VIRGINIA NICU EARLY INTERVENTION COLLABORATIVE
AN INITIATIVE FUNDED BY THE VIRGINIA BOARD FOR PEOPLE WITH DISABILITIES (VBPD)

Wanda Clevenger BSN, RN, MBA
VHHA, Director of Performance Improvement

Catherine Hancock MS, RN, PMHCNS, BC
Early Intervention Administrator
Dept. of Behavioral Health and Developmental Services
HOUSEKEEPING

- Slides were sent this morning
- Webinar is being recorded
- Please use the “telephone” option
  - Audio pin prompt
- All participants are muted
- Raise your hand
- Ask a question
- Warm up

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YOUR NICU EI SUPPORT TEAM

Catherine Hancock  MS, RN, PMHCNS, BC
Early Intervention Administrator
Dept. of Behavioral Health and Developmental Services

Abraham Segres
Vice President
Quality and Patient Safety

Betsy Cole Archer , MS, ASCP
Director, Performance Improvement

Wanda Clevenger BSN, RN, MBA
Director, Performance Improvement

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VHHA & VHREF - WHO ARE WE?

- Virginia Hospital & Healthcare Association
- Virginia Hospital Research & Education Foundation
  - Non-profit foundation
  - Alliance of 107 hospitals and 30 health systems in Virginia
- The Center for Healthcare Excellence
  - Improve healthcare by assisting members to achieve top-tier performance in quality, safety, & service

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For the past 30 years, Congress has recognized and supported Early Intervention (EI) legislation as a means to ensure that all children with disabilities from birth through the age of three would receive appropriate early intervention services.

In Virginia, the Department of Behavioral Health and Developmental Services (DBHDS), is designated as the State Lead Agency.

There are 40 local lead agencies that manage EI services across Virginia.

El programs and services may occur in a variety of settings, with a heavy emphasis on natural environments.

These programs and/or services are proven to be most effective when started as soon as the delay or disability is identified.

https://www.youtube.com/watch?v=y-M_P6HrZdA
WHAT ARE THE INDICATORS FOR EI REFERRAL

A child and family may receive EI supports and services if the child is up to three years old AND:

- At least 25% below chronological or adjusted age, in one or more areas of development, OR
- Manifests atypical development or behavior, which is demonstrated by one or more specified criteria (even in the absence of a 25% developmental delay).
- 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.

- Has a diagnosed condition that will very likely cause a developmental delay. This includes:
  - Genetic disorders, such as Down syndrome, Cleft lip and/or palate
  - NICU stay of greater than or equal to 28 days
  - Autism Spectrum Disorder
  - Vision and/or hearing loss


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WHAT ARE WE TRYING TO ACCOMPLISH?

- The Virginia NICU EI Collaborative (the Collaborative) aims to achieve systems change of practice and improvement in outcomes for all infants and young children by engaging Virginia NICUs and their community partners in a statewide learning and improvement collaborative to enhance linkages to EI services for NICU patients and families.
  - Improve/expand NICU referrals and follow up
  - Enhance policies, practices & competencies
  - Develop training models

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PROGRAM OVERVIEW

- 18 month program – October 2016 – May 2018
- Involvement of NICU and EI staff, subject matter experts and patient and family members
- Who are we helping?
  - Infants and young children with disabilities in VA
  - Virginia NICU staff, including nurses, social workers, etc.
  - Community support/service agencies to coordinate care for children and families

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HOW WILL WE ACHIEVE OUR AIM?
MONITOR OUTCOMES & SPREAD SUCCESS

- Collaboratives allow participants to:
  - Mutual understanding of baseline
  - Spread evidence-based best practices
  - Shared learning via virtual events
  - Monitor outcomes through data
  - Establish connection to local and statewide resources
Facility commitment and onboarding
- 22 hospital NICUs enrolled
- Outreach continuing with input from EI for VA border regions

Partnership with Virginia Early Intervention Administrator
- Completed
- Governor McAuliffe’s Press Release, June 2016
- CHCE Advisory Council and VA Interagency Coordinating Council (VICC) Meeting, September 2016
- Hospital Coordinator’s attendance at Richmond, NoVa, Staunton, South Boston and Tidewater System Manager Regional Infant & Toddler Connection Meetings.

