

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

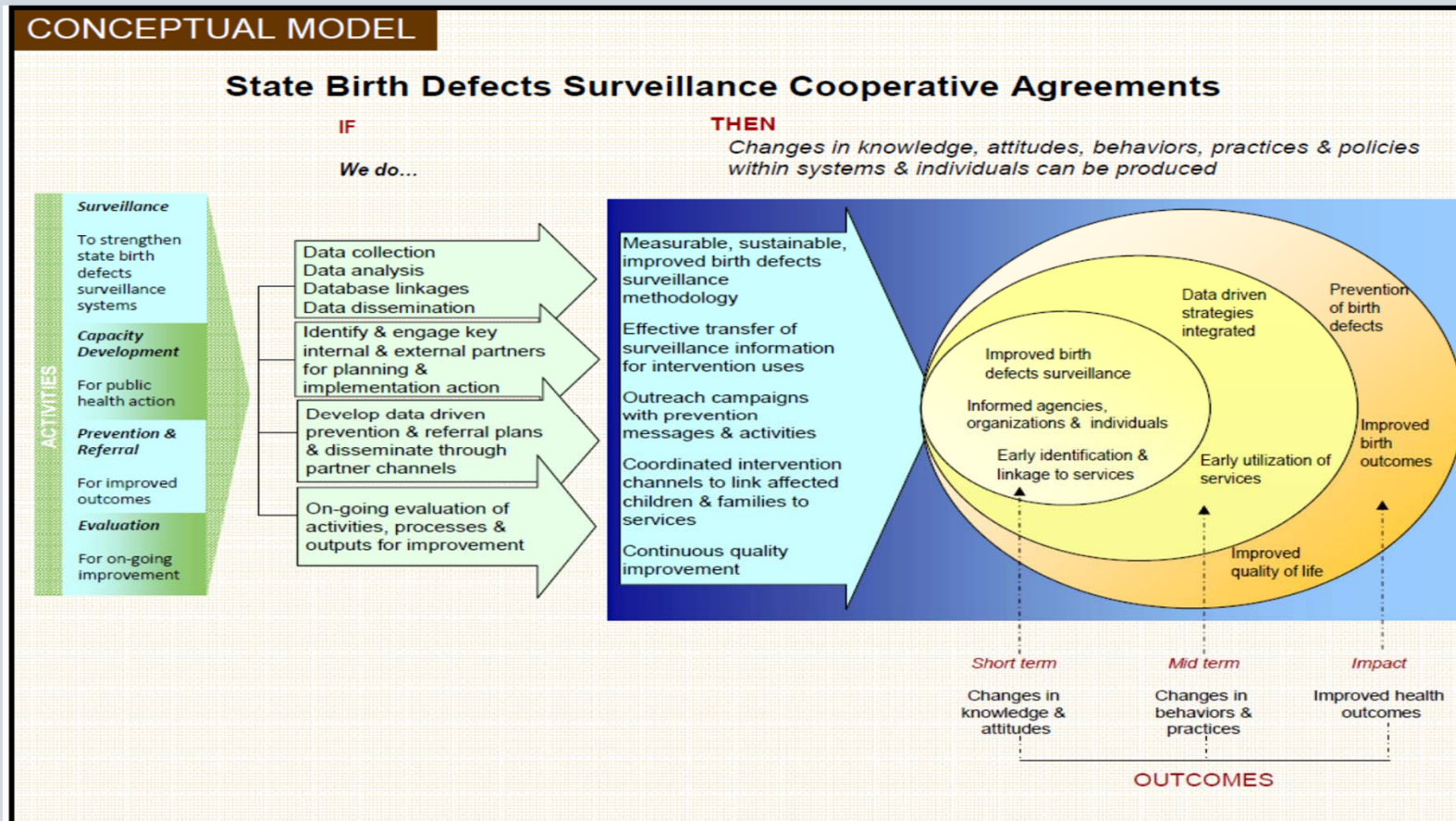
- Data used to identify high risk populations and prevention strategies are implemented.
- Plan to improve referral to health care and social services for individual with birth defects is documented and shared with CDC
- Facilitators and barriers to tracking children prospectively

