INNOVATIONS IN CHILD MALTREATMENT SURVEILLANCE:

Using Data to Move Towards Prevention

Essentials for Childhood
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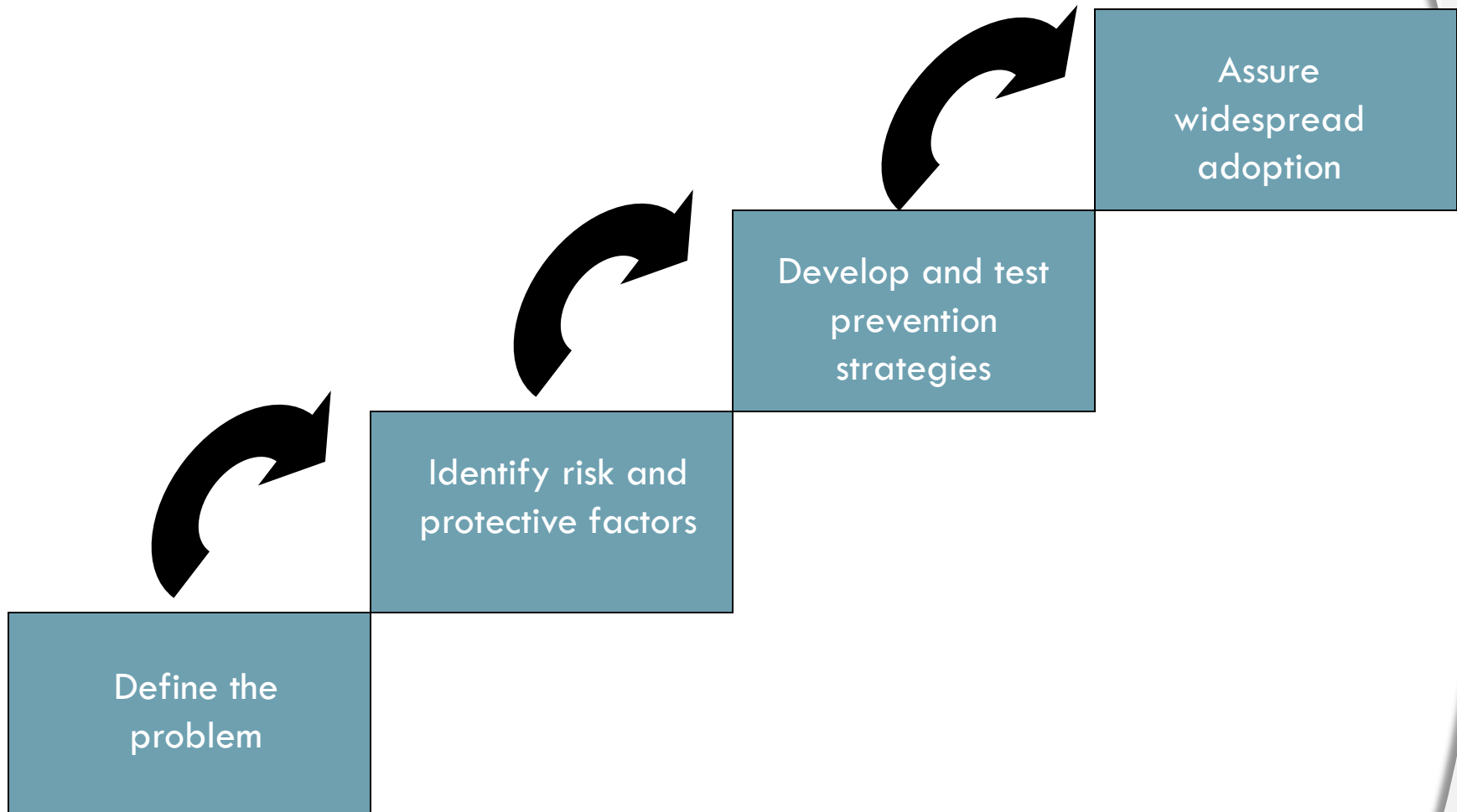University of North Carolina at Chapel Hill, Injury Prevention Research Center

Agenda

- Child Maltreatment (CM) from a Public Health Perspective
- Introducing PH Surveillance
  - What it is and is not
  - Objectives and types of PH surveillance
  - General CM PH surveillance
- Wake County Project
- Alaska Project

Applying a public health lens

- Burden of disease
- Risk factors
- Consequences (morbidity and mortality)
- Treatment
- Prevention
- Program evaluation
- Informing policy

Public Health Model

Define the problem → Identify risk and protective factors → Develop and test prevention strategies → Assure widespread adoption

Centers for Disease Control and Prevention. Injury Center: Violence Prevention. The public health approach to violence prevention. Available at: http://www.cdc.gov/ViolencePrevention/overview/publichealthapproach.html. Accessed on April 23rd, 2012.

Defining the Problem

- National Incidence Studies (NIS)
- CPS Reports
- Self-report
- Hospital discharge data

Public Health Surveillance

* Need reliable information about the status of disease in service population

* Process of collection, managing, analysis, interpretation, and reporting is surveillance

* Generally used to describe when and where health problems occur and who is affected