Promoting the Initiative (ongoing)
- Governor McAuliffe’s Press Release, June 2016
- CHCE Advisory Council and VA Interagency Coordinating Council (VICC) Meeting, September 2016
- Hospital Coordinator’s attendance at Richmond, NoVa, Staunton, South Boston and Tidewater System Manager Regional Infant & Toddler Connection Meetings.

Formed Advisory Council
- Members of Advisory Council on-board
- Ad hoc advisors to be included as needed
- Initial meeting via webinar/conference call scheduled for 2/14/2017.

Exploring Existing Patient and Family Advisory Councils
- Interviewing leaders of existing hospital NICU Patient and Family Advisory Councils
- Contacting lead for Arc of VA New Path Newsletter as mechanism to support family engagement and input on EI referral/access.

Performing Needs Assessment
- Determine components of data request: operational and performance outcome measures
- Collect baseline data
- Analyze results
- Share results and develop recommendations for change packet

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<table>
<thead>
<tr>
<th>VIRGINIA HOSPITAL NICU COMMITMENTS</th>
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<tbody>
<tr>
<td>Bon Secours Regional Memorial</td>
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<tr>
<td>Bon Secours St. Francis Medical Center</td>
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<tr>
<td>Bon Secours St. Mary's Hospital</td>
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<tr>
<td>Carilion Clinic – Carilion Children’s Hospital</td>
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<tr>
<td>Centra Virginia Baptist Hospital</td>
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<tr>
<td>Children’s Hospital of Richmond at VCU</td>
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<tr>
<td>Children’s Hospital of The King’s Daughters</td>
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<tr>
<td>Children’s National Medical Center, Washington DC</td>
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<tr>
<td>HCA Chippenham Hospital</td>
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<tr>
<td>HCA Henrico Doctors Hospital</td>
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<tr>
<td>HCA Johnston-Willis Hospital</td>
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<tr>
<td>Inova Alexandria Hospital</td>
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<tr>
<td>Inova Children’s Hospital</td>
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<td>Inova Fair Oaks Hospital</td>
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<tr>
<td>Inova Loudon Hospital</td>
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<tr>
<td>Mary Washington Hospital</td>
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<tr>
<td>Novant Health UVA Health System Prince William Medical Center</td>
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<tr>
<td>Riverside Regional</td>
</tr>
<tr>
<td>Sentara Princess Anne Hospital</td>
</tr>
<tr>
<td>University of Virginia Children’s Medical Center</td>
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<tr>
<td>Virginia Hospital Center</td>
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<tr>
<td>Winchester Medical Center</td>
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*Current as of 12/9/16*
HOSPITAL NICUs and EI REGIONS

1. Southwest
   - Carillon Clinic (Carillon Children’s Hospital)

2. Valley
   - University of Virginia Children’s Hospital

3. Northern Virginia
   - Children’s Hospital in Washington D.C.
   - Inova Alexandria Hospital
   - Inova Children’s Hospital
   - Inova Fair Oaks Hospital
   - Inova Loudoun Hospital
   - Mary Washington Hospital
   - Novant Prince William Medical Center
   - Winchester Medical Center
   - Virginia Hospital Center

4. Central
   - Centra Virginia Baptist Hospital

5. Richmond
   - Bon Secours Memorial Regional
   - Bon Secours St. Francis Medical Center
   - Bon Secours St. Mary’s Hospital
   - Children’s Hospital of Richmond at VCU
   - Chippenham Hospital
   - Henrico Doctors’ Hospital
   - Johnston-Willis Hospital

6. Tidewater
   - Children’s Hospital of the King’s Daughter’s
   - Riverside Regional
   - Sentara Princess Anne Hospital
### THE COLLABORATIVE’S ADVISORY COUNCIL