Birth Defects Surveillance Programs: Primary Activities & Functions

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

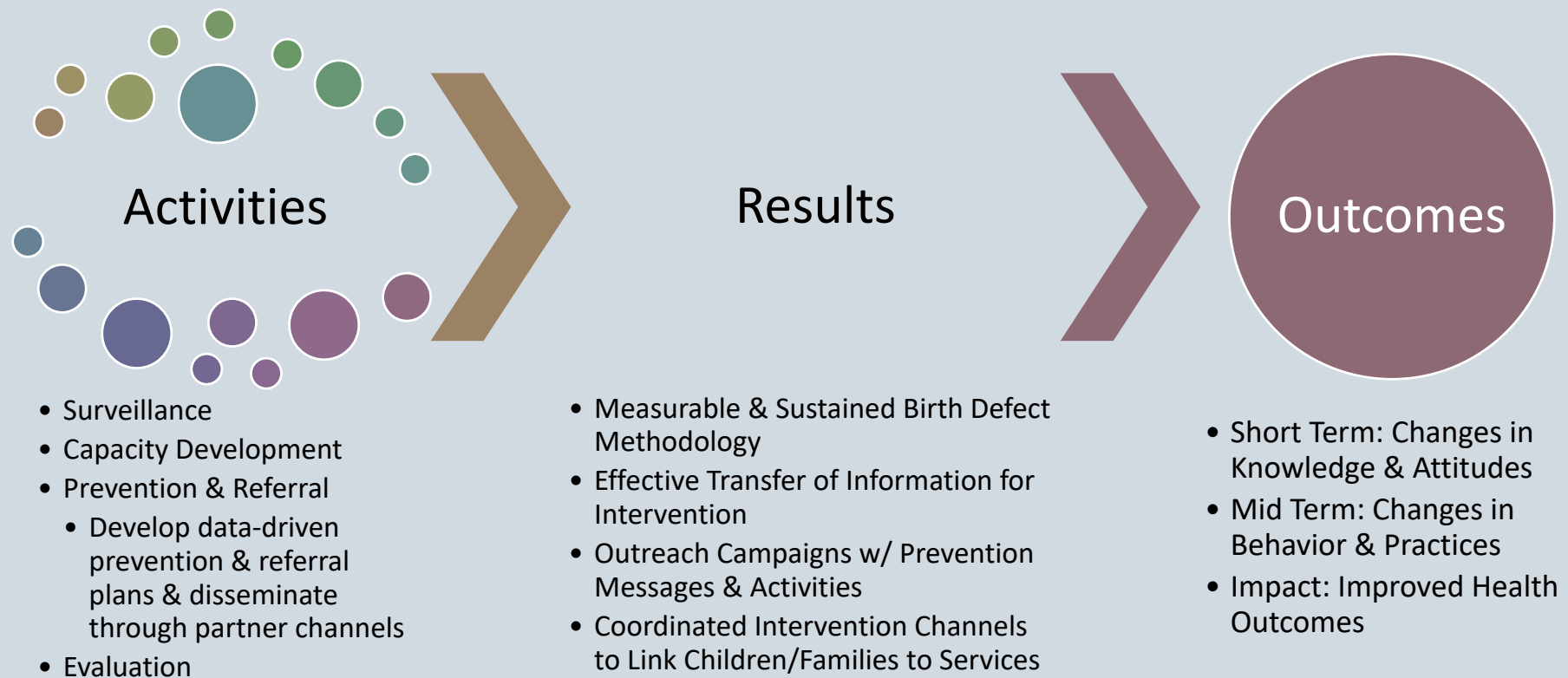
(AMCHP, 2022)

