VA NICU EARLY INTERVENTION COLLABORATIVE PROJECT OVERVIEW AND UPDATE

An initiative funded by the Virginia board for people with disabilities (VBPD)

Presentation to the VA Interagency Coordinating Council
March 8, 2017
NICU EI Collaborative Project Leaders

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Dept. of Behavioral Health and Developmental Services

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Vice President
Quality and Patient Safety

Betsy Cole Archer, MS, ASCP
Director, Performance Improvement

Wanda Clevenger BSN, RN, MBA
Director, Performance Improvement
VHHA, VHREF, and The Center

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

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 Street, 7th Floor, Richmond, VA 23219, (800) 846-4464, or visit the Board’s website at www.vaboard.org
What are we trying to accomplish?

• The **Virginia NICU Early Intervention Collaborative** (the Collaborative) will achieve **systems change of practice and improvement in outcomes** for all infants and young children by engaging all Virginia NICUs and their community partners in a statewide learning and improvement collaborative to **enhance linkages to Early Intervention (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:
  - Individuals with developmental and other disabilities Patient & Family Advisory Council (PFAC); and
  - Leaders in neonatal care, NICU, community engagement, and EI.
    - Guides the work of the collaborative

- 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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Activities & Status update

Facility commitment and onboarding

- 22 hospital NICUs enrolled

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.

Advisory Councils

- Members of Collaborative Advisory Council on-board and meeting held 2/14/2017
- Patient and Family Advisory Councils via partnership with NEW PATH and ARC of VA.

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>Bon Secours Regional Memorial</th>
<th>Inova Alexandria Hospital</th>
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<td>Bon Secours St. Francis Medical Center</td>
<td>Inova Children’s Hospital</td>
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<td>Bon Secours St. Mary’s Hospital</td>
<td>Inova Fair Oaks Hospital</td>
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<td>Carilion Clinic – Carilion Children’s Hospital</td>
<td>Inova Loudon Hospital</td>
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<tr>
<td>Centra Virginia Baptist Hospital</td>
<td>Mary Washington Hospital</td>
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<tr>
<td>Children’s Hospital of Richmond at VCU</td>
<td>Novant Health UVA Health System Prince William Medical Center</td>
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<td>Children’s Hospital of The King’s Daughters</td>
<td>Riverside Regional</td>
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<tr>
<td>Children’s National Medical Center, Washington DC</td>
<td>Sentara Princess Anne Hospital</td>
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<tr>
<td>HCA Chippenham Hospital</td>
<td>University of Virginia Children’s Medical Center</td>
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<tr>
<td>HCA Henrico Doctors Hospital</td>
<td>Virginia Hospital Center</td>
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<tr>
<td>HCA Johnston-Willis Hospital</td>
<td>Winchester Medical Center</td>
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The Collaborative’s Advisory Council

<table>
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<tr>
<th>Name</th>
<th>Role</th>
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<tbody>
<tr>
<td>Erin Close Austin, LCSW</td>
<td>Children’s Services Manager, Developmental Services Division Richmond Behavioral Health Authority</td>
</tr>
<tr>
<td>Gail Briceland, RN, CPNP, MSN</td>
<td>Infant &amp; Toddler Connection of Central VA</td>
</tr>
<tr>
<td>Wanda Clevenger, BSN, RN, MBA</td>
<td>Director, Performance Improvement, VHHA</td>
</tr>
<tr>
<td>Maria DeLalla RN BSN BA</td>
<td>Nurse Case Manager, Women &amp; Children’s Services, Healthy Families NSV Resource Specialist, Winchester Medical Center</td>
</tr>
<tr>
<td>Tracey Edman</td>
<td>New Path Family Support Coordinator, The ARC of VA</td>
</tr>
<tr>
<td>Catherine Hancock, MS, RN, PMHCNS, BC</td>
<td>EI Administrator, Dept. of Behavioral Health and Developmental Services</td>
</tr>
<tr>
<td>Jamie Liban</td>
<td>Executive Director, The ARC of VA</td>
</tr>
<tr>
<td>Jen Barnes-Maddox, M Ed</td>
<td>NICU Family Support Program Coordinator at Henrico Doctors’ Hospital March of Dimes</td>
</tr>
<tr>
<td>Kathleen McCauley, Attorney</td>
<td>Family representative and health care lawyer</td>
</tr>
<tr>
<td>Alan Picarillo, MD, FAAP</td>
<td>Sheridan Children Services Medical Director, NICU, Henrico Doctors’ Hospital</td>
</tr>
<tr>
<td>Laura Speer, RNC-NIC, MSN, BSN</td>
<td>Neonatal Intensive Care Unit, Clinical Director, Inova Children’s Hospital Inova Fairfax Medical Campus</td>
</tr>
<tr>
<td>Sharlene Stowers</td>
<td>Director of EI, Local System Manager Infant and Toddler Connection of Shenandoah Valley</td>
</tr>
<tr>
<td>Ad hoc members as needed</td>
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Engaging the Voice of the Patient and Family

Identifying how best to learn from the patient and family experience

- Partnership with Arc of VA New Path
  - Statewide work with 24 local chapters.
  - Input from new and graduate families on both NICU and community based experiences.
  - Link in to existing communication tools to engage, support and inform including newsletter and blog.

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How will we achieve our aim?

