Birth Defects Surveillance Programs and Referrals to Services

VIRTUAL ROUNDTABLE
AMCHP EPIDEMIOLOGY, EVALUATION & METRICS
FIRST...some affirmations
Birth Defects Surveillance Programs Are Important

Data
- Data Collection/Surveillance
- Birth Defects Research & Analysis
- Data Quality Improvement
- Data Product Production/Dissemination

Information
- Communications/Information Sharing
- Reporting/Relaying Information to Title V Programs

Education/Advocacy
- Birth Defects Intervention/Prevention Education & Promotion
- Advocacy/Assistance to Families

Referrals to Prevention/Intervention Services
Excerpts from State Cooperative Agreement Evaluation Expectations & Success Indicators

Expected evaluation for 2 of 3 categories

1. Surveillance
2. Improve Data Quality
3. **Improve Primary and Secondary Prevention**
   - Effectiveness of referral processes
   - Methods to improve prospective tracking of children with birth defects

**Success Indicators of Improve Primary and Secondary Prevention**

- Data used to identify high risk populations and prevention strategies are implemented.
- Plan to improve referral to health care and social services for individual with birth defects is documented and shared with CDC
- Facilitators and barriers to tracking children prospectively
## Birth Defects Surveillance Programs: Primary Activities & Functions

<table>
<thead>
<tr>
<th>Functions and Activities</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advisory Committee Administration and/or Participation (n=29)</td>
<td>41%</td>
<td>59%</td>
</tr>
<tr>
<td>Advocacy/Assistance to Families (n=30)</td>
<td>43%</td>
<td>57%</td>
</tr>
<tr>
<td>Birth Defects Research &amp; Analysis (n=30)</td>
<td>73%</td>
<td>23%</td>
</tr>
<tr>
<td>Birth Defects Intervention/Prevention Education &amp; Promotion (n=30)</td>
<td>63%</td>
<td>37%</td>
</tr>
<tr>
<td>Communications/Information Sharing (n=29)</td>
<td>83%</td>
<td>17%</td>
</tr>
<tr>
<td>Data Collection/Surveillance (n=30)</td>
<td>97%</td>
<td>3%</td>
</tr>
<tr>
<td>Data Product Production/Dissemination (n=30)</td>
<td>73%</td>
<td>23%</td>
</tr>
<tr>
<td>Data Quality Improvement (n=30)</td>
<td>87%</td>
<td>13%</td>
</tr>
<tr>
<td><strong>Referrals to Prevention/Intervention Services (n=30)</strong></td>
<td>57%</td>
<td>43%</td>
</tr>
<tr>
<td>Reporting/Relaying Information to a Title V MCH Program for Block Grant Planning/Reporting (n=30)</td>
<td>67%</td>
<td>33%</td>
</tr>
</tbody>
</table>

(AMCHP, 2022)
State BD Surveillance Cooperative Agreements

Conceptual Model

(Mai, Silverman, Boulet & Leary, 2009)
State BD Surveillance Cooperative Agreements Conceptual Model

Activities
- Surveillance
- Capacity Development
- Prevention & Referral
  - Develop data-driven prevention & referral plans & disseminate through partner channels
- Evaluation

Results
- Measurable & Sustained Birth Defect Methodology
- Effective Transfer of Information for Intervention
- Outreach Campaigns w/ Prevention Messages & Activities
- Coordinated Intervention Channels to Link Children/Families to Services

Outcomes
- Short Term: Changes in Knowledge & Attitudes
- Mid Term: Changes in Behavior & Practices
- Impact: Improved Health Outcomes

(Graphic based on Mai, Silverman, Boulet, & Leary, 2009)
State BD Surveillance Cooperative Agreements
Conceptual Model - Prevention & Referral Focus

Activities

Prevention & Referral
• Develop data-driven prevention & referral plans & disseminate through partner channels

Results

• Effective Transfer of Information for Intervention
• Outreach Campaigns w/ Prevention Messages & Activities
• Coordinated Intervention Channels to Link Children/Families to Services