* Most commonly used to monitor the occurrence of disease over time

What is PH surveillance?
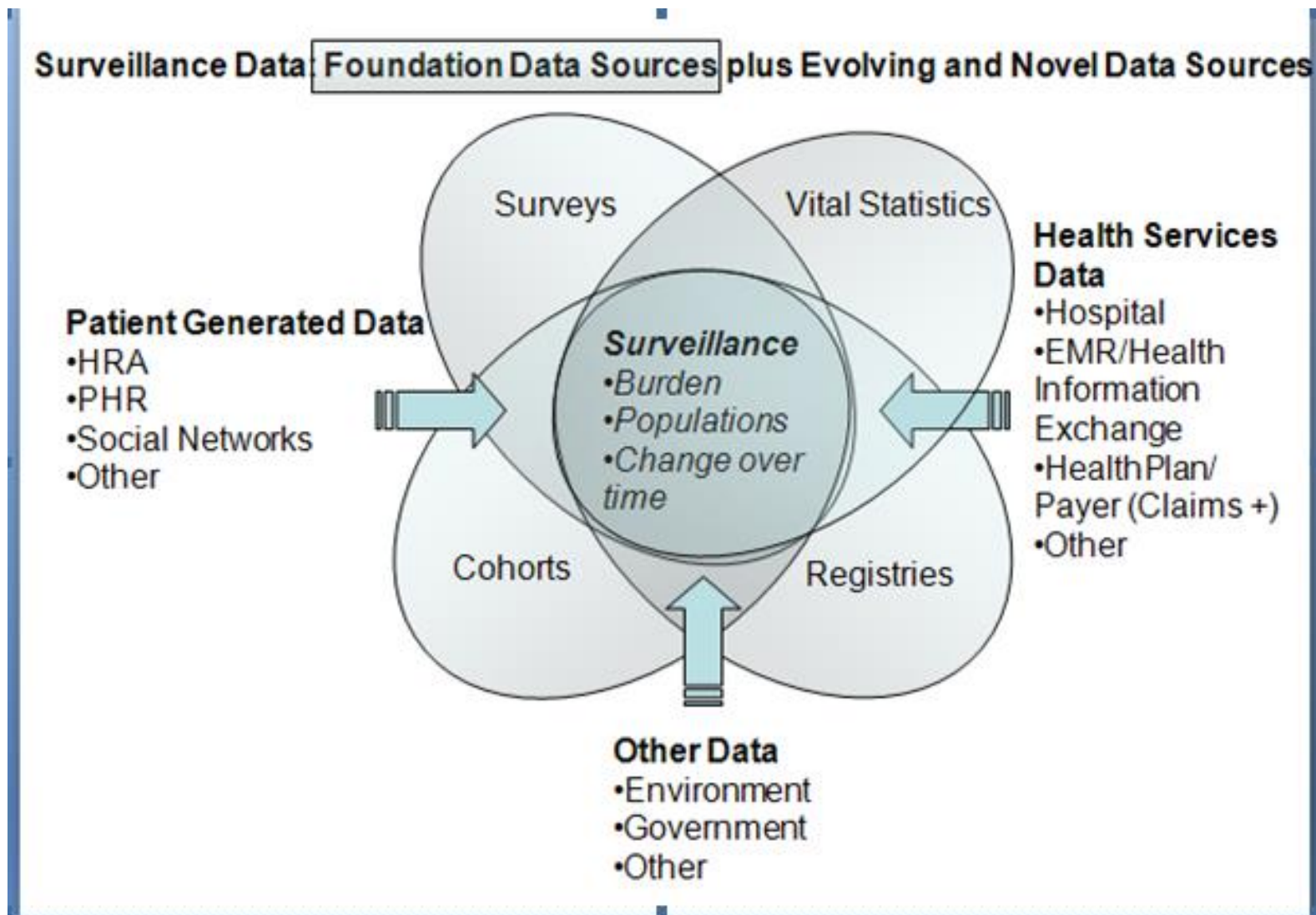
- General definition
  - <u>Ongoing</u> <u>systematic</u> assessment of <u>health</u> of a community, including <u>timely</u> collection, analysis, interpretation, dissemination, and subsequent use of data.
  - Ongoing scrutiny, using methods distinguished by their practicability, uniformity, and frequently their rapidity, rather than by complete accuracy.

The various objectives of Surveillance Studies

- Guide public health action
- Measure burden of disease
- Monitor disease trends
- Guide planning, implementation and evaluation of public health programs
- Evaluate public policy
- Detect changes in health practices
- Prioritize health resources
- Describe clinical course of disease
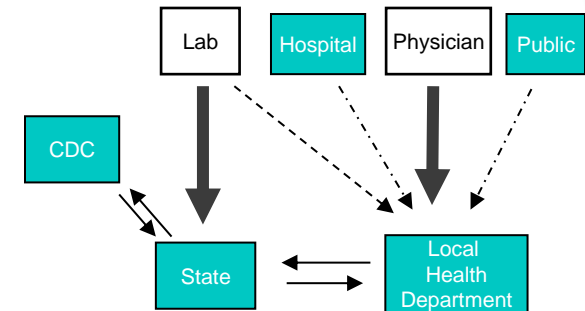- Provide basis for epidemiologic research

Where do surveillance data generally come from?

Surveillance Data: Foundation Data Sources plus Evolving and Novel Data Sources

Patient Generated Data
- HRA
- PHR
- Social Networks
- Other

Surveys

Vital Statistics

Health Services Data
- Hospital
- EMR/Health Information Exchange
- Health Plan/Payer (Claims +)
- Other

Surveillance
- *Burden*
- *Populations*
- *Change over time*

Cohorts

Registries

Other Data
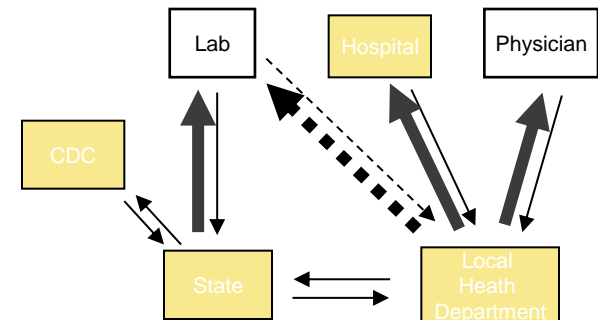- Environment
- Government
- Other

Type of surveillance studies

- Passive – routine notifiable disease
  - Simple, easy to maintain
  - Based on a standard case definition
  - Suffer from incompleteness

- Active – researcher contacts sources
  - Complete case ascertainment is desired
  - Often expensive
  - Outbreak investigations

- Syndromic – monitor indicators
  - Early detection of clusters
  - Clinical signs that we can categorize into syndromes
  - Low sensitivity and specificity
  - **NOT** a specific diagnosis!

Child Maltreatment (CM) Surveillance

Predominate approaches: multi-source linkages, and survey

Short list of examples:

- **Child maltreatment in Missouri: combining data for public health surveillance.** Schnitzer PG, Slusher P, Van Tuinen M. Am J Prev Med. 2004 Dec;27(5):379-84.

- **Building an effective child maltreatment surveillance system in North Carolina.** Zolotor AJ, Motsinger BM, Runyan DK, Sanford C. N C Med J. 2005 Sep-Oct;66(5):360-3.

- **A Public Health Approach to Child Maltreatment Surveillance: Evidence from a Data Linkage Project in the United States.** Emily Putnam-Hornstein[*], Daniel Webster, Barbara Needell, Joseph Magruder Child Abuse Review. 2011;20(4);256–73.

- **Tracking Child Abuse and Neglect: The Role of Multiple Data Sourced in Improving Child Safety.** Medina S, Sell K, Kavanagh J, Curtis C, Wood J. The Children's Hospital of Philadelphia, PolicyLab. 2012.

- **Children's Exposure to Violence: A Comprehensive National Survey.** Finkelhor D, Turner H, Ormrod R, Hamby S, Kracke K. U.S. DOJ Bulletin. 2009

Building CM surveillance

- Determine what the goal is (policy/prevention/intervention)
  - Comprehensive case ascertainment
  - Timely indicators of trend patterns…

- Establish partnerships
  - Become familiar with each others work!
  - NO "turf" wars
  - Public Health has a role in bringing agencies together and establishing cross-jurisdictional CM definitions and data

- Mortality and Morbidity surveillance (low hanging fruit)

Building CM surveillance cont.

