompts a referral to Early Intervention, hospital staff should work closely with the family to ensure the best possible outcome for the child. When a child is admitted to the hospital, the family should be engaged as a partner to participate in the care and understanding of their child’s medical and developmental needs

Before a provider begins working with a family, review the I&TC’s “[Explaining Early Intervention](#)” handout in Attachment E. At a minimum, the provider should inform the family about the child’s condition or screening results that may make them eligible to receive additional support services after their hospital stay. The care provider should provide easy to understand brochures and information about Early Intervention in the family’s preferred language, while explaining the benefits of both identifying the child’s condition early and accessing Early Intervention services. Hospital staff should share the video explaining Early Intervention developed by the I&TC, available [here](#). All parents should be informed that their child can receive an eligibility determination and multidisciplinary evaluation at no cost to the family. If the child is found eligible for participation, the family will guide the development of the Individualized Family Service

Plan (IFSP) which identifies the services and supports needed to promote the child's development and supports the family in their daily activities and routines with the child.

Hospital staff should receive training on effective communication skills when working with families of children under their care. It is important to ensure that caregivers feel informed and empowered to partner in their child's care, both during the hospital stay and after they go home. The Collaborative has developed an [online training video](#) to help nurses and other hospital staff develop and enhance their skills as coaches and trainers to parents. The training is accessible by any hospital staff on the Collaborative website and should be viewed by all providers working with families.

During the referral process, the care provider should communicate with the family by using the Referral Guidance Form in Attachment A. This document can help inform the family about the condition or assessment findings that have prompted the referral. It allows the care provider to obtain the parent's signature for the referral, indicating that the parent has been engaged in the referral process and is aware of the referral. The Referral Guidance Form provides additional information on the [Arc of Virginia's New Path](#) program, the support network for families in Early Intervention in Virginia. New Path assists families to evolve into self-sufficient advocates for their loved ones. New Path builds on families' commitment to learning, connecting and advocacy, by providing support and resources.

To build partnerships with parents and families during their infant's stay in Virginia hospitals, the Collaborative has developed a simple teaching tool, designed for parents to learn skills from care providers during their child's hospital stay that they will continue to use when they go home. The [On Your Way](#) tool (see Attachment D), developed by Kelly Walsh-Hill, PT, with input from Collaborative participants, provides a guide for coaching parents while their child is still in the hospital using the developmental methods and strategies that will promote bonding and healing, and help include caregivers in their child's daily care. Early Intervention providers will continue to coach caregivers when they go home as the child's needs change. This establishes a continuum of care to support the family.

Hospital staff can continue to be involved in the child's post-discharge development by collaborating with the child's Early Intervention team before or after the child's follow-up clinic visits. Care providers should also develop and maintain relationships with Early Intervention Coordinators providing services to the child and family.

What happens if a parent objects to a referral?

Should the family verbally decline the referral to Early Intervention when discussed during the hospital admission, the referral should not be sent. Instead, the hospital provider should offer the name and telephone number of the Early Intervention Local Lead Agency servicing the locality where the family resides. The family should be informed that they can contact the Early Intervention program anytime up until their child's third birthday, should they have any developmental concerns in the future. A multidisciplinary assessment can be provided at no cost to families. The family should be encouraged to discuss their child's development with their primary care provider. If the family has not verbally declined the referral, the referral can be made, with or without a parent signature.

Communicating and partnering with the family early in the hospital admission promotes continued family engagement and a likelihood for parents to successfully transition to the Early Intervention system. Should the family object to an Early Intervention referral, the hospital staff should continue partnering with the

family using the *On Your Way* tool in Attachment D to continue parent and family engagement to enhance the child's potential outcome.

What training is recommended?

TRAINING BEST PRACTICE RECOMMENDATIONS

- **EACH HOSPITAL DEVELOP A SCREENING, REFERRAL, AND EARLY INTERVENTION NEW EMPLOYEE ORIENTATION PACKET**
- **DESIGNATE A HOSPITAL OR UNIT-SPECIFIC REFERRAL CHAMPION TO PROVIDE TRAINING**
- **COLLABORATE WITH LOCAL EARLY INTERVENTION LEAD AGENCIES TO COORDINATE ON-SITE EDUCATION FOR HOSPITAL STAFF**
- **ACCESS THE *SHIFTING OUR MINDSET* LEARNING MODULE TO ENHANCE STAFF COACHING SKILLS FOR CAREGIVERS**
- **REVIEW COLLABORATIVE CONTENT ON THE COLLABORATIVE WEBSITE**

Virginia Law

Virginia regulation requires the Department of Behavioral Health and Developmental Services to train primary referral sources with respect to the basic components of Early Intervention services available in Virginia (12 V.A.C. 35-225-520(A)).

Recommended Best Practices

Hospital staff should familiarize themselves with available educational content and resources provided by I&TC. Any and all staff that care for children under the age of three within Virginia's hospitals should receive training on appropriate screening, referral process, and Early Intervention services available to their patients and families. The Collaborative developed educational content designed for hospital nurses and therapists on how to coach families to care for their child during and after hospitalization. This education, entitled *Shifting Our Mindset – the Role of NICU Staff as Trainers and Coaches*, can be accessed free of charge on the [Collaborative website](#). Additionally, hospital staff should read this Best Practice Protocol as a reference document. A referral champion within the hospital should provide training to other care providers on the use of the Referral Guidance Form in Attachment A, including training on appropriate screenings and conditions which may qualify for a referral. Hospital staff should view training content during nursing orientation and onboarding, and annually thereafter.