Outcomes

• Short Term: Changes in Knowledge & Attitudes
• Mid Term: Changes in Behavior & Practices
• Impact: Improved Health Outcomes

(Graphic based on Mai, Silverman, Boulet, & Leary, 2009)
Revised
10 Essential Public Health Services

The 10 Essential Public Health Services

- Build and maintain a strong organizational infrastructure for public health
- Improve and innovate through evaluation, research, and quality improvement
- Build a diverse and skilled workforce
- Enable equitable access
- Utilize legal and regulatory actions
- Communicate effectively to inform and educate
- Strengthen, support, and mobilize communities and partnerships
- Create, champion, and implement policies, plans, and laws
- Investigate, diagnose, and address health hazards and root causes
- Assess and monitor population health
### Revised 10 Essential Public Health Services

<table>
<thead>
<tr>
<th>Service</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assess and Monitor</td>
<td>Assess and monitor population health status, factors that influence health, and community needs and assets</td>
</tr>
<tr>
<td>Investigate &amp; Diagnose</td>
<td>Investigate, diagnose, and <strong>address</strong> health problems and hazards affecting the population.</td>
</tr>
<tr>
<td>Inform &amp; Educate</td>
<td>Communicate effectively to inform and educate people about health, factors that influence it, and how to improve it.</td>
</tr>
<tr>
<td>Support &amp; mobilize communities &amp; partnerships</td>
<td><strong>Strengthen</strong>, support, and mobilize communities and partnerships to improve health.</td>
</tr>
<tr>
<td>Implement Policies and Plans</td>
<td>Create, champion, and implement policies, plans, and laws that impact health.</td>
</tr>
<tr>
<td>Legal &amp; Regulatory Actions</td>
<td>Utilize legal and regulatory actions designed <strong>to improve</strong> and protect the public’s health.</td>
</tr>
<tr>
<td>Ensure Access to Services</td>
<td><strong>Assure an effective system that enables equitable access to the individual services and care needed to be healthy.</strong></td>
</tr>
<tr>
<td>Skilled Public Health Workforce</td>
<td><strong>Build and support a diverse</strong> and skilled public health workforce.</td>
</tr>
<tr>
<td>Evaluation, Research, and Quality Improvement</td>
<td><strong>Improve and innovate public health functions through ongoing evaluation, research, and continuous quality improvement.</strong></td>
</tr>
<tr>
<td>Research for New Insights and Innovative Infrastructure for Public Health</td>
<td><strong>Build and maintain a strong organizational infrastructure for public health.</strong></td>
</tr>
</tbody>
</table>
CDC Evaluation Framework & Standards
Framework for Assessing Outcomes from Newborn Screening

Measure Concepts
- Screening: Process & Screening Outcomes
- Care Consistency w/ Guidelines
- Patient/Client Care/Services: Medical Home, Processes, Transition
- Surveillance: Surveillance Systems, Registries, Clinical Studies/Trials

Primary Drivers
- Rapid/Reliable Detection & Diagnosis
- Provision of Evidence-based Therapeutic & Habilitative Care
- Coordination/Integration of Holistic Spectrum of Services
- CQI Mechanisms of Care, Discovery & Innovation

Outcomes: Improved Survival & Well-Being
- Mortality
- Major Complications
- Function
- Growth & Development
- Patient/Family Experience
- Disparities

Graphic based on Hinton et al., 2016
Framework for Assessing Newborn Screening - Sickle Cell Disease

Aim – Rapid/Reliable Detection & Diagnosis

**Example 1**

<table>
<thead>
<tr>
<th>Primary Drivers</th>
<th>Key Attribute</th>
<th>Measure Concepts: Screening</th>
<th>Data Sources</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Rapid &amp; Reliable Detection &amp; Diagnosis</td>
<td>• Universal Screening Performed</td>
<td>• SCD detected by NBS</td>
<td>• State NBS Programs</td>
<td>• #/of HbSS, HbSC, HbS-beta thalassemia detected at birth</td>
</tr>
<tr>
<td>• Diagnosis via Universal Screening</td>
<td>• SCD confirmed &amp; diagnosed</td>
<td>• CDC’s Sickle Cell Data Collection Program (SCDC)</td>
<td></td>
<td>• % infants with confirmed diagnoses before 2 months of age-Condition sub-type confirmed</td>
</tr>
</tbody>
</table>