- Common vision, not necessarily common definition between agencies

- Decision maker buy-in essential
  - Requires clear goals, objectives, and approach

- Jurisdictional boundaries are not constant across states or even counties (one size likely does not fit all)
  - Utility of data sources not always constant

Common CM surveillance data sources

- Child Protective Services Agency Data
- Hospital Administrative Data
- Death Certificate Data
- Law Enforcement Data
- Child Advocacy Center Data
- Juvenile Justice System Data
- Judiciary Data
- Survey Data (e.g. victimization study)
- Others…

Bringing data together

- It takes time!
  - Data sharing agreements
  - Public health authority (legal matters)
  - Bringing people together
- It takes data management!
  - Complex data linkages, translating data formats, development of decision processes, secure data storage
  - Ability to respond to individual agency changes in data management
  - The process must be repeatable! (systematic part)
- Once system established – don't change it
  - Take time during development

WAKE COUNTY CHILD MALTREATMENT SURVEILLANCE PROJECT

Overview

- 2005: NC IOM Task Force on Child Abuse Prevention recommendation
- IVPB received funding from John Rex Endowment to develop a child maltreatment surveillance system in Wake County
- Began December 2011

Project Goal

- Improve and expand child maltreatment tracking by developing a surveillance system and exploring potential linkages between already existing systems
- This goal will be accomplished by:
  - Assessing current data
  - Identifying data gaps
  - Create a surveillance system

Forming Partnerships

- Met with key stakeholders
  - CPS
  - Law enforcement
  - Wake County Child Protection Team
  - Medical examiner's office
  - Wake County DPH
  - Wake County Human Services
  - NC DSS
  - NC Child Fatality Task Force
  - Local hospital

Data Sources

- Current data sources
  - CPS records
  - Emergency department records
  - Medical examiner records
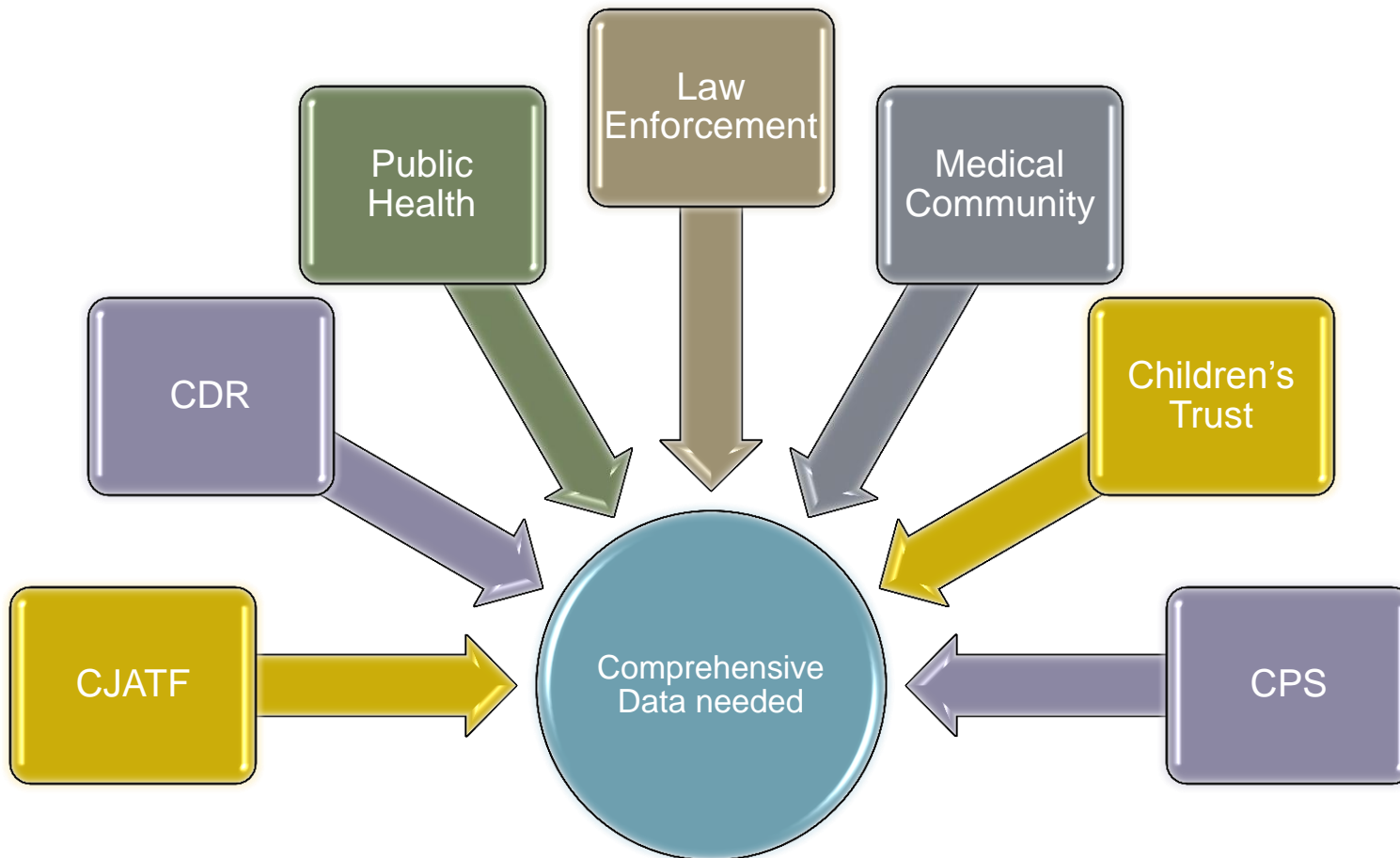 - Law enforcement

- Potential data sources?