Each hospital should develop and maintain a partnership with the local Early Intervention Lead Agency serving their patient communities. By meeting regularly, the two partners can work to enhance care coordination for patients and families. Hospitals have had success in inviting the local Early Intervention Intake Coordinator to attend discharge rounds once per week to gather information about infant needs and meet with parents prior to infant discharge. Some Virginia hospitals and local Early Intervention systems have partnered in providing regular on-site education to hospital staff on the benefits of Early Intervention, as taught by the Early Intervention Service Coordinator. This enhances the collaborative relationship between the providers, and ensures staff know how, when, and why they should refer a child to Early Intervention.

Individuals with questions about referral procedures or other aspects of Early Intervention should call the Infant and Toddler Connection of Virginia at 1-800-234-1448.

Appendix

Attachment A – Infant & Toddler Connection of Virginia Referral Guidance and Form

Attachment B – Infant & Toddler Connection of Virginia Referral Guide, *Making A Referral – Where?*

Attachment C – Virginia NICU EI Collaborative Encyclopedia of Measures

Attachment D – *On Your Way Skill Building Worksheets for Families and Caregivers*

Attachment E – I&TC Explaining Early Intervention Handout

**Attachment A – Infant & Toddler Connection of Virginia
Referral Guidance and Form**

Infant & Toddler Connection of Virginia Early Intervention Referral Guidance

Instructions: Use this checklist to determine if an infant has a condition or concern that puts that child at risk for developmental delays. This checklist below includes many but not all conditions or concerns that may make a child eligible for Virginia's Early Intervention (EI). Infants and toddlers with these conditions require close supervision and routine developmental screening.

If any member of the interdisciplinary care team identifies one or more of the conditions listed, complete this Guidance Form and at the time of discharge from the hospital, refer the child to the EI program using the EI Referral Form (page 2). Until time of discharge, use this information to share developmental concerns with the care team and parent/family. If this EI Referral Guidance form is completed while the child is in the hospital, include this form in the discharge summary forwarded to pediatrician for continuity of care.

Affix patient sticker here

Include both the Guidance Form (page 1) and Referral Form (page 2) in the Discharge Summary when completing the referral.

| Diagnoses Associated with Developmental Delays | |
|---|--|
| Admission Diagnosis | Congenital/Acquired Diagnosis |
| <input type="checkbox"/> Gestational age ≤ 28 weeks. All preterm infants are at risk for developmental delays, consider all diagnoses and conditions listed; <input type="checkbox"/> Intrauterine toxic exposure. (Including FAS, NAS, and exposure to chronic maternal use of illicit substances, anticonvulsants, antineoplastics, and anticoagulants. Type (if known): _____; <input type="checkbox"/> Hypoxic- Ischemic Encephalopathy <input type="checkbox"/> Chromosomal abnormalities, including Down syndrome; <input type="checkbox"/> Major congenital CNS malformation (Including meningocele and microcephaly) <input type="checkbox"/> Cleft lip or palate; For a listing of other eligible conditions, access the Infant & Toddler Connection Practice Manual . | <input type="checkbox"/> NICU stay of greater than or equal to 28 days; <input type="checkbox"/> Symptomatic congenital infection (including HSV, CMV, GBS meningitis); <input type="checkbox"/> Seizures with significant encephalopathy; <input type="checkbox"/> Grade 3 or Grade 4 intraventricular hemorrhage; <input type="checkbox"/> Periventricular leukomalacia; <input type="checkbox"/> Inborn errors of metabolism; <input type="checkbox"/> Congenital or acquired hearing loss; <input type="checkbox"/> Visual disabilities; <input type="checkbox"/> Brain or spinal cord trauma, with abnormal neurologic exam at discharge; <input type="checkbox"/> Failure to thrive; <input type="checkbox"/> Any medical diagnosis with a high probability of resulting in developmental delay; <input type="checkbox"/> Hemoglobinopathies with a high probability of resulting in developmental delay; |
| Other Conditions Impacting Development: Case by Case Assessment | |
| <input type="checkbox"/> Sensory-motor problems (such as abnormal muscle tone, limitations in joint range of motion, abnormal reflex or postural reactions, poor quality of movement patterns, atypical articulation, or oral-motor skills dysfunction, including feeding difficulties). <input type="checkbox"/> Social-emotional problems (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). <input type="checkbox"/> Speech/ language/communication delay <input type="checkbox"/> Other concern and/or diagnosis – specify _____ | |
| Referral Contact Name: _____ Date Completed: _____ Discussed with Parent/Family on (date): _____ | |

Infant & Toddler Connection Early Intervention Services Referral Form

Instructions and Form Guidance:

1. Referrals can be completed by any member of the patient care team.
2. Identify recipient of referral form:
 - a. The Infant & Toddler Connection of Virginia (ITCVA) provides Early Intervention (EI) services. Referrals to the ITCVA are made by contacting the early intervention central point of entry for the child's and family's locality. A list of Virginia counties and cities, and the corresponding point of entry, is provided [here](#). Referral information can also be obtained by calling the Virginia statewide central directory at (800) 234-1448 or by visiting www.infantva.org.
3. Fax this completed form and requested documents to:
 - a. Infant & Toddler Connection's local point of entry (as above).
 - b. Pediatrician, Follow-up Clinic or primary care physician identified at time of discharge.
4. Provide parents/families with resources:
 - a. Provide the ITCVA EI brochure and the link to *New Path, the Support Network for Families in Early Intervention*, www.new-path.thearcofva.org.

I am referring the child referenced below to the Infant & Toddler Connection of Virginia.