State BD Surveillance Cooperative Agreements Conceptual Model



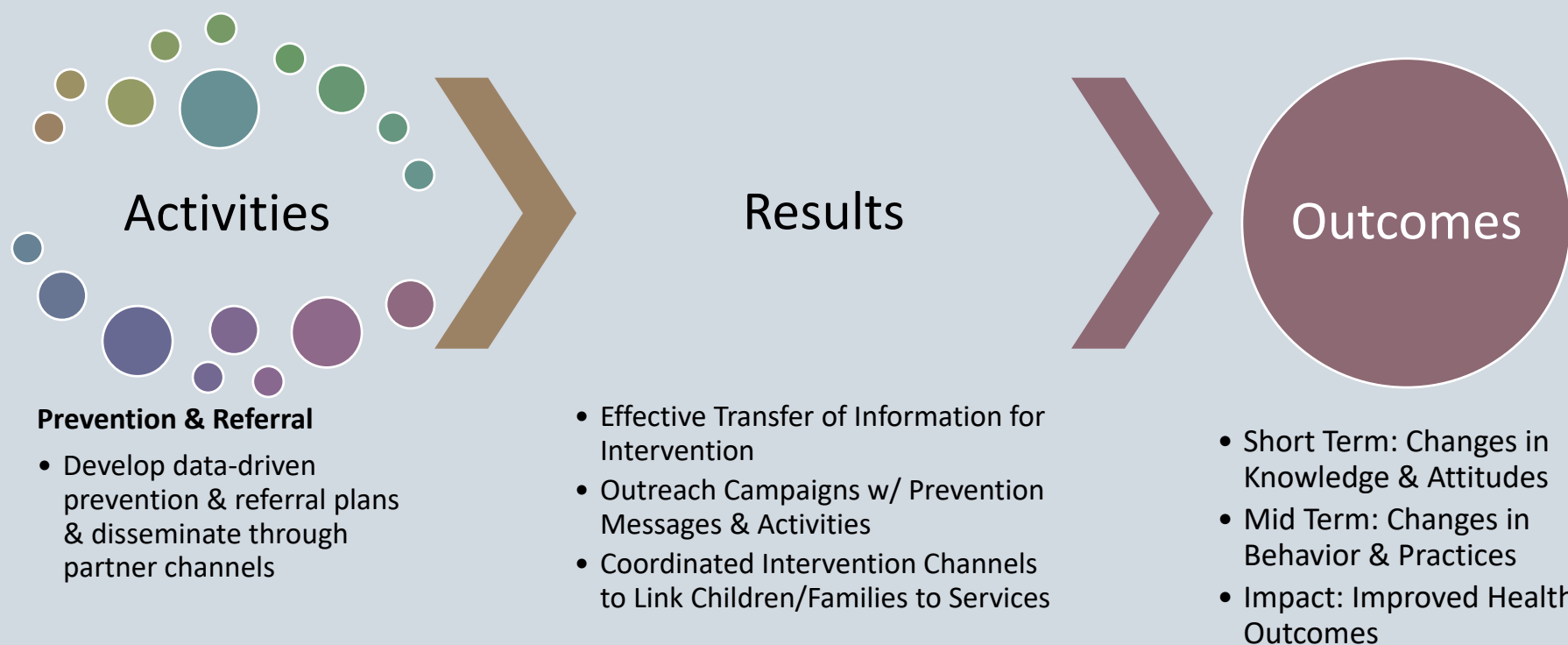
(Mai, Silverman, Boulet & Leary, 2009)

State BD Surveillance Cooperative Agreements Conceptual Model



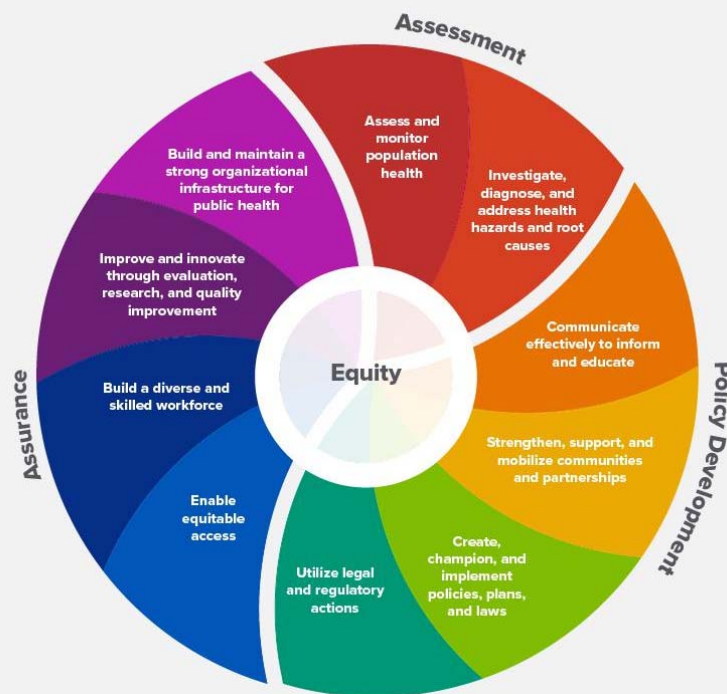
(Graphic based on Mai, Silverman, Boulet, & Leary, 2009)

State BD Surveillance Cooperative Agreements Conceptual Model - Prevention & Referral Focus



(Graphic based on Mai, Silverman, Boulet, & Leary, 2009)