• Improve/expand NICU referrals and follow up
• Enhance policies, practices & competencies
• Develop training models

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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

GAP
Key factors for change
Current State
Desired State
Action Plan

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Improving the Quality & Safety of Healthcare
What We Know From the Literature

- 65-70% of Children who enter EI with developmental delays are closer to age-expected skills when they exit EI\(^1\)
- Integrating community-based EI with medical pediatric care is recommended as a best practice by the American Academy of Pediatrics. \(^2\)
- Multiple studies identify that eligible infants may be missed and not referred to EI\(^3,4\) and \(^5\)
  - A study comparing EI referral rates to those of infants on oxygen to pulmonology and infants with vision impairment to ophthalmology concluded that referrals of developmentally delayed infants to EI were due to quality improvement or system issues. \(^6\)
- Reasons for gaps in EI referrals include: simple oversights or communication failures between hospitals, EI and families.
- Lack of formal tracking of referral outcomes precludes identification of best practice and standardization.


\(^6\) Ibid.

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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

Data Sources: States’ and territories’ definitions of/criteria for IDEA Part C eligibility (updated March 4, 2015)
Infant & Toddler Connection of Virginia, http://www.infantva.org/Families.htm website accessed 2/7/2017
Birthrate Stable but EI Need Increasing

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, VDH

EI Referrals All Sources 2016

Referral Outcome (16,019 infants)

- Receiving Services 60%
- Unable to Contact 14%
- Declined Evaluation 14%
- Determined Ineligible 10%

Note 2% received services from another provider.

(Data Source: Report on Virginia’s Part C Early Intervention System FY2016 (July 1, 2015 – June 30, 2016))
NICU Referrals to EI?

- Are NICUs referring all infants that are eligible and/or have a condition or diagnosis that makes them highly probable of being eligible are referred to EI?
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-specialty
  • Infant and Toddler Online Tracking System (ITOTS)
    • Limited data set that is not linked to other State systems

Discrepancy between sources may be due to infants transferred

Are all providers categorizing buckets based on same criteria?

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Agreed to Baseline

• Use the Infant & Toddler Connection of VA Practice Manual (Chapter 5 Eligibility Criteria) list of diagnoses and conditions that either:
  • automatically qualify an infant for EI services or
  • indicates that it is highly probable the infant will have developmental delays related to the diagnosis and would benefit from EI services

• Take the English descriptions of diagnosis and conditions and assign ICD10 codes.

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Other Baseline and Performance Data

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<th>Denominator</th>
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<tbody>
<tr>
<td>1) Number of families receiving information on EI and availability of EI services post NICU discharge</td>
<td># families who received EI information while on the NICU</td>
<td># infants discharged from NICU</td>
</tr>
<tr>
<td>2) Number of infants DC from hospital with diagnosed condition (using ICD 10 Codes) that meets EI eligibility criteria Separate data by NICU and other hospital bed</td>
<td>NICU and other hospital bed discharges in specified ICD10 Codes</td>
<td>All infants DC from Hospital</td>
</tr>
<tr>
<td>3) Number of infants DC from hospital with diagnosed condition (using ICD 10 Codes) considered a risk factor for developmental delays and thus, supporting EI referral. Separate data by NICU and other hospital bed.</td>
<td>NICU and other hospital bed discharges in specified ICD10 Codes</td>
<td>All infants DC from Hospital</td>
</tr>
<tr>
<td>4) Number NICU referrals to EI</td>
<td># NICU referrals to EI</td>
<td>NICU discharges</td>
</tr>
<tr>
<td>5) Number of NICU grads eligible for services and whose family declined services, include why services were declined.</td>
<td># EI eligible NICU grads referred to EI whose family declined assessment</td>
<td># EI eligible NICU grads referred to EI</td>
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A special thank you to Mary Anne White, EI System Manager for her work on the ICD10 Coding of the Practice Manual!

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## Other Baseline and Performance Data cont.

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<td>6) Number of NICU grads eligible for services and whose family declined services, include why services were declined.</td>
<td># EI eligible NICU grads referred to EI whose family declined assessment</td>
<td># EI eligible NICU grads referred to EI</td>
</tr>
<tr>
<td>7) EI Referral source distribution by region</td>
<td>EI Hospital referral</td>
<td>All EI referrals</td>
</tr>
</tbody>
</table>
| 8) Number of NICU discharges going to foster care that are referred to EI, number that agree to EI, number that decline EI. | o # NICU DC’s to foster care AND referred to EI  
 o # NICU grads in foster care that agree to EI  
 o # NICU grads in foster care that decline EI | # NICU DC’s to foster care  
 # NICU grads in foster care and referred to EI |
| 9) Number of infants and/or young children with disabilities who have the services/supports needed to reach developmental goals. | to be determined | EI – IFSP |
| 10) Number of infants receiving benefit from EI services | to be determined | EI – IFSP |

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Quantitative and Qualitative Information

• Understanding the challenges to engagement
  • 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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Surveys & Site Visits/Meetings to Learn Best Practices and Service Gaps

- Parent/Family
- EI System Managers
- NICU Leaders

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Early Insights

No Single Point/Process for EI Referral/Access

Variations

- The process for introducing EI services to family members
- The timing of when an EI referral is made
- The information provided as part of EI referral
- Education materials provided to parents
- Mis-information exists related to EI services (i.e., if you are in a NICU Follow Along Clinic you cannot access EI services)

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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"

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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, EI Regional System Managers and New Path

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Activities planned: Qtrs. 1 & 2, 2017

Foundation for Improvement

- Needs Assessment
- Collect Baseline Data
- Perform Gap Analysis
- Begin Work for Change Package

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Questions/Comments/Suggestions

Wanda Clevenger, wclevenger@vhha.com or (804) 965-1202