INNOVATIONS IN CHILD MALTREATMENT SURVEILLANCE:

Using Data to Move Towards Prevention

South by Southwest Injury Control Network Webinar
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Agenda

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

Child Maltreatment

Act of commission (abuse) or omission (neglect) by a parent or other caregiver that results in harm, the potential for harm, or threat of harm to a child.

Leeb RT, Paulozzi L, Melanson C, Simon T, Arias I. Child Maltreatment Surveillance: Uniform Definitions for Public Health and Recommended Data Elements, Version 1.0. Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2008

Child maltreatment outcomes

- Child maltreatment has been associated with many negative outcomes
  - Immediate health and well-being
  - Long term consequences
    - Poor mental and emotional health
    - Cognitive difficulties
    - Social and behavioral problems
    - Physical health problems
  - Total lifetime cost: $124 billion/yr

Child Welfare Information Gateway. Long-term consequences of child abuse and neglect. Available at: http://www.childwelfare.gov/pubs/factsheets/long_term_consequences.cfm#summ. Accessed on March 1, 2012.

Fang X, Brown DS, Florence CS, Mercy JA. The economic burden of child maltreatment in the United States and implications for prevention. Child Abuse & Neglect 2012;36(2):156-165.

Adverse Childhood Experiences (ACE) Study

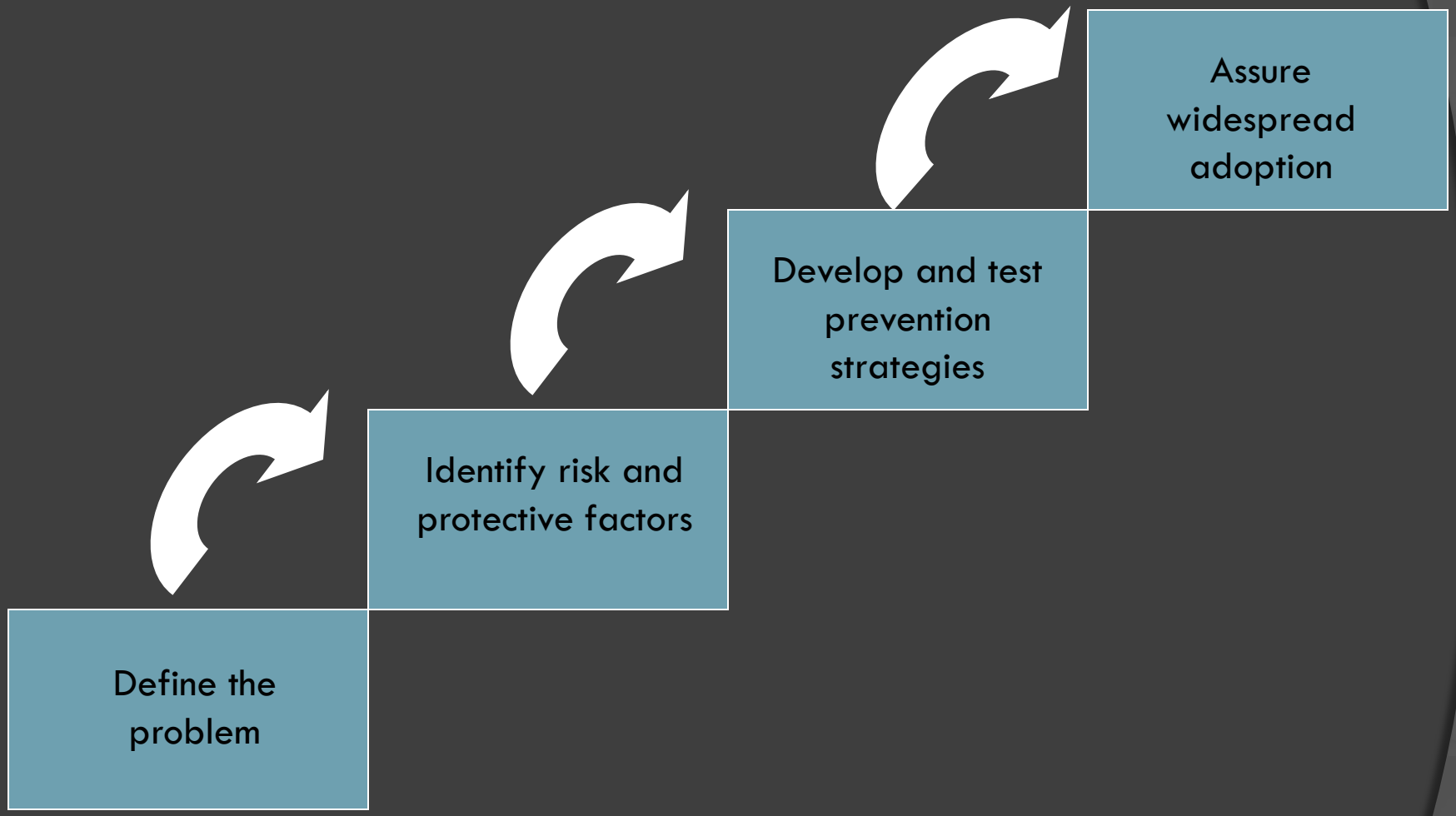
- Primary care setting
- >17,000 participants completed survey
- 26% had 1 ACE
- 12.5% had 4 or more ACEs
- Relationship between ACEs and numerous health problems

