IMPROVING SYSTEMS TO SUPPORT EARLY IDENTIFICATION OF CHILDREN WITH DEVELOPMENTAL DELAY

14. October. 2021

Eileen Auer-Bennett
Dawn Magnusson
Today’s Goals

- Review key findings from Colorado’s needs assessment
- Reflect on barriers and opportunities identified by the Colorado Early Childhood Screening and Referral Policy Council
- Discuss potential solutions
Project Purpose:
Support Early Childhood State Systems through the Act Early Network to Strengthen Resilience of and Resources for Children, Families, and Communities

Objectives:
Identify current barriers and opportunities across various early childhood systems/programs to improve each of the 4 steps of early identification

- Parent-engaged developmental monitoring
- Developmental and autism screening
- Referral
- Receipt of EI services for 0 to 5
Define Project Scope
Work alongside key stakeholders to clarify the purpose of the assessment.

Oct-Nov 2020

Review Existing Data
Collect and summarize data from local, state, and national surveys.

Nov-Feb 2020 – 2021

Community Survey
Design and administer survey to Colorado families.

Mar-Sep 2021

Establish Priorities
Review findings, identify potential gaps, and prioritize key issues

Sep 2021 – Sep 2022

Develop Action Plan
Establish goals and objectives and implement actionable solutions.
1 in 4* children under the age of 5 Years at risk for experiencing developmental delays

Developmental Progress

<table>
<thead>
<tr>
<th>Age</th>
<th>Birth</th>
<th>5 Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delay</td>
<td>Severe</td>
<td>“Typical” Development</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Moderate Delay</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Severe Delay</td>
</tr>
</tbody>
</table>

Delays can persist and in some cases worsen as children age – further contributing to health disparities and poor health outcomes later in life.

This risk is greatest for children with limited social and financial resources, and children representing racial and ethnic minorities.

*National Survey of Children's Health, 2018-19
Key Findings

Screening

45% of caregivers recall a screener being completed in the last year:

- 36% Black & Hispanic
- 60% White
- 25% Public Ins.
- 69% Private Ins.

Monitoring

Primary Sources of Information:
- Pediatrician 67%
- Child Care Provider 17%
- All Others ≤5%

20% of respondents reported not receiving any information about child’s growth or development

Referral

40-80% of infants and toddlers with concerning screeners referred to EI

Difficulty getting referral:

- 8% Wrong Service Area
- 4% Not Eligible
- 18% Family Declined
- 16% Contact Unsuccessful
- 25% In Progress, Active, or Enrolled

Sources:
- CDPHE Health eMoms Survey, 2018 Cohort
- National Survey of Children's Health, CO 2018-19
- National Survey of Children's Health, CO 2018-19
16% of referrals closed because family declined participation (7,798 children)
19% of referrals closed because attempts to contact family were unsuccessful (9,260 children)
**SERVICE USE**

- Nothing
- Cost of services / no insurance
- Limited or no services nearby
- Concerned about missing work/pay
- Other
- Long wait times
- Confused by health care system
- Transportation issues
- Language barriers

**Referral Outcome (Service Use)**
- Wrong Service Area
- Not Eligible
- Family Declined
- Contact Unsuccessful
- In Progress, Active, or Enrolled

ABCD Survey, 2021
<table>
<thead>
<tr>
<th>Society</th>
<th>Organization</th>
<th>Clinician</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Stigma</td>
<td>• Resource Availability</td>
<td>• Knowledge of Eligibility Criteria and Referral Processes</td>
<td>• Caregiver Knowledge and Beliefs</td>
</tr>
<tr>
<td>• Discrimination</td>
<td>• Data and Systems Coordination</td>
<td>• Beliefs regarding Service Efficacy</td>
<td>• Family Values and Priorities</td>
</tr>
<tr>
<td>• Historical Trauma</td>
<td>• Process Standardization</td>
<td></td>
<td>• Chronic Stress (e.g., Social, Emotional, Financial)</td>
</tr>
<tr>
<td>• COVID-19</td>
<td>• Access – Hours; Cultural/Linguistic</td>
<td></td>
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</table>
One third of referrals to EI close secondary to families declining services or children and families being lost to follow-up. Current local and state data indicate Black and Indigenous children of color (BIPOC children) and families with limited financial resources are most likely to fall through our state’s service cracks.
Goal #1 (Knowledge and Awareness)

Increase caregiver/community awareness about the importance of early developmental milestones and the caregiver’s critical role in developmental monitoring.
Goal #2 (Behaviors)

Foster meaningful conversations and shared decisions between caregivers of children with developmental concerns and early childhood professionals.