Next steps

- Link datasets
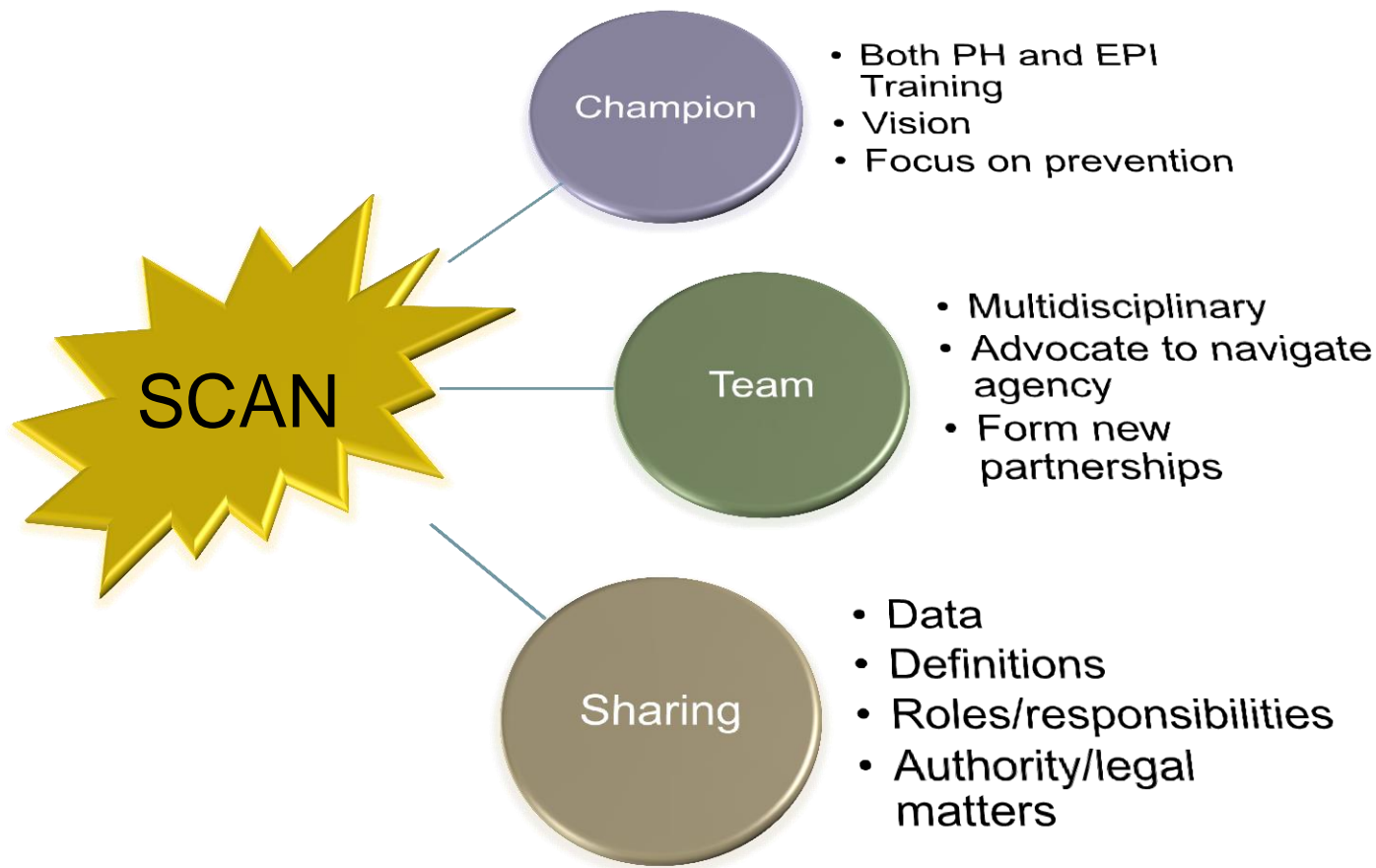- Analyze data
- Disseminate results
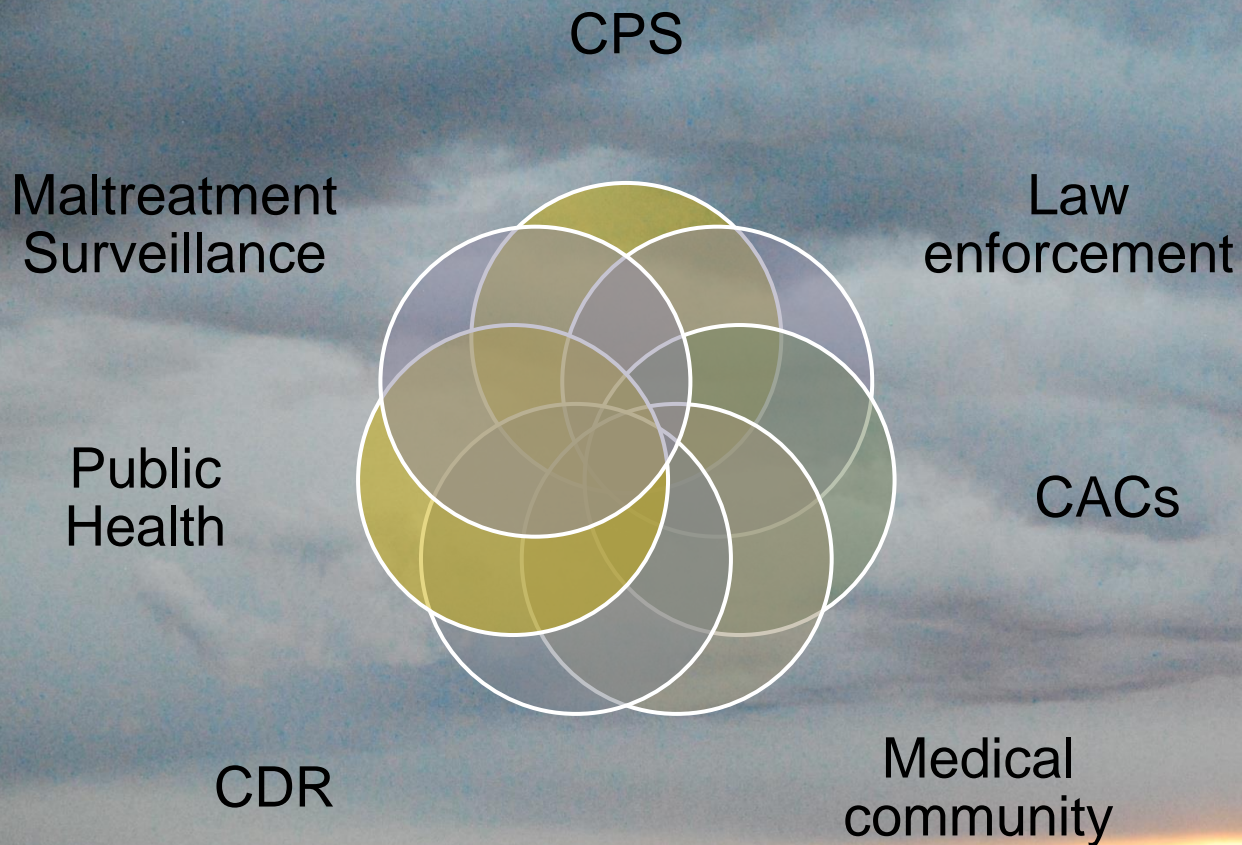
Recognition of a Need