THE 10 ESSENTIAL PUBLIC HEALTH SERVICES



Revised
10 Essential
Public Health Services

Revised 10 Essential Public Health Services

Assess and Monitor	<ul style="list-style-type: none">• Assess and monitor population health status, <u>factors that influence health, and community needs and assets</u>
Investigate & Diagnose	<ul style="list-style-type: none">• Investigate, diagnose, and <u>address</u> health problems and hazards affecting the population.
Inform & Educate	<ul style="list-style-type: none">• <u>Communicate effectively</u> to inform and educate people about health, factors that influence it, and how to improve it.
Support & mobilize communities & partnerships	<ul style="list-style-type: none">• <u>Strengthen, support, and mobilize communities and partnerships to improve health.</u>
Implement Policies and Plans	<ul style="list-style-type: none">• Create, champion, and implement policies, plans, and laws that impact health.
Legal & Regulatory Actions	<ul style="list-style-type: none">• Utilize legal and regulatory actions designed <u>to improve</u> and protect the public's health.
Ensure Access to Services	<ul style="list-style-type: none">• Assure an effective system that <u>enables equitable access to the individual services and care needed to be healthy.</u>
Skilled Public Health Workforce	<ul style="list-style-type: none">• Build and support a <u>diverse</u> and skilled public health workforce.
Evaluation, Research, and Quality Improvement	<ul style="list-style-type: none">• <u>Improve and innovate public health functions through ongoing evaluation, research, and continuous quality improvement.</u>
Research for New Insights and Innovative Infrastructure for Public Health	<ul style="list-style-type: none">• <u>Build and maintain a strong organizational infrastructure for public health.</u>

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

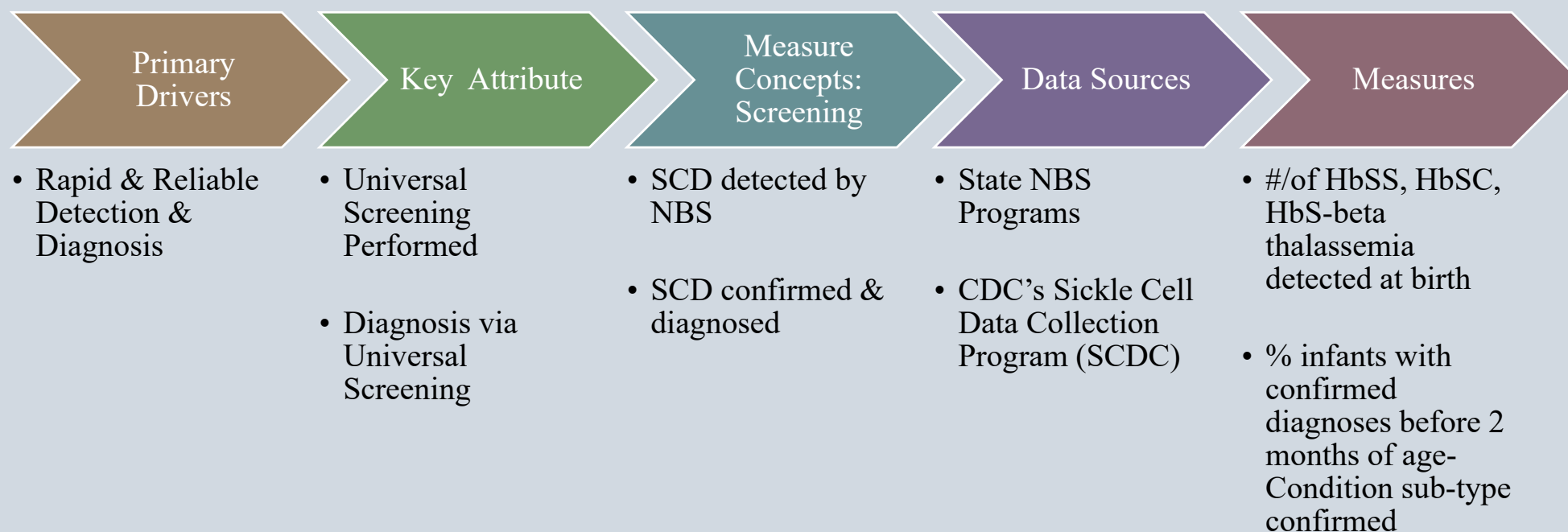
- Mortality
- Major Complications
- Function
- Growth & Development
- Patient/Family Experience
- Disparities