- Decision Support Intervention
- Family Navigation Programs
- Referral Tracking System
- Universal Screening
Goal #3
Reduce disparities in developmental screening, referral, and service use.
CLOSING DEVELOPMENTAL SCREENING AND EARLY INTERVENTION SERVICES GAPS FOR NON-ENGLISH, NON-SPANISH SPEAKING CHILDREN

Kristi Knuti Rodrigues, MD, MPH, Denver Health Refugee Immigrant, and Migrant Navigation Program
Betsy Ruckard, Denver Health Refugee and Immigrant Services Coordinator
Kuang Oo, Denver Health Refugee Immigrant, and Migrant Navigator
Eileen Auer Bennett, Executive Director, Assuring Better Child Health & Development
Michele Ebendick, Early Childhood Wellness Coordinator at Tri-County Health Department
Shannon Banks, Rocky Mountain Human Services Early Intervention Engagement Specialist
Heidi Troutman, MA, ECSE, Director of Early Intervention at Developmental Pathways
BACKGROUND

• Non-English, non-Spanish speaking (NENS) patients have decreased access to health care and lower odds of receiving developmental screening and surveillance1-3

Developmental Screening Disparities for Languages Other than English and Spanish

Kristine Knuti Rodrigues, MD, MPH; Simon J. Hambidge, MD, PhD; Miriam Galbraith AA; Douglas B. Richardson, MAS; Arthur J. Davidson, MD, MSPH

From the Department of Pediatrics (Drs Knuti Rodrigues and Hambidge), Department of Family Medicine (Drs Dake and McAninch-Dake), University of Colorado School of Medicine, Colorado School of Public Health (Drs Hambidge, Dickinson, and Davidson), and Community Health Services (Drs Knuti Rodrigues and Hambidge, and Mr Richardson), and Department (Dr Davidson), Denver Health and Hospital Authority, Denver, Colo. The authors declare that they have no conflict of interest. Address correspondence to Kristine Knuti Rodrigues, MD, MPH, Denver Health and Hospital Authority, 777 Bannock St, Denver, CO 80204 (e-mail: Kristine.Rodrigues@dhha.org). Received for publication April 3, 2015; and in revised form October 19, 2015. accepted December 20, 2015.

ABSTRACT

BACKGROUND: Limited English proficiency (LEP) is a known barrier to preventive care. Children from families with LEP face socioeconomic circumstances associated with increased odds of developmental delays and decreased participation in early care

RESULTS: Compared to the English-speaking, non-Spanish group had lower developmental surveillance at 100% of WCV (confidence interval, 0.2. 0.5) and of being...

WHY CULTURALLY RESPONSIVE NAVIGATION?

“We trust our people more than other communities. ...More than other persons. I can explain my problems fully to the person who speaks my language and I know he belongs to me....”

“If they have a Somali person working there as a health care provider, or a nurse or a translator, it will help a lot to facilitate understanding between the doctors and the clients and the Somali moms or fathers.”

Reference: Illustrative quotes from pilot NENS community member focus groups and community leader interviews.
DENVER HEALTH
REFUGEE, IMMIGRANT, AND
MIGRANT (RIM)
NAVIGATION

Program Oversight:
- Kristi Knuti Rodrigues, MD, MPH
- Betsy Ruckard, Refugee Services Coordinator

NENS Navigators:
- Adrien Matadi
  Languages: Amharic, Arabic, French, Lingala, Swahili
- Kuang Oo
  Languages: Burmese, Karen, Pwo Karen
- Rasulo Rasulo
  Languages: Maay Maay, Somali
PROJECT TIMELINE

- **NENS Navigator Training on ASQ®-3 and Survey of Well-being of Young Children™ (SWYC™)**
- **Plan, Do Study, Act (PDSA) Cycles for ASQ®-3 and SWYC™**
- **EDUCA Radio Shows, CAO Outreach**
- **Began Offering NENS Navigator ASQ®-3 Assistance to NENS at Lowry Family Health Center**
- **Early Intervention Services Referrals Collaboration with Denver Health RIM Navigation, Rocky Mountain Human Services, Developmental Pathways, Denver Public Schools, ABCD, and Tri-Country Health Department**
- **Ongoing Monitoring of Screening Rates**
- **Before and After Data Analysis**
- **Adjustments for COVID-19**

**Timeline:**
- **Oct 2017**
- **Dec 2017**
- **Jan 2018**
- **Apr 2018**
- **Jul 2019**
- **Mar 2020**
CULTURALLY RESPONSIVE ADJUSTMENTS TO ASQ®-3

2. Does your baby successfully pick up a crumb or Cheerio by using her thumb and all of her fingers in a raking motion? (9-Month ASQ-3™)

3. After a crumb or a Cheerio is dropped into a small, clear bottle, does your child turn the bottle over to dump it out? (18-Month ASQ-3™)

Navigator Adjustment
“Not so many people in my community know about a crumb or Cheerio, so I use rice as an example to make it more appropriate for my community.”
CULTURALLY RESPONSIVE ADJUSTMENTS TO ASQ®-3