Affix patient sticker here

Hospital: _____

Referral Contact Name: _____

Phone #: _____ Email: _____

Date of Referral: _____

Child's Name: _____ Date of Birth: _____ Gender: __M__F

Family's primary language/mode of communication: _____ Interpreter needed? __Yes__ No

Parent/Guardian Name: _____

Relationship: __Mother__ Father__ Other (describe) _____

Primary Contact #: _____ Alternate Contact #: _____ Email: _____

Address: _____ City or County _____

ICD 10 Diagnosis Code (if available): _____

Name of Pediatrician or Primary Care Physician: _____ Phone # _____

- Include the following documents with this referral:
- ☐ Discharge Summary
 - ☐ Completed Early Intervention Referral Guidance Form
 - ☐ NICU Therapy Assessments (PT, OT, Hearing, Speech) – Initial & Discharge Evaluations
 - ☐ Signed consent to release protected health information*

**Hospitals are asked to seek input from legal counsel on amending their NICU consent form to reference Infant & Toddler Connection of Virginia Early Intervention OR alternatively, completing one of the ITCVA provided consent forms – [Physician Referral](#) or [Non-Physician Referral](#).*

For the purposes of continuity of care, I authorize the Infant & Toddler Connection of Virginia to send information regarding the status of the referral to my child's pediatrician, primary health care provider, and referral source.

Parent/Guardian Signature** _____ **Date:** _____

***Signature not required to complete the referral. Absence of signature means EI cannot share information/status of referral with referral source, pediatrician, and/or primary health care provider.*

**Attachment B – Infant & Toddler Connection of Virginia Referral
Guide, Making A Referral – Where?**

Making A Referral – Who & How?



**Infant & Toddler
Connection of Virginia**

A Program of the Department of
Behavioral Health and Developmental Services

The **Infant & Toddler Connection of Virginia** assists families with infants and toddlers birth to three with developmental delays and/or disabilities help their children learn and develop through everyday activities and routines so that they can participate fully in family and community activities. In order to take advantage of the services and supports available, families need to know about the system and how to access these resources! Please help to inform families of their options by becoming familiar with this guide.

Who is eligible for the Infant & Toddler Connection of Virginia?

- Infants and toddlers with 25% or greater delay in one or more developmental area(s): cognitive, adaptive, receptive or expressive language, social/emotional, fine motor, gross motor, vision, hearing development
- Infants and toddlers with atypical development – as demonstrated by atypical/questionable sensory-motor responses, social-emotional development, or behaviors, or an impairment in social interaction and communication skills along with restricted and repetitive behaviors
- Infants and toddlers with a diagnosed physical or mental condition that has a high probability of resulting in developmental delay – e.g., cerebral palsy, hearing or vision impairment, Down syndrome or other chromosomal abnormalities, central nervous system disorders, effects of toxic exposure, failure to thrive, etc.

What prompts a referral?

- You or the parent of an infant or toddler has concerns or suspicions about the child's development. Screening using a standardized developmental screening test (as recommended by the American Academy of Pediatrics) will help identify children who may be in need of early intervention services.

A diagnosed physical or mental condition is not required.

How are referrals made?

- Contact the Infant & Toddler Connection “central point of entry” for the city or county in which the family resides or call the state toll free number: 1-800-234-1448, or click on “Central Directory” at www.infantva.org. You may make the referral for the family, or provide contact information to the family.

Referrals should be made as soon as the concern is identified.

What information should be provided to the early intervention system when referring a child?

- Child's name, gender, and date of birth
- Name, address, and telephone number of the parent or legal guardian
- Reason for referral (child has suspected or confirmed developmental delay or disability)
- Health and physical information, including vision and hearing, results of any neurological or developmental evaluations and any other information pertinent to the child's physical and developmental status and needs
- Your name and telephone number

What should I discuss with the family?

- All children referred receive an eligibility determination, with parent consent. Eligibility determination plus any needed developmental screenings and assessments are provided at no cost to the family.
- The family is not obligated to accept services
- If the child is found eligible for participation in the system, the family will guide the development of an Individualized Family Service Plan (IFSP) that identifies the services and supports needed to promote the child's development and support the family in their daily activities and routines with their child
- No child or family is denied services and supports identified on the IFSP because of their inability to pay

What else can I do to support the family?

- Volunteer to provide input into the development of each family's IFSP and to monitor its implementation
- Develop and maintain relationships with those providing early intervention services to the child and family

The Arc of Virginia is a resource for family support. Please call: 1-888-604-2677

Making A Referral—Where?



**Infant & Toddler
Connection of Virginia**
A Program of the Department of
Behavioral Health and Developmental Services

Referrals to the **Infant & Toddler Connection of Virginia** are made by contacting the early intervention **central point of entry** for the child's and family's locality. A list of Virginia counties and cities, and the corresponding point of entry, is provided below. Referral information can also be obtained by calling the Virginia statewide central directory at (800) 234-1448 or by visiting www.infantva.org