Graphic based on Hinton et al., 2016

Framework for Assessing Newborn Screening - Sickle Cell Disease

Aim – Rapid/Reliable Detection & Diagnosis

Example 1

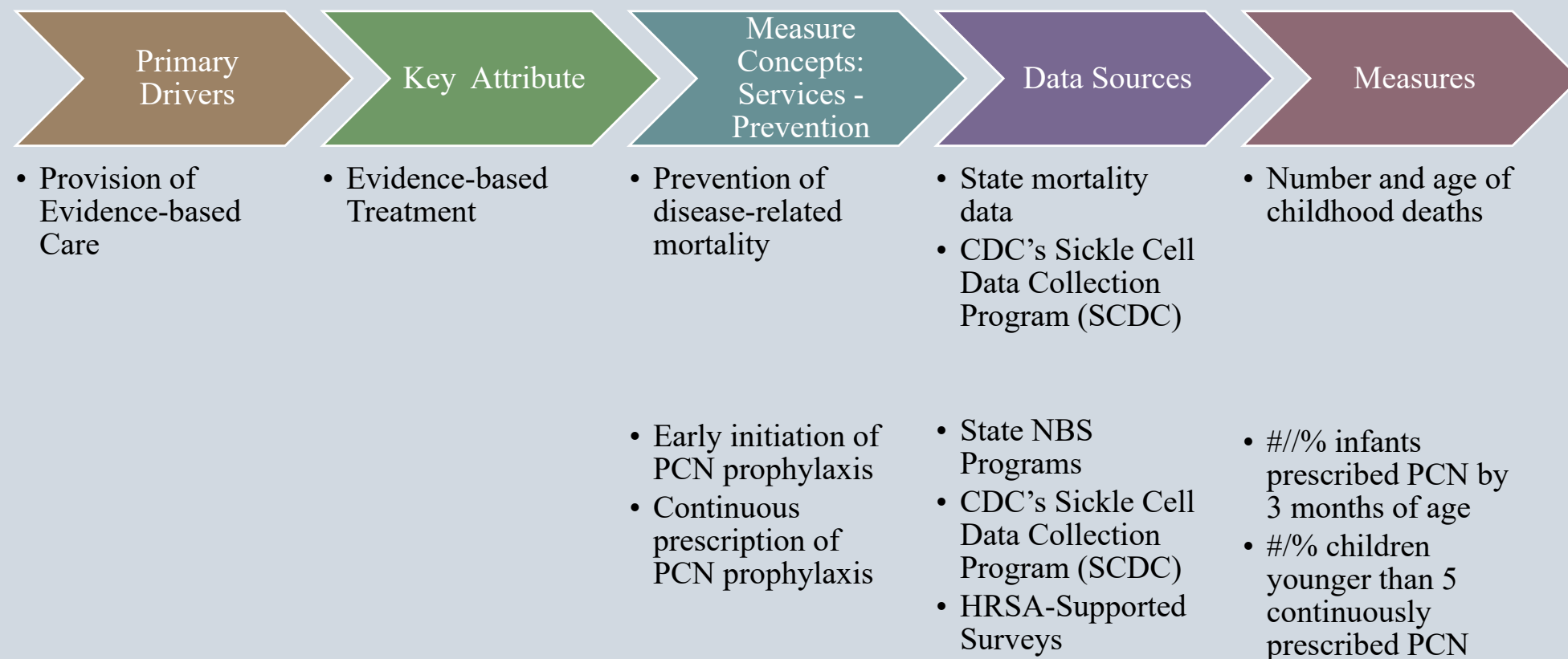


Graphic based on Hinton et al., 2016

Framework for Assessing Newborn Screening

Aim – Provision of Evidence-based Care for SCD

Example 2