- No single agency has jurisdictional responsibility for al CM: limited cross-discipline assessments of CM
- Need for a focus on prevention
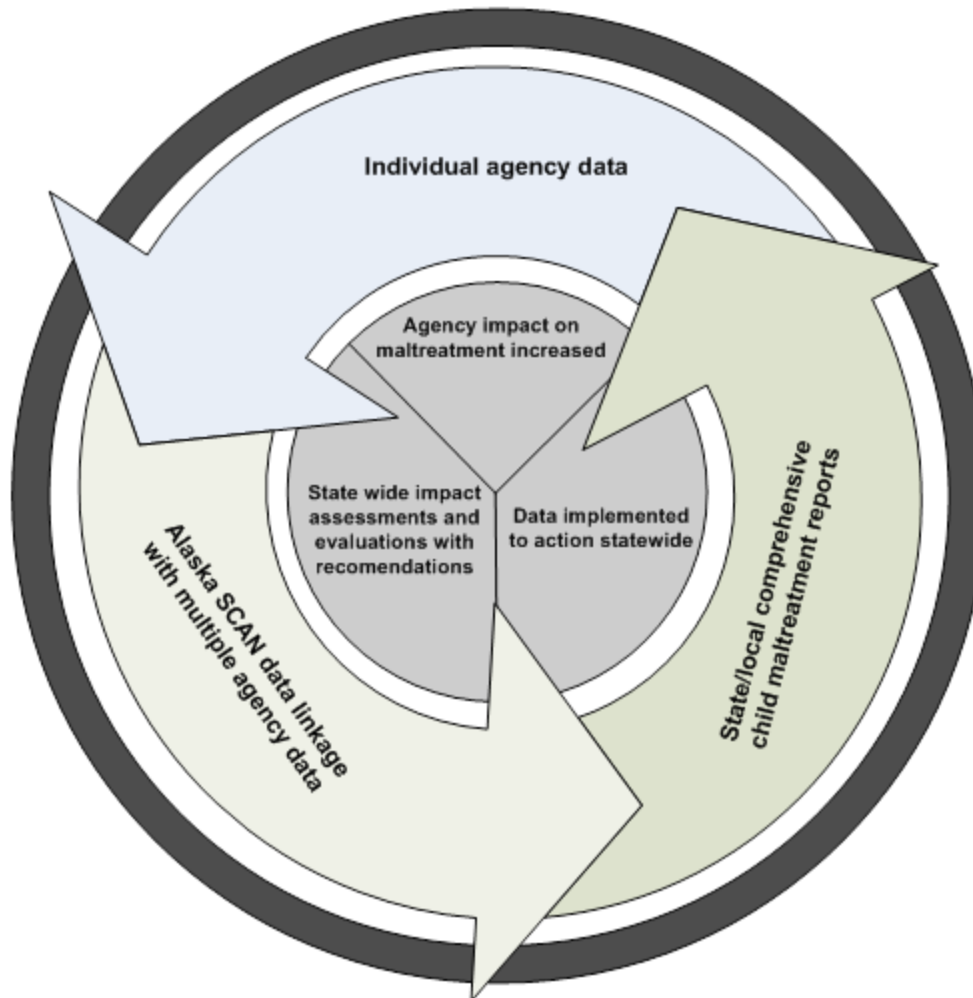
Establishing surveillance in AK: Key components

Champion
- Both PH and EPI Training
- Vision
- Focus on prevention

Team
- Multidisciplinary
- Advocate to navigate agency
- Form new partnerships

Sharing
- Data
- Definitions
- Roles/responsibilities
- Authority/legal matters

SCAN

Key partnerships

CPS

Law enforcement

CACs

Medical community

CDR

Public Health
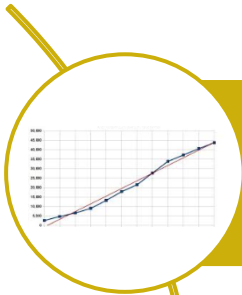
Maltreatment Surveillance
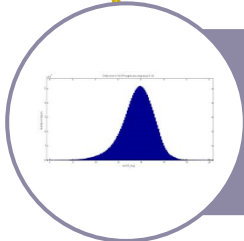
Interactive systems framework

SCAN goals

- Ongoing systematic collection and unification of existing data (data linkages)
    - Apply public health tiered definitions (working algorithms)
- Measure a more inclusive assessment of the problem over time (resistant to policy changes and staffing)
- Measure the life course of maltreatment
- Understand risk/protective factors
    - Targeted prevention efforts and evaluate interventions
    - Move from programs the "feel right" to those that "show impact"
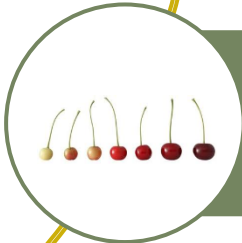
The Three components of SCAN

Surveillance

- Sentinel/sydromic approach
- Consistency and timeliness rather than complete case ascertainment
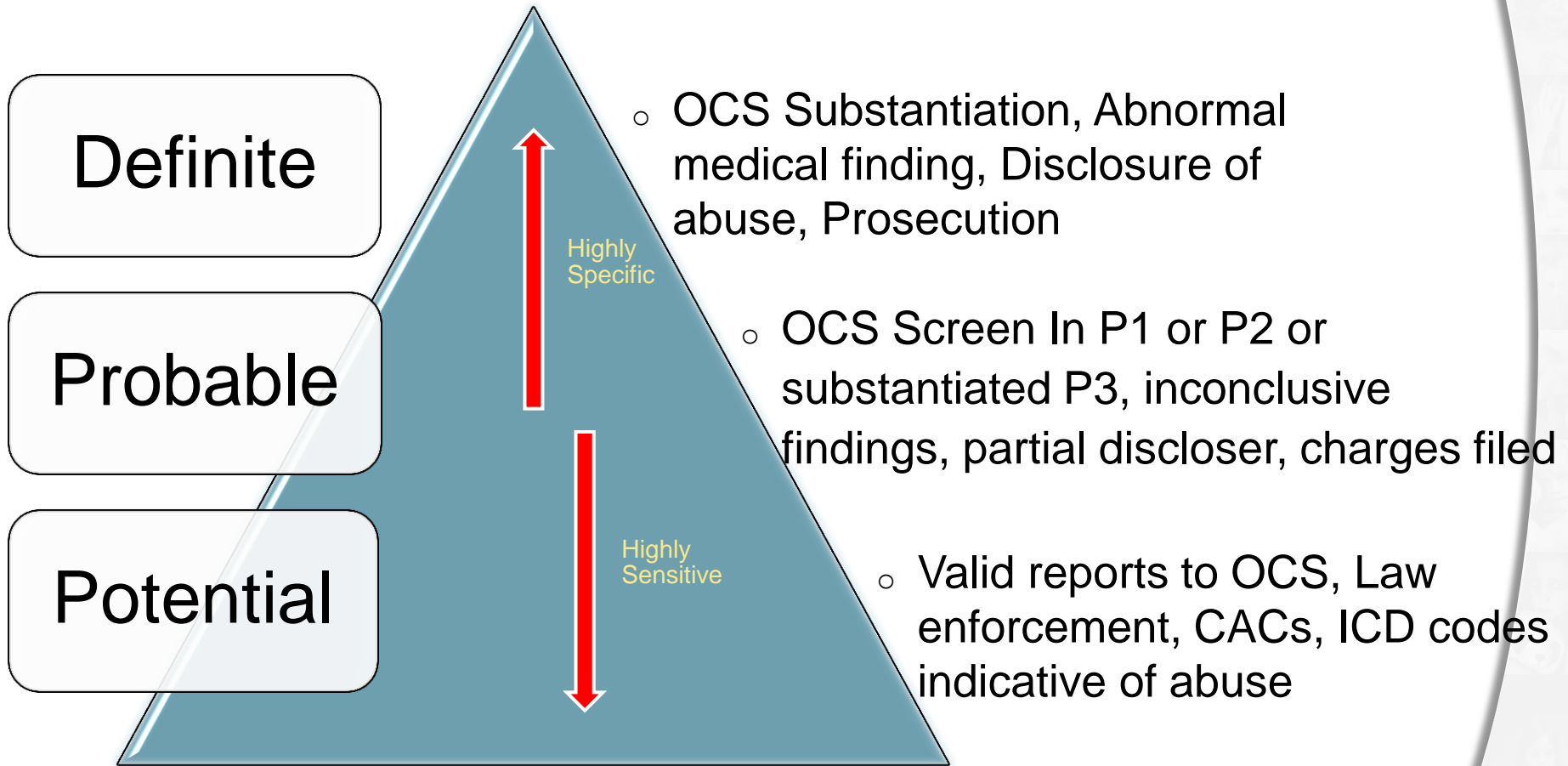
Magnitude Assessment