11/2017

COUNTIES

| | | | |
|----|----------------|---------------|------------------|
| 13 | Accomack | 23 | Richmond |
| 05 | Albemarle | 33 | Roanoke |
| 02 | Allegheny | 34 | Rockbridge |
| 20 | Amelia | 18 | Rockingham |
| 06 | Amherst | 10 | Russell |
| 06 | Appomattox | 12 | Scott |
| 03 | Arlington | 35 | Shenandoah |
| 04 | Augusta | 24 | Smyth |
| 34 | Bath | 39 | Southampton |
| 06 | Bedford | 30 | Spotsylvania |
| 24 | Bland | 30 | Stafford |
| 33 | Botetourt | 09 | Surry |
| 36 | Brunswick | 09 | Sussex |
| 10 | Buchanan | 10 | Tazewell |
| 20 | Buckingham | 35 | Warren |
| 06 | Campbell | 21 | Washington |
| 30 | Caroline | 23 | Westmoreland |
| 24 | Carroll | 12 | Wise |
| 19 | Charles City | 24 | Wythe |
| 20 | Charlotte | 40 | York |
| 08 | Chesterfield | CITIES | |
| 35 | Clarke | 21 | Abingdon |
| 33 | Craig | 01 | Alexandria |
| 31 | Culpeper | 03 | Arlington |
| 20 | Cumberland | 06 | Bedford |
| 12 | Dickenson | 21 | Bristol |
| 09 | Dinwiddie | 34 | Buena Vista |
| 23 | Essex | 05 | Charlottesville |
| 14 | Fairfax | 07 | Chesapeake |
| 31 | Fauquier | 02 | Clifton Forge |
| 25 | Floyd | 23 | Colonial Beach |
| 05 | Fluvanna | 09 | Colonial Heights |
| 27 | Franklin | 02 | Covington |
| 35 | Frederick | 11 | Danville |
| 25 | Giles | 09 | Emporia |
| 23 | Gloucester | 14 | Fairfax |
| 15 | Goochland | 14 | Falls Church |
| 24 | Grayson | 04 | Fishersville |
| 05 | Greene | 39 | Franklin |
| 09 | Greensville | 24 | Galax |
| 36 | Halifax | 16 | Hampton |
| 17 | Hanover | 18 | Harrisonburg |
| 19 | Henrico | 09 | Hopewell |
| 27 | Henry | 34 | Lexington |
| 04 | Highland | 06 | Lynchburg |
| 39 | Isle of Wight | 29 | Manassas |
| 40 | James City | 29 | Manassas Park |
| 23 | King & Queen | 24 | Marion |
| 30 | King George | 27 | Martinsville |
| 23 | King William | 16 | Newport News |
| 23 | Lancaster | 26 | Norfolk |
| 12 | Lee | 12 | Norton |
| 22 | Loudoun | 09 | Petersburg |
| 05 | Louisa | 40 | Poquoson |
| 20 | Lunenburg | 28 | Portsmouth |
| 13 | Northhampton | 29 | Quantico |
| 23 | Northumberland | 25 | Radford |
| 20 | Nottoway | 32 | Richmond |
| 31 | Orange | 33 | Roanoke |
| 35 | Page | 33 | Salem |
| 27 | Patrick | 36 | South Boston |
| 11 | Pittsylvania | 36 | South Hill |
| 15 | Powhatan | 14 | Springfield |
| 20 | Prince Edward | 37 | Staunton |
| 09 | Prince George | 39 | Suffolk |
| 29 | Prince William | 38 | Virginia Beach |
| 25 | Pulaski | 37 | Waynesboro |
| 31 | Rappahannock | 23 | West Point |
| | | 40 | Williamsburg |
| | | 35 | Winchester |

Step 1 – Locate family's county or city.

Step 2 – Note number to left of county or city.

Step 3 – Match number to corresponding central point of entry below.

CENTRAL POINTS OF ENTRY

| Infant & Toddler Connection of: | Phone | Fax |
|---|--------------------------|----------------|
| 01 Alexandria | (703) 746-3387 | (703) 746-6939 |
| 02 Alleghany Highlands | (540) 863-1620 | (540) 863-1625 |
| 03 Arlington | (703) 228-1630 | (703) 228-1126 |
| 04 Augusta-Highland | (540) 245-5133 | (540) 245-5275 |
| 05 the Blue Ridge | (434) 970-1391 | (434) 972-1827 |
| 06 Central Virginia | (434) 947-2888 | (434) 947-2389 |
| 07 Chesapeake | (757) 547-8929 | (757) 547-3477 |
| 08 Chesterfield | (804) 768-7205 | (804) 272-2200 |
| 09 Crater District | (804) 862-8002 ext. 3160 | (804) 863-1695 |
| 10 Cumberland Mountain | (276) 964-6702 | (276) 964-0265 |
| 11 Danville - Pittsylvania | (434) 799-0456 | (434) 799-3100 |
| 12 DILENOWISCO | (276) 431-4370 | (276) 431-2863 |
| 13 Eastern Shore | (800) 568-9269 | (757) 490-2936 |
| 14 Fairfax - Falls Church | (703) 246-7121 | (703) 653-1385 |
| 15 Goochland - Powhatan | (804) 657-2010 | (804) 556-9165 |
| 16 Hampton - Newport News | (757) 726-4012 | (757) 726-4011 |
| 17 Hanover | (804) 723-2070 | (804) 723-2079 |
| 18 Harrisonburg - Rockingham | (540) 433-7144 | (540) 432-6989 |
| 19 Henrico - Charles City - New Kent | (804) 727-8372 | (804) 727-8666 |
| 20 Heartland | (434) 395-2967 | (434) 395-2969 |
| 21 Highlands | (276) 619-2406 | (276) 525-1530 |
| 22 Loudoun | (703) 777-0561 | (703) 737-8235 |
| 23 Middle Peninsula - Northern Neck | (804) 758-5250 | (804) 758-5183 |
| 24 Mount Rogers | (276) 223-3270 | (276) 223-3295 |
| 25 New River Valley | (540) 831-7529 | (540) 831-6908 |
| 26 Norfolk | (757) 441-1186 | (757) 441-5995 |
| 27 Piedmont | (276) 632-7128 | (276) 632-0127 |
| 28 Portsmouth | (757) 393-8321 | (757) 393-5299 |
| 29 Prince William, Manassas & Manassas Park | (703) 792-7879 | (703) 792-4954 |
| 30 Rappahannock Area | (540) 372-3561 | (540) 940-2286 |
| 31 Rappahannock Rapidan | (540) 829-7480 | (540) 829-7456 |
| 32 Richmond | (804) 855-2742 | (804) 343-7697 |
| 33 Roanoke Valley | (540) 204-9983 | (540) 857-7309 |
| 34 Rockbridge Area | (540) 462-6638 | (540) 462-6714 |
| 35 Shenandoah Valley | (540) 635-2452 | (540) 635-3558 |
| 36 Southside | (434) 570-1505 | (434) 374-3221 |
| 37 Staunton-Waynesboro | (540) 245-5133 | (540) 885-0871 |
| 38 Virginia Beach | (757) 385-4400 | (757) 496-6825 |
| 39 Western Tidewater | (757) 562-6806 | (757) 562-2992 |
| 40 Williamsburg * James City * York * Poquoson | (757) 566-8687 | (757) 566-8977 |