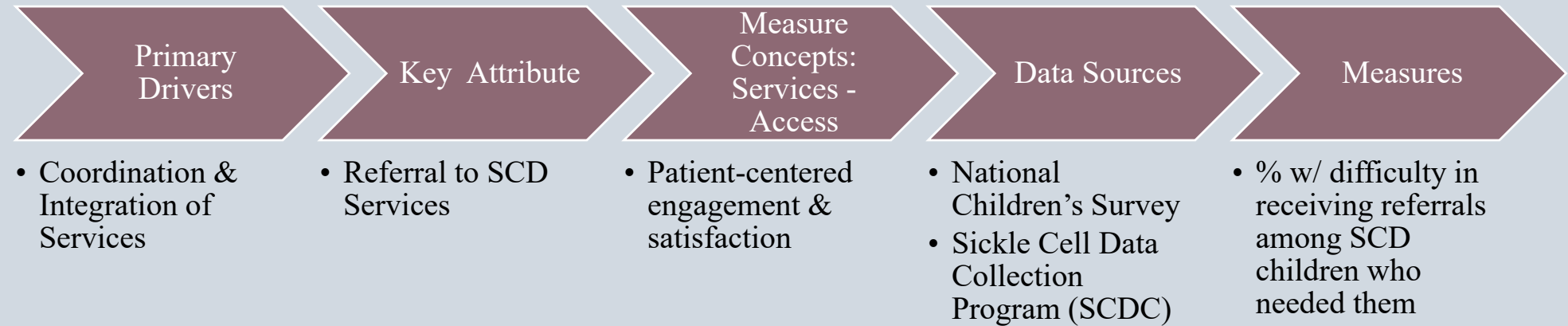


Graphic based on Hinton et al., 2016

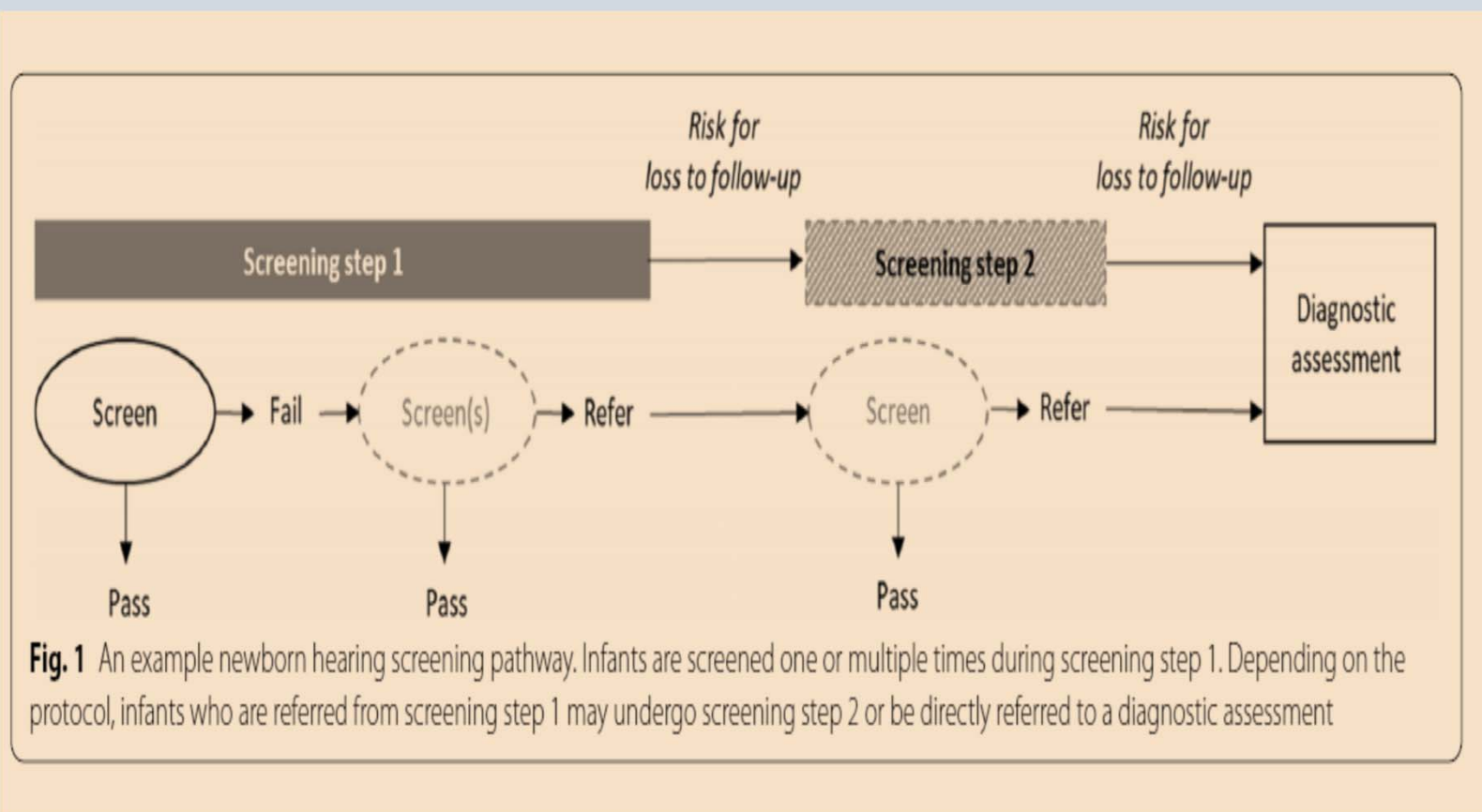
Framework for Assessing Newborn Screening

Aim – Coordination & Integration of SCD Services/Interventions

Example 3



Example: Protocol and Program Factors Associated with Referral and Loss to follow-up from Newborn Hearing Screening: A Systematic Review