- Tri-annual statewide assessment
- Complete case ascertainment

Longitudinal life course

- Prospective 2008 birth cohort followed through data linkages
- Sub-cohort with expansive data linkages and methodology

Public Health Case Designation

Definite

Probable

Potential

Highly
Specific

Highly
Sensitive

○ OCS Substantiation, Abnormal medical finding, Disclosure of abuse, Prosecution

○ OCS Screen In P1 or P2 or substantiated P3, inconclusive findings, partial discloser, charges filed

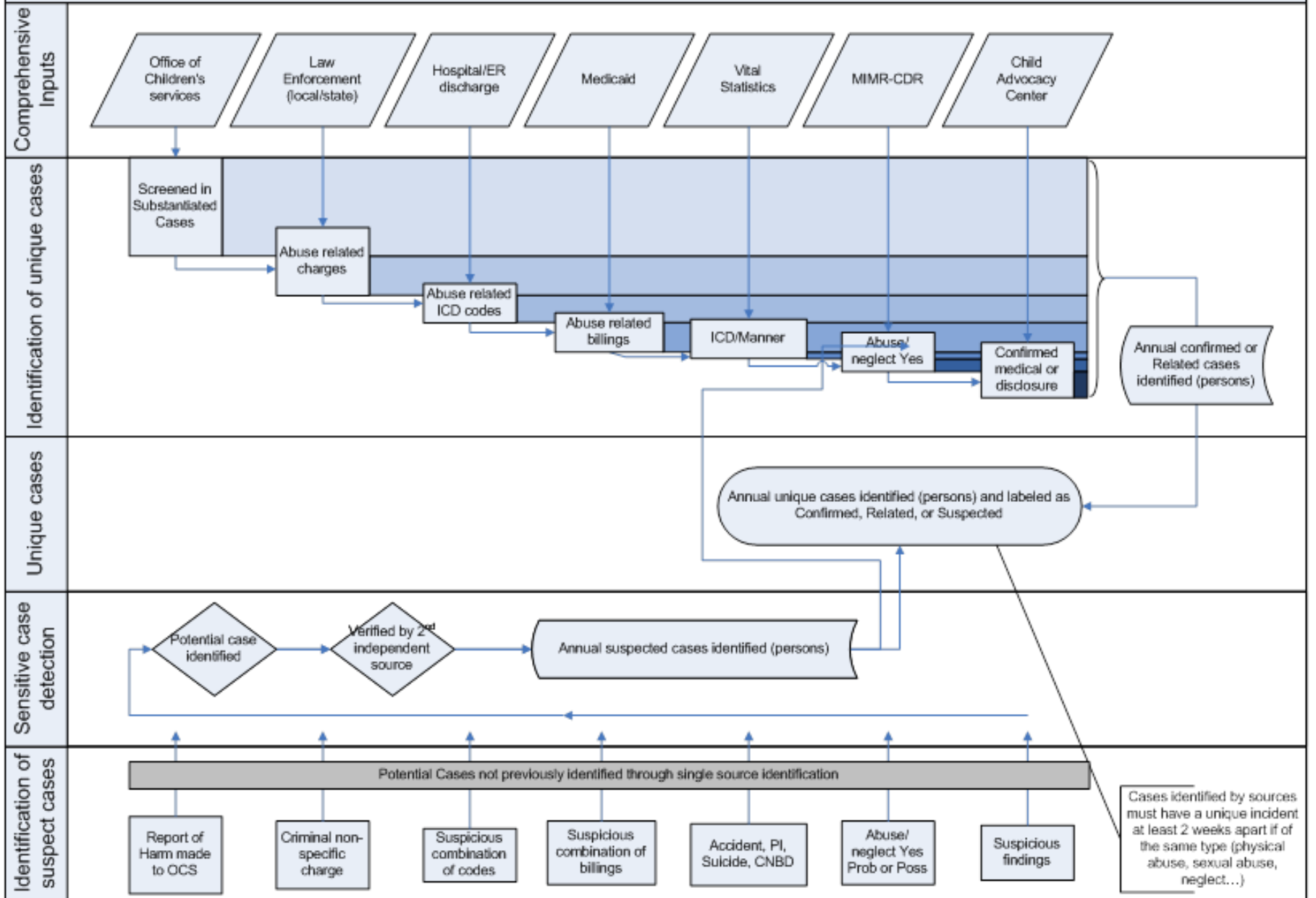○ Valid reports to OCS, Law enforcement, CACs, ICD codes indicative of abuse

Making Surveillance work

★ Sentinel site - surveillance CAC, OCS, Law enforcement, health clinic

Alaska surveillance of child abuse and neglect – Comprehensive cross-jurisdictional working case detection

Comprehensive Inputs

- Office of Children's services
- Law Enforcement (local/state)
- Hospital/ER discharge
- Medicaid
- Vital Statistics
- MIMR-CDR
- Child Advocacy Center

Identification of unique cases

- Screened in Substantiated Cases
- Abuse related charges
- Abuse related ICD codes
- Abuse related billings
- ICD/Manner
- Abuse/ neglect Yes
- Confirmed medical or disclosure
- Annual confirmed or Related cases identified (persons)

Unique cases

- Annual unique cases identified (persons) and labeled as Confirmed, Related, or Suspected

Sensitive case detection

- Potential case identified
- Verified by 2nd independent source
- Annual suspected cases identified (persons)

Identification of suspect cases

Potential Cases not previously identified through single source identification

- Report of Harm made to OCS
- Criminal non-specific charge
- Suspicious combination of codes
- Suspicious combination of billings
- Accident, PI, Suicide, CNBD
- Abuse/ neglect Yes Prob or Poss
- Suspicious findings

Cases identified by sources must have a unique incident at least 2 weeks apart if of the same type (physical abuse, sexual abuse, neglect…)