**Attachment C – Virginia NICU EI Collaborative
Encyclopedia of Measures**

Virginia NICU Early Intervention Collaborative

An initiative funded by the Virginia Board for People with Disabilities (VBPD)

Encyclopedia of Measures (EOM)

Program evaluation measures: Baseline and performance measure data request

Abbreviations:

DC Discharge

EI Early Intervention

IFSP Individual Family Services Plan

ITOTS Infant and Toddler Online Tracking System

NAS Neonatal Abstinence Syndrome

NICU Neonatal Intensive Care Unit

SEI Substance Exposed Infants

| <u>Measure #</u> | <u>VA NICU EI Measure Description</u> | <u>Numerator</u> | <u>Denominator</u> | <u>Baseline Period</u> | <u>Monitoring Period:</u> | <u>Sources (may vary by hospital)</u> | <u>Comments</u> |
|--------------------------------------|--|--------------------------------|---------------------|-------------------------------|---------------------------|---------------------------------------|---|
| NICU Data from Hospital Project Lead | | | | | | | |
| NICU A-2 | 2. Percent of NICU patients referred to EI | # NICU patients referred to EI | All NICU discharges | Preferred: Calendar Year 2016 | Quarterly | Hospital DC form, DC note | If your hospital does not collect this information, submit N/A for baseline. For monitoring period, develop process to collect this data. |

Virginia NICU Early Intervention Collaborative

An initiative funded by the Virginia Board for People with Disabilities (VBPD)

| <u>Measure #</u> | <u>VA NICU EI Measure Description</u> | <u>Numerator</u> | <u>Denominator</u> | <u>Baseline Period</u> | <u>Monitoring Period:</u> | <u>Sources (may vary by hospital)</u> | <u>Comments</u> |
|---|--|---|--|-------------------------------|---------------------------|--|---|
| NICU A-4 | 3. Percent of infants DCd from hospital with diagnosed condition(s) (using ICD 10 Codes) that meet or are highly likely to meet EI eligibility criteria. Refer to Infant & Toddler Connection of Virginia Practice Manual, Chapter 5 | # of preterm, newborn, and infants with diagnosed condition(s) (using ICD 10 Codes) that meet or are highly likely to meet EI eligibility criteria. This will be provided by the VHHA Analytics database. | All NICU and other infant hospital bed discharges aged Preterm, newborn, and infant. This will be provided by the VHHA Analytics database. | Preferred: Calendar Year 2016 | Quarterly | Hospital DC form VHHA Analytics | Refer to Infant & Toddler Connection of Virginia Practice Manual, Chapter 5 and Excel sheet for list of ICD10 codes used for this analysis. |
| NICU A-5 | 4. Percent of Substance Exposed Infants (SEI) referred to EI | # of infants with SEI diagnosis referred to EI | This data will be subset of NICU A-4 and as such, provided to hospital. | Preferred: Calendar Year 2016 | Quarterly | Hospital DC form | **See below Effects of Toxic Exposure ICD-10 codes. |
| Early Intervention data from the Infant & Toddler Online Tracking System (ITOTS) NOTE: The ITOTS referral source 'Hospital' here includes NICU, PICU, Pediatric, nursery... and other hospital units. | | | | | | | |
| EI A-1 | 1. Percent of hospital referrals to EI that EI case manager could not reach post hospital DC. | # of hospital referrals to EI that Case Manager was 'Unable to Contact' | # of hospital referrals to EI | Preferred: Calendar Year 2016 | Quarterly | ITOTS | |
| EI A-2 | 2. Percent of referrals to EI from hospital that EI case manager noted declined evaluation post hospital DC. | Number of referrals to EI from hospital that 'Declined Evaluation' | Number of referrals to EI from hospital. | Preferred: Calendar Year 2016 | Quarterly | ITOTS | |
| EI A-3 | 3. Percent of qualified preterm, newborns, infants and toddlers referred to EI from hospital and not receiving EI services. | # of preterm/newborn/infant and toddlers referred from hospital, determined eligible for | # of preterm/newborn/infant and toddlers referred from hospital, and determined eligible for EI services. | Preferred: Calendar Year 2016 | Quarterly | ITOTS | Completed EI assessment and then family did not want services |

Virginia NICU Early Intervention Collaborative

An initiative funded by the Virginia Board for People with Disabilities (VBPD)

| <u>Measure #</u> | <u>VA NICU EI Measure Description</u> | <u>Numerator</u> | <u>Denominator</u> | <u>Baseline Period</u> | <u>Monitoring Period:</u> | <u>Sources (may vary by hospital)</u> | <u>Comments</u> |
|------------------|--|--|-----------------------------|-------------------------------|---------------------------|---------------------------------------|--|
| | | EI and whose family declined services. | | | | | |
| EI A-4 | 4. List of reasons why family with infant/toddler eligible for EI services, does not receive these services. | Reasons why hospital families eligible for EI do not receive EI services | # EI referrals by hospital. | Preferred: Calendar Year 2016 | Quarterly | ITOTS | ITOTS does not identify referring hospital's name. |