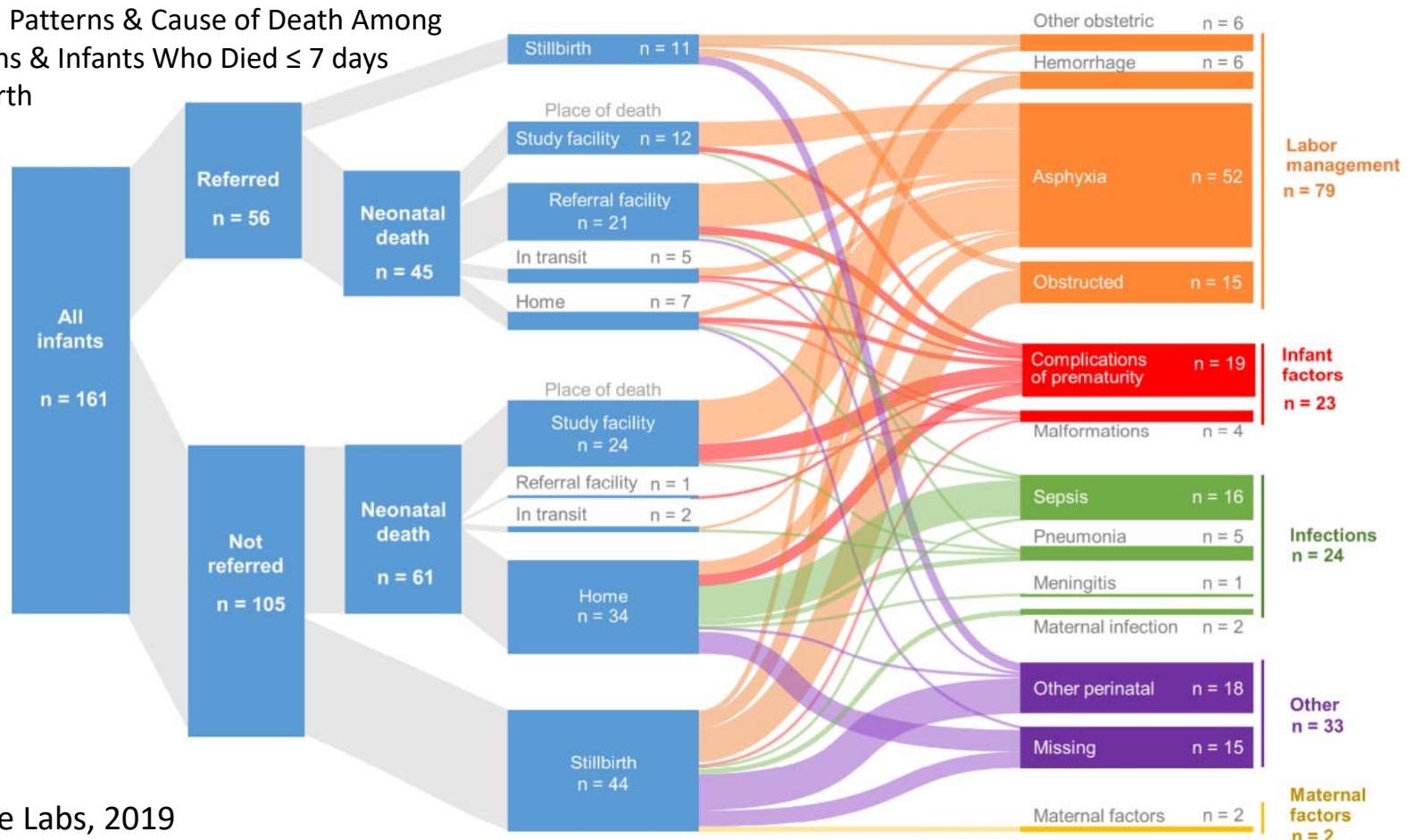


Example: Protocol and program factors associated with referral and loss to follow-up from newborn hearing screening: a systematic review

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

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!)

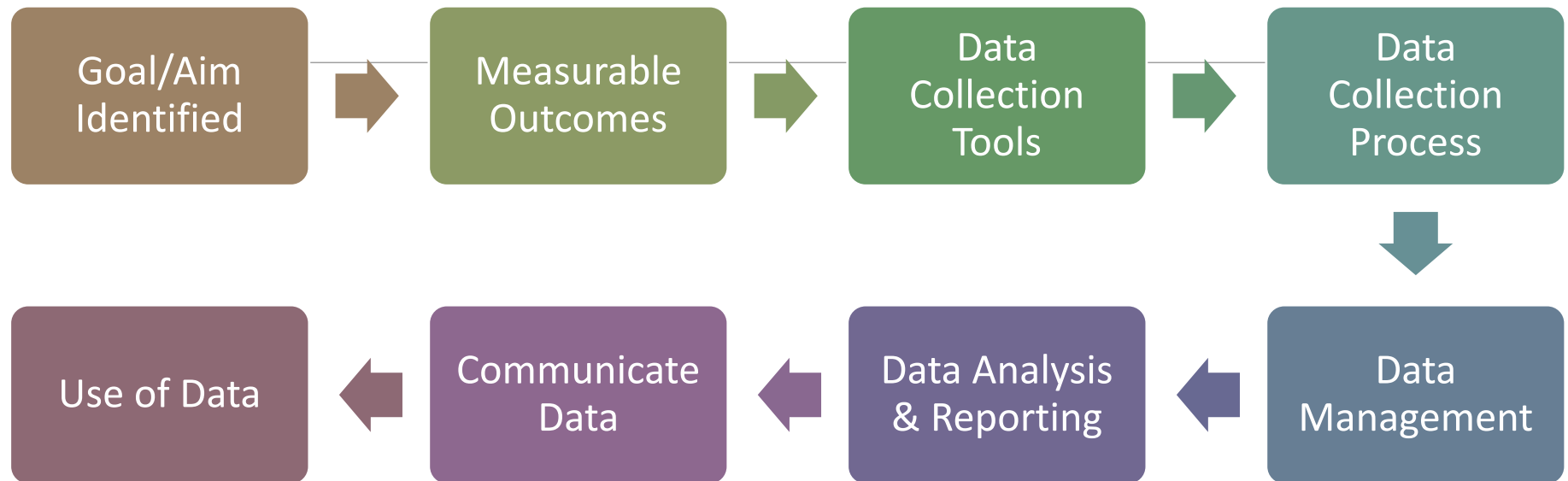
- Wilder Collaboration Factors Inventory (Wilder Foundation)
- Collaboration Assessment Tool (Prevention Institute)
- Power Awareness Tool (Partos/The Spindle)