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Erin Close Austin, LCSW</td>
<td>Family Representative and EI System Manager</td>
</tr>
<tr>
<td>Jen Barnes-Maddox, M Ed</td>
<td>March of Dimes, NICU Family Support Coordinator</td>
</tr>
<tr>
<td>Gail Briceland,</td>
<td>EI System Manager</td>
</tr>
<tr>
<td>Wanda Clevenger, BSN, RN, MBA</td>
<td>Project’s Hospital Coordinator</td>
</tr>
<tr>
<td>Maria DeLalla RN BSN BA</td>
<td>Nurse Case Manager, Women &amp; Children’s Services, member of Shenandoah Valley Substance Abuse Coalition</td>
</tr>
<tr>
<td>Catherine Hancock, MS, RN, PMHCNS, BC</td>
<td>Early Intervention Administrator</td>
</tr>
<tr>
<td>Kathleen McCauley, Attorney</td>
<td>Family Representative</td>
</tr>
<tr>
<td>Dr. Alan Picarillo, MD, FAAP</td>
<td>Medical Director, NICU Experience with NICU EI Collaborative in MA</td>
</tr>
<tr>
<td>Sharlene Stowers,</td>
<td>Director, EI Services System Manager</td>
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<tr>
<td>Subject matter experts and Ad Hoc Members as needed</td>
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**Role of Advisory Council:** Steering project development, implementation and evaluation activities including:

- Facilitate cooperation and engagement
- Provide feedback and insights regarding current barriers to effective referral, transition and follow-up from NICU to EI services
- Assist in EI service access evaluation and improvement
- Assist in determining best practice for referral, transition and follow-up from NICU to EI services
- Design robust baseline and monitoring data measures for the project
- Guide the setting of project priorities
ENGAGING THE VOICE OF THE PATIENT AND FAMILY

Identifying how best to learn from the patient and family experience

- Interviewing and learning from leaders of existing Patient and Family Advisory Councils
- Engaging lead for Arc of VA New Path which utilizes Newsletter and blog as mechanisms to educate, inform and support families.
- Attending Virginia Interagency Coordinating Council

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HOW DO WE KNOW THERE’S A NEED TO IMPROVE?

Perform needs assessment
Collect baseline data
Perform gap analysis
Develop change package

Gap Analysis

Current State
Key factors for change
Desired State

Action Plan

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WHAT DO WE KNOW ABOUT THE POPULATION SERVED BY EI?

VA Total Population for <1 and Between 1 and 3 y.o. and % in EI services

<table>
<thead>
<tr>
<th>Year</th>
<th>&lt;1</th>
<th>1-3 years old</th>
<th>Total Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007</td>
<td>2.5%</td>
<td>2.7%</td>
<td>3.0%</td>
</tr>
<tr>
<td>2008</td>
<td>2.7%</td>
<td>3.0%</td>
<td>3.5%</td>
</tr>
<tr>
<td>2009</td>
<td>2.7%</td>
<td>3.5%</td>
<td>3.9%</td>
</tr>
<tr>
<td>2010</td>
<td>2.7%</td>
<td>3.9%</td>
<td>4.1%</td>
</tr>
<tr>
<td>2011</td>
<td>3.0%</td>
<td>4.1%</td>
<td>4.2%</td>
</tr>
<tr>
<td>2012</td>
<td>3.5%</td>
<td>4.2%</td>
<td>4.7%</td>
</tr>
<tr>
<td>2013</td>
<td>3.9%</td>
<td>4.7%</td>
<td>5.7%</td>
</tr>
<tr>
<td>2014</td>
<td>3.8%</td>
<td>5.7%</td>
<td>6.6%</td>
</tr>
<tr>
<td>2015</td>
<td>3.9%</td>
<td>6.6%</td>
<td>7.8%</td>
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TOTAL BIRTHS AND OTHER CONSIDERATIONS

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Data Sources: Zehner, Anne “Neonatal Abstinence Syndrome in Virginia: A Report on Current findings and Trends from Hospital Discharge Data, 1999-2013” Office of Family Health Services, Virginia Department of Health
www.vdh.virginia.gov/data/maternal-child-health/
WHAT DO WE KNOW ABOUT VIRGINIA’S EI REFERRALS?

NICUs, NICU Follow Along Clinics, pediatric specialty clinics and pediatrician offices are the main referral sources to EI services.