**

| Part C Automatic Qualifiers for Services: Disabling Condition | ICD-9 Code | ICD-10 code | Description |
|--|------------|-------------|--|
| Effects of toxic exposure including fetal alcohol syndrome, drug withdrawal, exposure to chronic maternal use of anticonvulsants, antineoplastics and anticoagulants | | | |
| Drug withdrawal syndrome in newborn | 779.50 | P96.1 | Neonatal withdrawal symptoms from maternal use of drugs of addiction |
| Fetal hydantoin syndrome/Other | 760.79 | P04.8 | Newborn (suspected to be) affected by other maternal noxious substances |
| Narcotics exposure | 760.72 | P04.49 | Newborn (suspected to be) affected by other maternal use of other drugs of addiction |
| Hallucinogenic agent exposure | 760.73 | P04.49 | Newborn (suspected to be) affected by other maternal use of drugs of addiction |
| Cocaine exposure | 760.75 | P04.41 | Newborn (suspected to be) affected by other maternal use of cocaine |
| anticonvulsant exposure | 760.77 | P04.1 | Newborn (suspected to be) affected by other maternal medication |
| Other noxious influences affecting fetus or newborn via placenta or breast milk | 760.79 | P04.8 | Newborn (suspected to be) affected by other maternal noxious substances |
| Drug Withdrawl Syndrome | 799.50 | P96.1 | Neonatal withdrawl symptoms of maternal use of |
| | | P96.2 | Withdrawal symptom from therapeutic use of drugs of newborn |
| Fetal Alcohol Syndrome | 760.71 | Q86.0 | Fetal alcohol syndrome (dysmorphic) |
| | | P04.3 | Newborn (suspected to be) affected by maternal use of alcohol |

**Attachment D – On Your Way Skill Building Worksheets for
Families and Caregivers**



“On Your Way” - Skill Building Worksheets for Families and Caregivers

Dear Mom and Dad (or Caregiver),

Congratulations on the birth of your baby! We know that being in the NICU may be scary and overwhelming. We are a Team and want you to know that your presence here will help your baby! Hearing your voice, smelling you, and touching you will make your baby feel safe and secure. We will work together so you understand medical procedures, equipment, and developmental information and feel comfortable being involved in the decision making process. We value your participation in helping your baby grow healthy.

The NICU can be a stressful place for families and there are many things to remember each day. As you go through the learning process, please ask us questions. We don't expect you to “get it” the first time. The more you are able to practice the strategies and skills taught to you, the more comfortable you will feel in managing your baby's daily care. Our goal is to provide the coaching you need to become confident in caring for your baby to get you...On Your Way!

The following worksheets explain how your baby senses and manages stimulation in the NICU and how you can learn specific strategies to help protect your baby from stress; give your baby comfort; and support your baby's development. In each section, your NICU Team will coach you in the techniques and strategies and give you opportunities to practice. When you feel comfortable doing them on your own, you will sign off with someone from your Team.

When your baby is ready to go home we will discuss a referral to Early Intervention. Early Intervention is a community resource available after discharge that will continue to coach and support you in helping your baby develop.

YOUR NICU TEAM

75% of the funding for this project was provided by the Virginia Board for People with Disabilities under the Federal Developmental Disabilities and Bill of Rights Act. For more information on the Board, please contact: Virginia Board for People with Disabilities 1100 Bank St. 7th Floor Richmond, Va. 23219; 800-846-4464 or visit our website at www.vaboard.org

Primary Author: Kelly Walsh-Hill, PT, October, 2017

RECOGNIZING STRESS: Look at my face, hands, posture, and movement to understand how I am feeling (READING MY CUES). **This is how I look when I am:**

| Body Part | Feeling Calm and Relaxed | Feeling Stress |
|-----------|---|---|
| Face | Relaxed, calm | Frown or worry |
| Mouth | “O” shape, relaxed lips | Tight lips, clenched jaw |
| Hands | Gently fisted, close to chest/mouth | Clenched fists, splayed fingers, scratching face |
| Body | Arms & Legs bent towards the tummy/chest | Arched head/neck, arms & legs stretched out away from the body |
| Movement | Random, movement of arms/legs in and out | Jerky, shaky, or rigid movement of arms/legs away from the body |
| Eyes | Open or closed | Looking away, squinting |
| Actions | Sucking pacifier, sucking hands, quiet/calm stare, sleeping | Excessive yawns, sneezes, hiccups, high pitch cry, whimper |

CALM



Relaxed face and mouth with hands towards face and tummy



Arms and hands close to chest and face with relaxed eyes and mouth

STRESS



Frown, arching my head, with arm and leg moving away from body



Frown with both arms away from the body and fingers open (splayed)

CALM



Quiet, alert face



Sucking on hands with relaxed face

STRESS



Frown with eyes and lips tightly closed



Frown with high pitch cry

I/We are able to recognize our baby's cues to understand how he/she feels _____(initial/date)

Comments:

How to help me calm:

- giving me a finger to hold
- swaddling or containing me
- holding me and talking to me softly
- changing my position
- giving me a pacifier



In a nest, on my side, with gentle hands to contain me



Offering me a pacifier helps me soothe myself



Sleeping swaddled on my side



Holding me and talking to me softly while swaddled

I/We know how to calm our baby and help him/her relax _____(initial/date)

Comments:

SLEEP: I love it when you visit! But if I am sleeping when you arrive, please let me stay asleep.
When I'm sleeping:

- My brain is working hard to make new cells and new connections
- I can manage stress, relax, and focus on growing

How to help me rest:

- Turn the lights and sounds down
- Offer me a pacifier – sucking is calming for me and helps me self-soothe
- Help me feel contained – nesting or swaddling
- Make sure I am warm



Swaddled, warm and cozy on my back



Sleeping on my tummy sometimes helps me rest more comfortably

While I am in the NICU on a monitor and under 24 hour medical care, I can sleep in different positions like on my side or on my tummy. But when I go home I should always sleep on my back. My NICU Team will explain why SAFE SLEEP is important for me.

I/We know how to control the lights and sounds around my baby's bedside _____ (initial/date)

I/We know ways to calm and comfort my baby so he/she can sleep _____ (initial/date)

Comments:

TOUCH: Nothing feels better than touching and feeling you! It helps me bond with you, relax, and know you are there to take care of me! Touching me too lightly (tickle or stroking) may startle me or feel unpleasant. I like gentle pressure better.