*Center for Substance Abuse Treatment, 2000

V-RTable Talk



Where Is Your Program?



- 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

BDES Family Outreach Evaluation Form

SurveyMonkey ID: _____

Insurance Type: ☐ Medicaid ☐ Private ☐ Not Insured ☐ Unknown ☐ Other: _____

Identify number of attempts to contact by: Letter(s) Mailed: _____ Phone call(s): _____ Home Visit(s): _____

Social Worker Assessment

1. Please select the outcome of your attempt to contact the family:

- ☐ Able to contact and complete evaluation form.
- ☐ Able to contact but did NOT complete form/family declined assistance (continue to Social Worker Contact Information)
- ☐ Able to contact but family no longer lives in Texas. (continue to Demographics)
- ☐ Unable to contact. (continue to Social Worker Contact Information)
- ☐ Child is deceased. (continue to Social Worker Contact Information)

1a. How was your successful contact completed?

- ☐ Phone call
- ☐ In person/home visit

2. When was [client] diagnosed with [defect/list defects]?

- ☐ During pregnancy
- ☐ At birth/delivery (while mother was in hospital for delivery)
- ☐ After delivery/discharge from facility
- ☐ Does not know/remember
- ☐ Parent indicates child was misdiagnosed or does not have a birth defect (continue to Demographics)

3. Has [client] been meeting developmental milestones (i.e. - not falling behind physically or in their learning)? Please review CDC's Developmental Milestones checklist (provided at caseload distribution) based on child's age.

- ☐ Yes
- ☐ No

3a. Has family been told by a healthcare provider (doctor, nurse, physical therapist etc.) that [client] is not meeting developmental milestones?

- ☐ Yes
- ☐ No

Program Services Currently Receiving and Referred

4. Select all boxes for services the child or guardian is either "Receiving," or has been "Referred" to by the social worker. If service is not applicable or family declines the service, select "N/A". If the service is unavailable or there is another barrier to access, please select "Unavailable". If the family is already on a waitlist to receive the service prior to the social work contact, select "On Waitlist".

	On Waitlist	Receiving	Referred	N/A	Unavailable
Pediatrician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialty Care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dental	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical/Speech/Occupational Therapies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Audiologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical Transportation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicaid Waiver Program	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health Insurance Premium Payment (HIPP) Program	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Supplemental Security Income (SSI)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Supplemental Nutrition Assistance Program (SNAP)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Temporary Assistance for Needy Families (TANF)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Women, Infants, and Children (WIC)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community First Choice (CFC)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Texas BDR Family Outreach Referrals (2)

Referrals to Programs

Referral Category	Programs in Referral Category	% of Referrals Made (n=3,097)
Family Support	<ul style="list-style-type: none"> • Counseling services • Immigration/Legal Assistance • Parent training and information centers (PTI) • TX Parent to Parent • English as a Second Language (ESL) • Parenting classes • Share Program 	29%
Developmental	<ul style="list-style-type: none"> • Community First Choice (CFC) • Early Childhood Intervention (ECI) • Personal Care Service • Skilled Nursing Care • Head Start • Children with Special Healthcare Needs (CSHCN) • Driscoll high-risk clinic • School programs 	29%
Financial Assistance	<ul style="list-style-type: none"> • Medicaid Waiver Program • Health Insurance Premium Payment (HIPP) Program • Supplemental Security Income (SSI) • Supplemental Nutrition Assistance Program (SNAP) • Temporary Assistance for Needy Families (TANF) • Women Infants and Children (WIC) • Child Support 	28%
Medical/Dental	<ul style="list-style-type: none"> • Pediatrician • Specialty Care • Dental • Physical/Speech/Occupational therapy • Audiologists • Medical Transportation 	14%