Graphic based on Hinton et al., 2016
Framework for Assessing Newborn Screening
Aim – Provision of Evidence-based Care for SCD

Example 2

Primary Drivers
- Provision of Evidence-based Care

Key Attribute
- Evidence-based Treatment

Measure Concepts: Services - Prevention
- Prevention of disease-related mortality

Data Sources
- State mortality data
- CDC’s Sickle Cell Data Collection Program (SCDC)
- State NBS Programs
- CDC’s Sickle Cell Data Collection Program (SCDC)
- HRSA-Supported Surveys

Measures
- Number and age of childhood deaths
- Early initiation of PCN prophylaxis
- State NBS Programs
- CDC’s Sickle Cell Data Collection Program (SCDC)
- HRSA-Supported Surveys
- #/% infants prescribed PCN by 3 months of age
- #/% children younger than 5 continuously prescribed PCN

Graphic based on Hinton et al., 2016
Framework for Assessing Newborn Screening
Aim – Coordination & Integration of SCD Services/Interventions

*Example 3*

- **Primary Drivers**
  - Coordination & Integration of Services

- **Key Attribute**
  - Referral to SCD Services

- **Measure Concepts: Services - Access**
  - Patient-centered engagement & satisfaction

- **Data Sources**
  - National Children’s Survey
  - Sickle Cell Data Collection Program (SCDC)

- **Measures**
  - % w/ difficulty in receiving referrals among SCD children who needed them
Example: Protocol and Program Factors Associated with Referral and Loss to follow-up from Newborn Hearing Screening: A Systematic Review

Fig. 1 An example newborn hearing screening pathway. Infants are screened one or multiple times during screening step 1. Depending on the protocol, infants who are referred from screening step 1 may undergo screening step 2 or be directly referred to a diagnostic assessment.
Example: Protocol and program factors associated with referral and loss to follow-up from newborn hearing screening: a systematic review

<table>
<thead>
<tr>
<th>Assessment Factor</th>
<th>Loss to Follow-Up (high/low)</th>
<th>Referral Rates (lower/higher)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Screening Method</td>
<td>aABR, TEOAE</td>
<td></td>
</tr>
<tr>
<td>Program Factors</td>
<td>Hospital Size Program Organization</td>
<td></td>
</tr>
<tr>
<td>Screener-Level Factors</td>
<td>Lower LTFU* for techs vs. nurses &amp; volunteers (*moderated by audiologist presence)</td>
<td></td>
</tr>
<tr>
<td>Professional &amp; Experience</td>
<td>Lower LTFU for local NHS embedded within larger NHS</td>
<td></td>
</tr>
<tr>
<td>Level of NHS organization</td>
<td>Lower LTFU for larger hospitals</td>
<td></td>
</tr>
<tr>
<td>Hospital Size</td>
<td>Sleeping/quiet – lower Infant Age since birth (increase age -&gt; lower) NICU Status Inpatient v. Outpatient</td>
<td></td>
</tr>
<tr>
<td>Infant Factors</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Mapping Outcomes by Referral Status

Referral Patterns & Cause of Death Among Stillbirths & Infants Who Died ≤ 7 days from Birth

Ariande Labs, 2019
Process Evaluation
Communication Intervention of Positive Newborn Bloodspot Screening Results
(Chudleigh et al., 2021)

**Objective:** implement and evaluate interventions to improve communication of positive newborn bloodspot screening results

**Process Evaluation of Interventions:** Standardized lab forms, communication checklists, and an email/letter template

**Outcome Measures:** Acceptability and feasibility of the communication interventions

**Methods**

- Audit of completion of interventions: staff asked to send completed forms & communication checklists that were checked for completeness & accuracy
- Semi-structured interviews:
  - Health providers views on acceptability, feasibility and usability
  - Parents who rec’d positive NBS screening with and without communication interventions: views on experiences and perceptions of communication interventions

**Results**

- Wide variation in communication forms and checklists completion attributed to organization and contextual barriers
- Health providers had positive feedback in relation to the purpose of the interventions and the ease of completion
- Parents reported consistency, pacing and tailoring of information as well as providing reliable information
Case for Evaluating Collaborations/Partnerships

“Authentically Connected” - An integrated network in which agencies function as equal players with each other and with the client to identify and address the complex interplay of needs*

• The biggest benefit of collaboration among health agencies is the improved health of clients and therefore of the community.
• Leadership and vision among collaborative agencies can make a difference in the quality of a community health care system and in the cost-effectiveness of the care provided.