Demonstrative Data

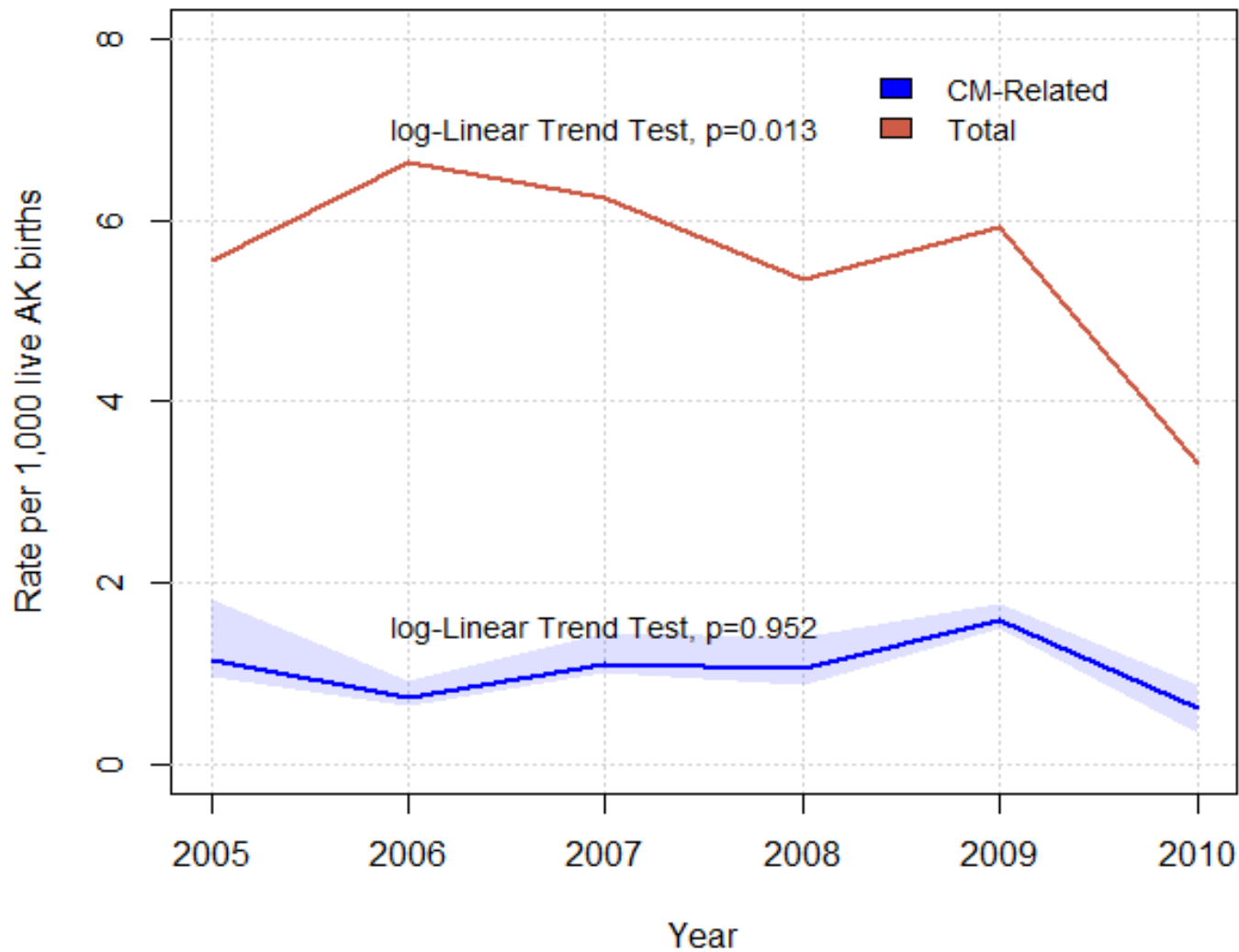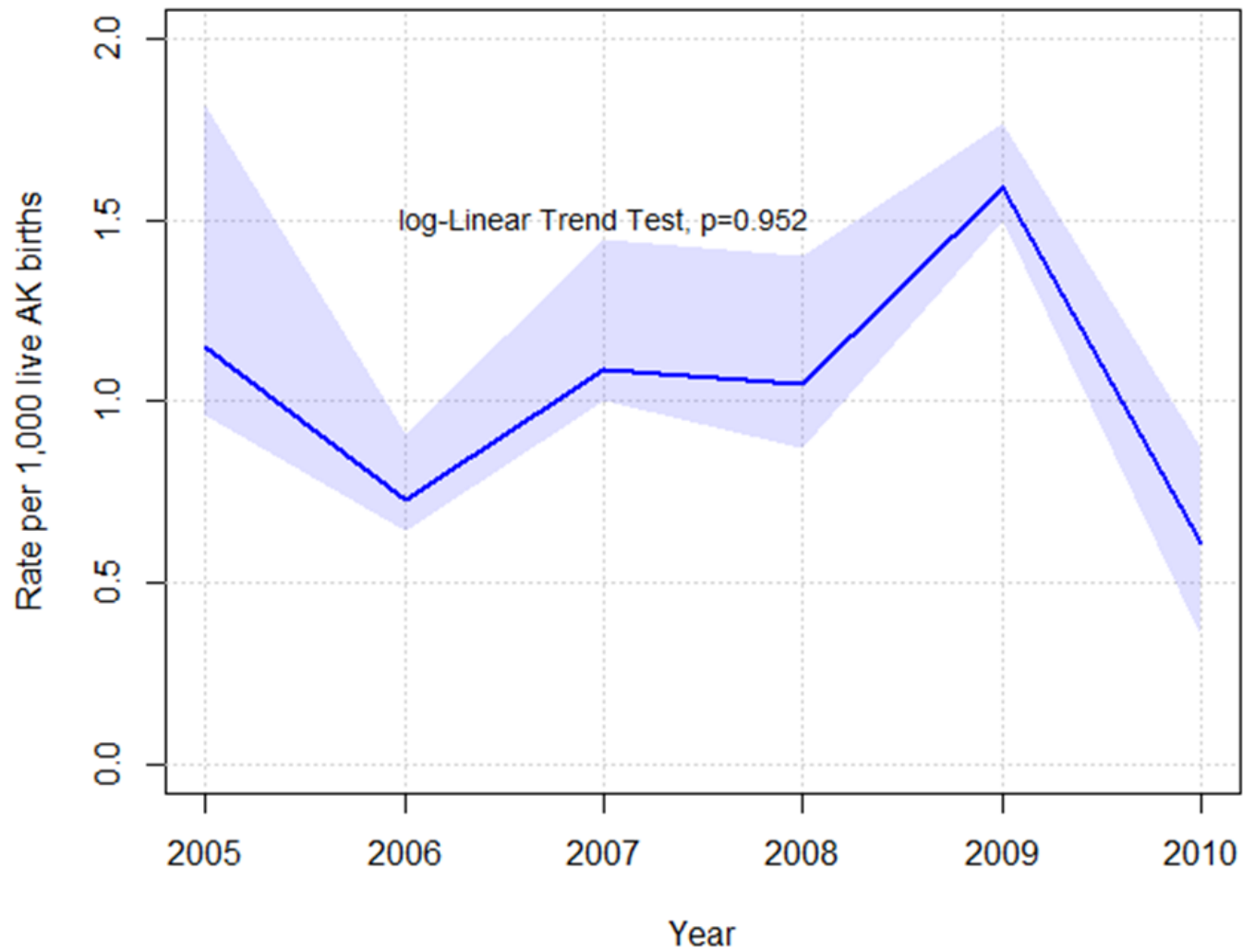# Infant maltreatment-related fatalities