6. When you ask, “What is your name?” does your child say both her first and last name? (36-Month ASQ-3™, Communication)

Navigator Adjustment
“For Burmese children, I mark this question as ‘Yes’ if the parent states that the child knows his or her name because in the Burmese community we don’t use first and last names.”
PARTNERS & COLLABORATORS

- Denver Health RIM Navigation Program
- Assuring Better Child Health and Development (ABCD)
- Tri-County Health Department
- Early Intervention
  - Rocky Mountain Human Services
  - Developmental Pathways
  - Denver Public Schools
- Lowry and Westside Family Health Centers
- Epic Champions at Denver Health
- Public Health Institute at Denver Health
- Colorado African Organization
- EDUCA Radio
- Southwest Denver Launch Together
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PROJECT EVALUATION: DEVELOPMENTAL SCREENING

• Starting 4/23/2018, NENS families at one clinic (Lowry Family Health Center) within Denver Health (DH), and large, integrated community health system in Denver, Colorado, USA, were offered NENS navigator assistance with ASQ-3s™ at 8-48 month well child visits (WCVs)

• Reviewed and approved by Colorado Multiple Institutional Review Board
PROJECT EVALUATION:
DEVELOPMENTAL SCREENING

• Collected demographic and ASQ completion data for NENS children offered NENS navigator assistance

• Calculated monthly developmental screening rates for 8-48 month WCVs before, during, and after implementation of NENS navigator ASQ-3™ assistance (Figure 1)

• Through a retrospective observational cohort study of all NENS children, system-wide, who attended 8-48 month WCVs 5/1/2018-7/31/2019, compared ASQ screening for those offered assistance to those who were not with multiple logistic regression analysis
RESULTS: DEVELOPMENTAL SCREENING

• From 4/23/2018 to 7/31/2019, families of 341 NENS children were offered ASQ assistance at WCVs by NENS navigators (77% one WCV, 23% ≥one WCV)

• NENS families accepted 88% of the time

• Of those who accepted assistance, the ASQ was completed 98% of the time, and 41% had family/navigator language concordance

• Most common languages: Amharic (20%), Burmese (16%), Nepali (11%), and Arabic (11%)
RESULTS

Figure 1. Developmental Screening Rates Before, During, and After Implementation of Non-English, Non-Spanish Navigation at 8-48 Month Well Child Visits

- Mean Developmental Screening Rate for English- and Spanish-Speaking Children at All Denver Health Clinics
- Mean Developmental Screening Rates for Non-English, Non-Spanish Speaking (NENS) Children at Lowry Family Health Center (Before and After)
- 95% Confidence Interval

- Monthly NENS Developmental Screening Rates at Lowry Family Health Center
RESULTS

Figure 1. Developmental Screening Rates Before, During, and After Implementation of Non-English, Non-Spanish Navigation at 8-48 Month Well Child Visits

65.1% [95% CI, 59.1%, 71.1%]

76.5% [95% CI, 71.2%, 81.7%]

89.3% [95% CI, 88.3%, 90.3%]

Mean Developmental Screening Rate for English- and Spanish-Speaking Children at All Denver Health Clinics

Mean Developmental Screening Rates for Non-English, Non-Spanish Speaking (NENS) Children at Lowry Family Health Center (Before and After)

95% Confidence Interval

Monthly NENS Developmental Screening Rates at Lowry Family Health Center
RESULTS: DEVELOPMENTAL SCREENING

- NENS children offered NENS navigator assistance had higher odds of completing an ASQ [adjusted odds ratio 7.78; 95% CI, 3.02, 20.11]
RESULTS

Figure 1. Developmental Screening Rates Before, During, and After Implementation of Non-English, Non-Spanish Navigation at 8-48 Month Well Child Visits

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Mean Developmental Screening Rate for English- and Spanish-Speaking Children at All Denver Health Clinics
Mean Developmental Screening Rates for Non-English, Non-Spanish Speaking (NENS) Children at Lowry Family Health Center (Before and After)

95% Confidence Interval
RESULTS: DEVELOPMENTAL SCREENING

More Recent Lowry Family Health Center NENS Developmental Screening Rates:

- August 2019: 87.7%
- September 2019: 77.2%
- October 2019: 77.3%
- November 2019: 76.9%
- December 2019: 63.6%
- January 2020: 77.2%
- February 2020: 81.8%

Project’s lead NENS navigator out on leave
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ACKNOWLEDGMENTS

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Thank you to our many partners and collaborators.
QUESTIONS OR ADDITIONAL INFORMATION

Denver Health RIM Navigation
Kristine.Rodrigues@dhha.org
Betsy.Ruckard@dhha.org
PANEL DISCUSSION

• Reflections on Developmental Screening Project Component
• Collaboration between Denver Health, Rocky Mountain Human Services, Developmental Pathways, Denver Public Schools, ACBD, and Tri-County Health Department to Improve NENS Access to Early Intervention Services