How to touch me so it feels good:

- Grasp your finger in my palm
- Skin to Skin (Kangaroo care) where I lie against your chest and feel your heart beat and your warmth and smell! Daddy can do this with me too!
- Before you move or unswaddle me, give me gentle pressure on the top of my head and bottom together for 20-30 sec. so I don't startle and talk to me quietly. This is called **containment** and helps me get ready for our time together!
- Massage (instructed by someone Certified in Neonatal Massage)

I/We know how to provide gentle pressure containment _____(initial/date)

I/We know how to do Skin to Skin _____(initial/date)



Skin to skin on Mom's chest



Gentle pressure on my head and bottom helps me feel contained and safe



Holding my Mom's hand helps me feel connected to you



Learning how to massage me using gentle pressure on my back

Comments:

POSITIONING: If I am in one position for too long my skin, neck, shoulders, and hips hurt! My head will get flat because my skull is soft. If I stretch my arms and legs out, I'm not strong enough to pull them back in. When my arms and legs are close to my body, I am more **organized** and happy!

How to help me change position and rest comfortably:

- Keep my arms and legs tucked towards the middle of my body with my hands together on my chest
- Build a nest so I feel contained using rolled blankets, bendy bumpers, or other devices my NICU team can provide ***Devices used in the NICU are not designed for home use.
- Swaddle me in a blanket or swaddler to help me feel contained
- Turn me onto my tummy or side every few hours so I'm not always on my back!
- Turn me **SLOWLY**, keeping my arms and legs tucked in a cradled position, and support my head

I/We know how to build a nest so our baby is contained _____ (initial/date)

I/We know how to swaddle our baby with arms and legs towards the tummy and chest _____ (initial/date)

I/We know how to roll our baby over so he/she doesn't startle _____ (initial/date)



Nested with blanket rolls so my arms and legs are bent towards the middle of my body



Rolling me to my side, keeping my hands towards my chest and my neck straight



Arms and legs tucked towards the middle of my body with my hands on my chest

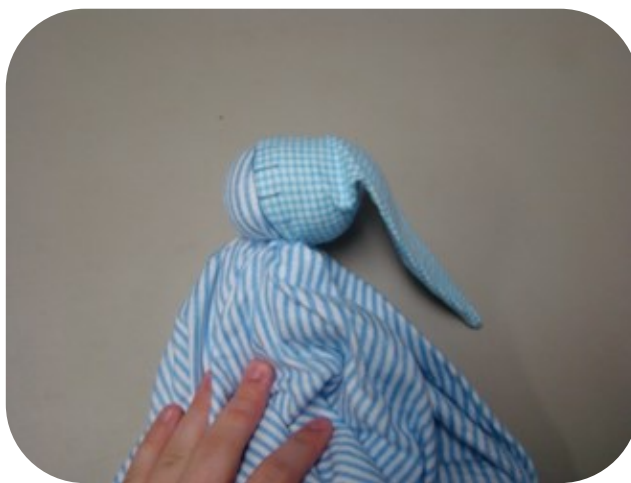


On my tummy in a swaddler helps me relax and sleep

Comments:

SMELL: I can smell everything pretty well! Smells like heavy perfume or smoke will bother me and make it hard for me to breathe or make me sneeze. If you put a piece of cloth with your skin scent on it in my bed, I will remember how good it felt to have you close by.

I/We know how to make a scent cloth for our baby_____ (initial/date)



Smell cloth to put in my crib

Comments:

LISTENING: I know the sound of your voice and it makes me feel better! I can hear you much better than I can see you. My hearing is very sensitive and loud, sudden noises and voices can startle and upset me or make it hard for me to sleep.

How to help me manage sounds:

- Talk, hum, or sing to me softly (you can make a recording of your voice for the Nurses to play when you aren't able to be there)
- Read me a story (live or recorded)
- Play me soft music (such as lullabies and classical music)
- Sometimes I like background sounds (called white noise) like a fan humming; rain falling; heart beating; motor running; ocean sounds, etc.
- Do not talk on your phone or speak loudly with others in the room if I am taking a nap.

I/We played music for our baby today _____ (initial/date)

I/We read our baby a story _____ (initial/date)



Musical pacifier



Reading me a story. Photo by Robert Boston

Comments:

LOOKING: My eyes don't see very well so trying to focus is hard work and tires me out! The lights in the NICU are very bright and I have to shut my eyes when they are on. As I get older I will learn to find you with my eyes by hearing your voice. When I try to focus, my eyes might cross or I might have to look away quickly. This is hard work.

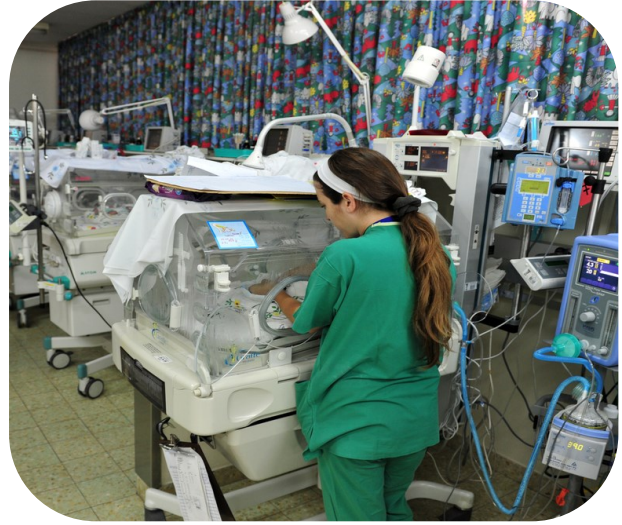
How to protect my eyes from the lights:

- Dimming the lights around my crib
- Covering my isolette with a blanket or specially designed isolette cover
- Shielding my eyes with your hand if you are holding me

I/We know how to manage the light around our baby's bedside _____ (initial/date)



Covering my isolette with a blanket protects my eyes from bright light



Dimming the lights and blanket covers help me rest

Comments:

Cluster Care: The Nurses take care of me by doing a bunch of tasks when I wake up. They will take my temperature and blood pressure; change my diaper; give me medicine; and change my position. This is called **Cluster Care**. If I can eat, this usually happens around a feeding time. Afterwards, I can rest for a longer period of time without being woken up. I like it when my Mom and Dad participate in my Cluster Care!