- From 2005 - 2010
  - 366 infant deaths occurred
  - 69 (19%) were maltreatment-related
    - Abuse or neglect contributed or probably contributed, or if negligence contributed
  - Low as 16% and high as 25%
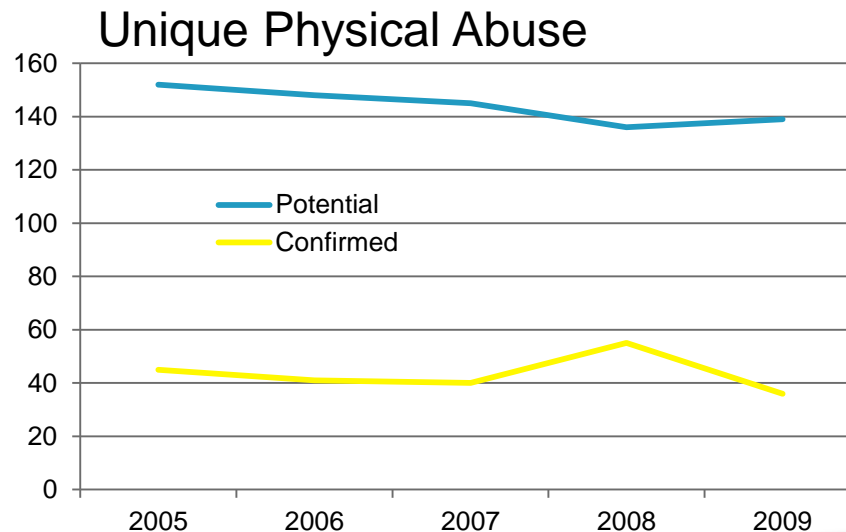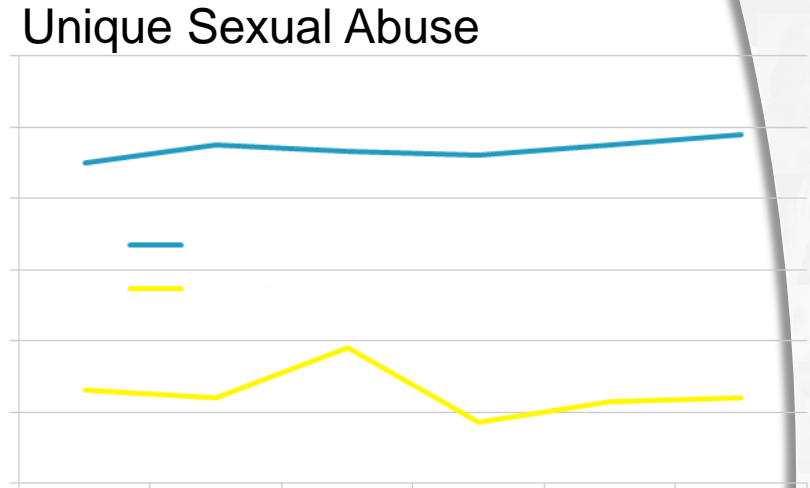   - Only definite abuse included, possible abuse or neglect or probable negligence included, respectively
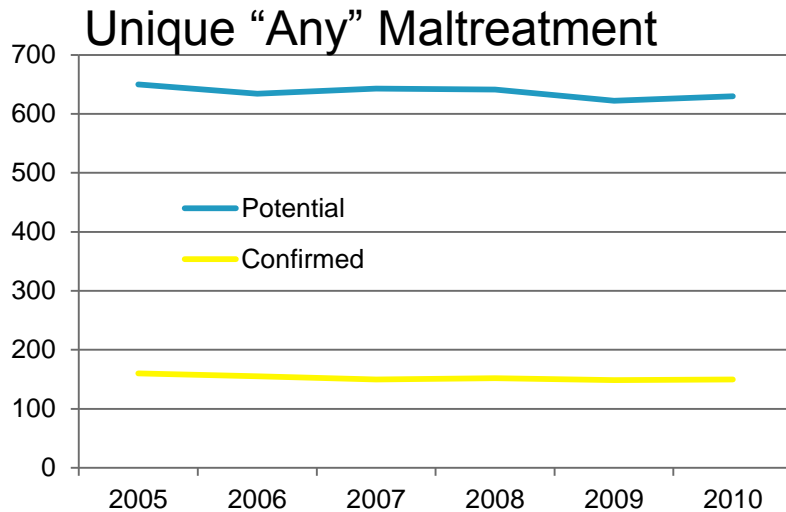
Alaska total infant and maltreatment-related mortality, Alaska 2005-2010

Alaska maltreatment-related
mortality, Alaska 2005-2010

log-Linear Trend Test, p=0.952

Maltreatment rates among children 0-17 yrs, during 2005-2010 (per 10,000 children)

Maltreatment by age 4

- 2,145 (19%) children with at least 1 allegation
  - 36% among Alaska Native, 13% non-Native
  - Crude HR 2.6 (95%CI 2.3, 2.8)
  - Adjusted* HR 1.4 (95%CI 1.3, 1.6)

  *adjusted for marital status, maternal age and education, and paternal name on birth certificate

Abusive Head Trauma

- Abusive Head Trauma (2005 – 2010)
  - 34.4 (95CI 25.1, 46.1) per 100,000 children <2 yrs
    - 56.0 (95%CI 39.4, 77.1) among infants
  - Detected 49% more AHT cases than any single source
- Single Source (Hospital Discharges):
  - North Carolina: 35.9 (95%CI 26.3, 47.7) per 100k infants
  - Alaska: 27.9 (95%CI 15.6, 46.0)

Two important lessons learned

1) Child Maltreatment algorithms broke down substantially at age 14, and performed the best for ages <10 years. (exception was SA).
    - Resulted in shift in focus.

2) Our first capture re-capture attempt failed.

Data usage

- Every year presented to State legislators alongside child protective services (strong relationship)
- Used to evaluate current home visitation and abusive head trauma prevention programs
- Working in partnership with law enforcement to address specific needs to aid in response
- Health department, CAC's, and Hospitals…
- AK Native/non-Native distinctions (Different issues require different types of prevention efforts)

SCAN Wrap-up

- For public health to operate, population based numbers are imperative
  - anecdotal prevention efforts to science based
- Relationships are about understanding roles and purpose, opposed to redefining jobs
  - A few minor 'modification' were needed by some agencies in the form of data collection to avoid repeated efforts…e.g. Child Death Review team was trained on PH definitions.
  - Operate within expertise!
- Formalize the process to avoid "starting over"
- Avoid the "road to nowhere" – definitions and agendas!

Conclusions

- CM is hard to measure accurately
- Public health surveillance may help us better quantify and describe child maltreatment
- Important to be flexible!
- Once system is established, need to be consistent

Questions?

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