In FY2016, there were 16,019 referrals to EI

- Of these referrals, 60% went on to receive EI services*
  - 2,307 (14%) EI were unable to contact
  - 2,270 (14%) declined evaluation, assessment or services
  - 1,539 (10%) determined ineligible after initial evaluation but may have been referred to other service providers and/or recommended for reevaluation at later date.
  - 9,427 (59%) will receive services
  - 34 (0.2%) choose to receive services from another service provider

* 34 (0.2%) choose to receive services from another service provider

(Data Source: Report on Virginia’s Part C Early Intervention System FY2016 (July 1, 2015 – June 30, 2016))
WE NEED TO UNDERSTAND THE CHALLENGES TO ENGAGEMENT

- Challenges
  - How to best engage a parent who may be overwhelmed by his/her infant’s medical condition
  - How to best engage a teen parent
  - How best to engage an addicted parent and infant with Neonatal Abstinence Syndrome (NAS)
  - How best to engage a parent in denial
  - How best to engage a parent without a stable home
  - How best to clarify roles and support from NICU specialty clinics, pediatrician, EI, Department of Education…
  - How best to support completion of forms that will provide access to services

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EARLY INSIGHTS FROM DISCUSSIONS WITH EI REGIONAL SYSTEM MANAGERS AND NICU STAFF

Specific to the NICU:

- NICU leaders were aware of EI services however hospitals and EI System Managers discussed different practices
  - The process for introducing EI services to family members varies
  - The timing of when an EI referral is made varies
  - The information provided as part of EI referral varies
  - Education materials provided to parents varies
  - Mis-information exists related to EI services (i.e., if you are in a NICU Follow Along Clinic you cannot access EI services)
- Tracking the quality of referral (families that go on for EI services and duration of engagement) by source is not available (at this time)

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HOW WILL WE KNOW A BEST PRACTICE WHEN WE SEE ONE?
WE NEED YOUR DATA – QUANTITATIVE AND QUALITATIVE

- Hospital
- Early Intervention
- Patient and Family
- Virginia Department of Health

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THE POWER OF STORIES…

EVERYONE HAS A STORY

“Stories are about 22 times more memorable than facts alone”
Jerome Bruner, "Actual Minds, Possible Worlds"
WHAT CHANGES CAN WE MAKE THAT WILL RESULT IN AN IMPROVEMENT?

- Review and optimize policies/procedures
- Design and conduct training programs
- Facilitate dialogue between NICU services and Regional System managers of the Infant & Toddlers Connection of Virginia

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PLANS FOR QUARTER 1 2017
ACTIVITIES TO DATE AND PLANS FOR Q1 2017 (JANUARY – MARCH, 2017)
### ACTIVITIES PLANNED: QUARTER 1, 2017

<table>
<thead>
<tr>
<th>Foundation for Improvement</th>
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<tbody>
<tr>
<td>Needs Assessment</td>
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NEEDS ASSESSMENT

- NICU Leaders will receive NICU EI survey link and request for information
  - Policies and procedures related to EI referral process
  - Educational materials related to EI
  - Policies/procedures related to NICU Discharge Rounds
  - Discharge summary form
  - List of documents that accompany EI referral
- Site Visits will be scheduled once survey and requested data are received
- EI program will receive survey link and request for information

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BASELINE DATA – AGREE TO TRUE DATA SOURCE

Challenges

- Virginia Dept. of Health
  - Only captures NICU admissions through data entered on birth certificate
  - Most recent data available is 2013 (5,029 NICU Admissions)

- Virginia Health Information (VHI)
  - Does not specify NICU as a bed type for 2013, 2014 and 2015 discharges from these beds 9,244; 9,143; and 17,810, respectfully
    - Infant intermediate
    - Infant specialty
    - Infant sub-speciality

- Infant and Toddler Online Tracking System (ITOTS)
  - Limited data set that is not linked to other State systems

Large data discrepancy between sources may be due to infants transferred to NICU after birth.

Are all providers categorizing buckets based on same criteria?

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GAP ANALYSIS

- Identify current situation and desired future state
  - Utilize baseline data
  - Ongoing data collection from hospitals and EI
  - Review of policies and procedures
  - Compile survey responses
  - Obtain feedback from patient and family council
  - Link NICU, EI and Patient/family data

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NEXT STEPS

- Advisory Council webinar/conference call scheduled for 2/14
- Hospital NICU survey link 2/15
- Hospital NICU data request 2/15 with response requested by 2/28
- EI survey link 2/15 with response requested by 2/28
- EI data request 2/15 with response requested by 2/28

- Site visits scheduled once survey and requested data submitted.

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QUESTIONS?
Please contact Wanda Clevenger  wclevenger@vhha.com or (804) 965-1202