I/We know how to:

- Take our baby's temperature _____ (initial/date)
- Change our baby's diaper _____ (initial/date)
- Give our baby a bath _____ (initial/date)



Swaddled bathing helps me stay warm



Watching my Dad take my temperature



Changing my diaper



Comfort care is skin to skin time with my Dad

Comments:

Feeding: If I am too small or too young to eat, they will feed me using a tube going through my nose or mouth and down my throat (gavage feeding).

- Hold me and let me suck on a pacifier during my tube feedings so I can begin to bond with you and understand that sucking makes me feel full!



Pacifier sucking during a tube feeding

How do you know if I am hungry? When I am ready I will:

- Wake up and move my lips in a sucking motion
- Suck on my hands or pacifier
- Turn my mouth to the side to search for food (Rooting reflex)

When the Doctor says I can eat, I will need to go slow at first. It is a lot of work to coordinate sucking, swallowing and breathing all at the same time. I will need patience and practice!

I might need:

- A slower flow nipple
- A special bottle
- Fortified breast milk or donor milk
- A different type of formula
- A therapist to evaluate me and teach you special ways to help me coordinate my sucking and swallowing and pace myself so I don't tire out, choke or spit up.
- A Lactation Specialist to work with my Mommy on pumping so she can provide breastmilk, and possibly breastfeed.



Eating on left side with pillow support



Holding my hands towards my chest helps me coordinate suck, swallow and breathing



Learning to breastfeed may be something we can do when I get bigger



My NICU team will coach you on ways to help me eat. Photo by lehighvalleymagazine.com

I/We know how to feed and burp our baby using:

_____ nipple _____ bottle _____ formula/breast milk (initial/date)

I/We know how to help our baby eat more easily by: _____

_____ (initial/date)

Comments:

NEXT STEP..... ON YOUR WAY TO EARLY INTERVENTION!

What is Early Intervention? Early Intervention is a community-based program that provides services to infants and toddlers, birth to three years of age, who have developmental delays or disabilities. Some babies that have been in the NICU may need help learning the skills typically acquired in the first three years of life such as crawling, walking, communicating, playing, eating, and dressing. In Virginia, most programs are called the Infant-Toddler Connection, but they can also be called Parent-Infant Education (PIE) or Child Development Center (CDC). Early Intervention providers can be Physical Therapists, Occupational Therapists, Speech Therapists, Nurses, or Early Childhood Educators.

How do I get Early Intervention? Your NICU team will go over the Referral form with you and fax it to the local program where you live when your baby is discharged. Your baby may have a diagnosis that makes them automatically eligible. In other cases, an Early Intervention Team will evaluate your baby and talk with you to determine eligibility. You will be assigned a Service Coordinator to help you through the process below:



Where do I get Early Intervention? The Federal mandate for Part C of IDEA states that services will be provided in the baby's **natural environment**. Once your Plan is set up, the Provider will meet at your home, daycare, playground, or any place you and your baby spend time.

How much does it Cost? When your Doctor signs off on the Plan, the Early Intervention program will bill your Private Insurance or Medicaid for the billable services. You may have a co-pay if your Insurance Policy requires it. You will be assigned a monthly cap so, regardless of what your insurance pays, you will never be charged more than that amount. Based on the Federal mandate, children cannot be denied services based on a family's inability to pay.

Your Early Intervention Program is _____

Attachment E – I&TC Explaining Early Intervention Handout

Explaining Early Intervention

The Issue: Local system managers requested a short statement that could be used to concisely and consistently explain to families, physicians and others what early intervention is, what it looks like and why we do it the way we do. Local system managers, early intervention providers, families and physicians provided input during development of the statement.

The Statement: *Early Intervention supports families of infants and toddlers, ages birth to three years, with developmental delays and disabilities. Children learn best with people they know and in the places they spend most of their time. Early Intervention professionals help families build on the things they do every day to support their child's learning and development in order to reach their goals for their child.*

A Bonus: In addition to the statement, a video, "What Is Early Intervention in Virginia" (http://youtu.be/y-M_P6HrZdA), has been developed to help explain early intervention. The video includes wording from each sentence of the statement followed by additional comments, video and photos that further explain the concepts of what early intervention is, what it looks like and why it works. The statement and video have been posted on the VEIPD homepage (<http://www.veipd.org/main/index.html>) and "Early Intervention: What It Is and Why It Works" page (http://www.veipd.org/main/ei_what_why.html).

Ways to Use the Statement: Since a short statement can never fully explain early intervention, if used, the statement must be used in the context of other explanatory information and resources.

- With families ...
 - Incorporate the statement with the other talking points in Chapter 3 of the Practice Manual when sharing basic information after referral
 - Revisit the statement when covering the intake topics listed in Chapter 4 of the Practice Manual
 - Direct families to the *Strengthening Partnerships* booklet as a resource that further explains early intervention
 - Share the video with families who are newly referred to early intervention {add url}
 - Use the statement or parts of it when responding to questions that come to the single point of entry and direct the caller to the video for further information
 - Include the statement in local public awareness and informational materials
- With referral sources ...
 - Share the video, http://youtu.be/y-M_P6HrZdA, (for their own knowledge and to share with families, perhaps by running it on the waiting room television)
 - Include the statement and video url in a letter of introduction to a new physician
 - Use the statement in a verbal explanation of EI when delivering brochures to the referral source
- Other/General
 - Add the statement on the home page of the local system or program website. Include a link to the video.
 - Run the video during public awareness and child find events/activities