Collaboration Evaluations Tools (Free!)

• Wilder Collaboration Factors Inventory (Wilder Foundation)
• Collaboration Assessment Tool (Prevention Institute)
• Power Awareness Tool (Partos/The Spindle)

*Center for Substance Abuse Treatment, 2000
V-RTable Talk
Where Is Your Program?

- **Goal/Aim Identified**
- **Measurable Outcomes**
- **Data Collection Tools**
- **Data Collection Process**
- **Use of Data**
- **Communicate Data**
- **Data Analysis & Reporting**
- **Data Management**

- Thinking/Contemplating - No Action
- Planning/Preparation
- Initiation/Implementing
- Implemented/Maintenance

- No Action, need help
- Action, but need help
- Doing ok, need a little help/reassurance
- Doing great, no help needed
For where you are...

What are barriers for progressing?

What are lessons learned on the journey so far?

What are means to meeting and managing expectations?

What defines success for your program?
Thank You!

VIRTUAL ROUNDTABLE
AMCHP EPIDEMIOLOGY, EVALUATION & METRICS
Texas BDR Family Outreach Referrals (1)

Social Work Data Collection Form

- Social workers complete a data collection form for each child referred
- The information on the form submitted to BDES
- Some of the information collected on the form includes:
  - Outcome of attempt to contact
  - Health insurance
  - Referrals made
  - CDC milestones and more

Betancourt, 2023
## Texas BDR Family Outreach Referrals (2)

### Referrals to Programs

<table>
<thead>
<tr>
<th>Referral Category</th>
<th>Programs in Referral Category</th>
<th>% of Referrals Made (n=3,097)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Support</td>
<td>Counseling services&lt;br&gt;Immigration/Legal Assistance&lt;br&gt;Parent training and information centers (PTI)</td>
<td>29%</td>
</tr>
<tr>
<td></td>
<td>TX Parent to Parent&lt;br&gt;English as a Second Language (ESL)&lt;br&gt;Parenting classes&lt;br&gt;Share Program</td>
<td></td>
</tr>
<tr>
<td>Developmental</td>
<td>Community First Choice (CFC)&lt;br&gt;Early Childhood Intervention (ECI)&lt;br&gt;Personal Care Service&lt;br&gt;Skilled Nursing Care&lt;br&gt;Head Start</td>
<td>29%</td>
</tr>
<tr>
<td></td>
<td>Children with Special Healthcare Needs (CSHCN)&lt;br&gt;Driscoll high-risk clinic&lt;br&gt;School programs</td>
<td></td>
</tr>
<tr>
<td>Financial Assistance</td>
<td>Medicaid Waiver Program&lt;br&gt;Health Insurance Premium Payment (HIPP) Program&lt;br&gt;Supplemental Security Income (SSI)&lt;br&gt;Supplemental Nutrition Assistance Program (SNAP)</td>
<td>28%</td>
</tr>
<tr>
<td></td>
<td>Temporary Assistance for Needy Families (TANF)&lt;br&gt;Women Infants and Children (WIC)&lt;br&gt;Child Support</td>
<td></td>
</tr>
<tr>
<td>Medical/Dental</td>
<td>Pediatrician&lt;br&gt;Specialty Care&lt;br&gt;Dental</td>
<td>14%</td>
</tr>
<tr>
<td></td>
<td>Physical/Speech/Occupational therapy&lt;br&gt;Audiologists&lt;br&gt;Medical Transportation</td>
<td></td>
</tr>
</tbody>
</table>

Betancourt, 2023