Centers for disease control and prevention. Adverse Childhood Experiences (ACE) Study. Data and Statistics. Prevalence of Individual Adverse Childhood Experiences. Available at: http://www.cdc.gov/ace/prevalence.htm
Felitti VJ, Anda RF, Nordenberg D, Williamson DF, Spitz AM, Edwards V, Koss MP, Marks JS. Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults: The adverse childhood experiences (ACE) study. Am J Prev Med 1998;14(4):245-257

Applying a public health lens

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

Public Health Model



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

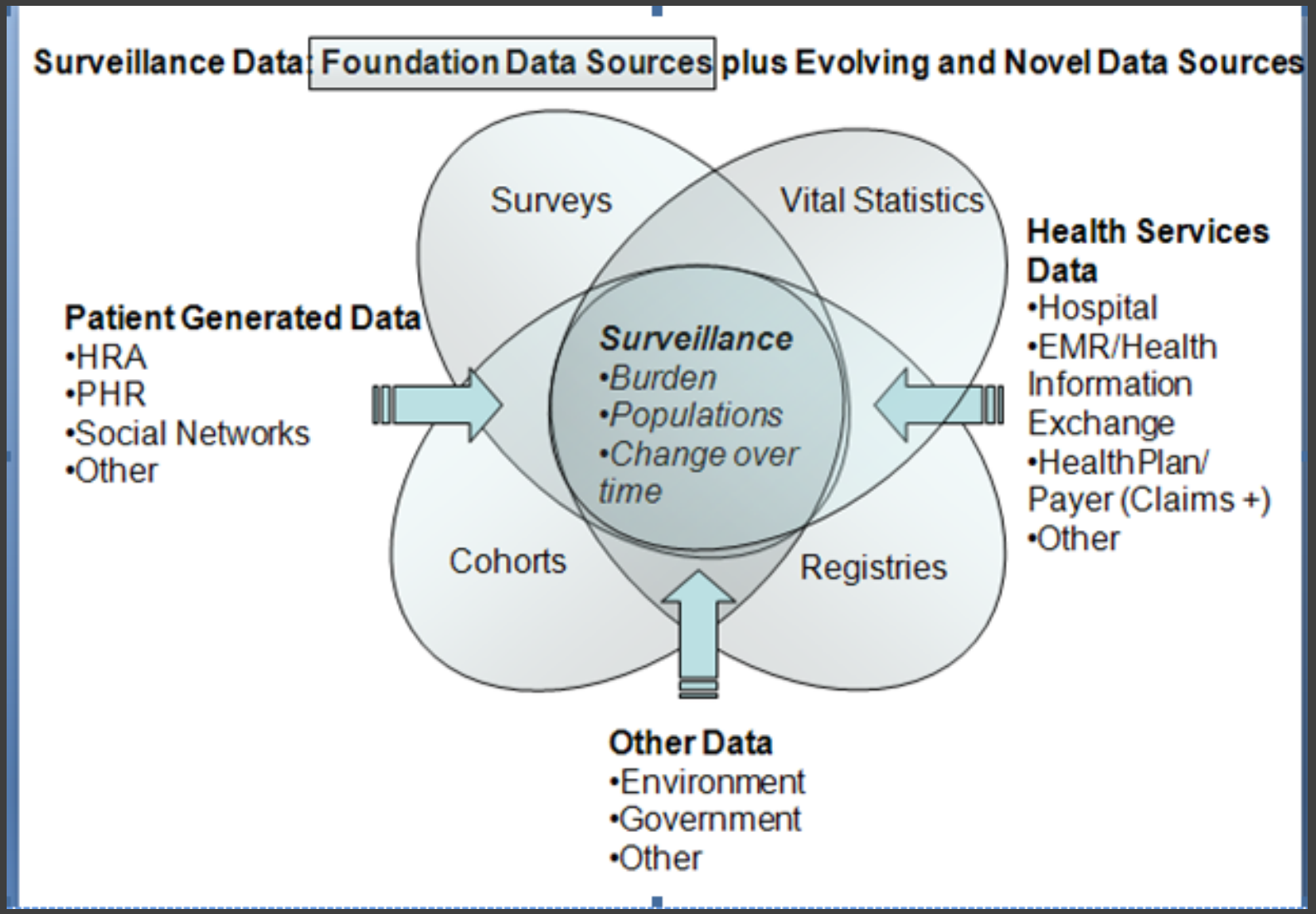
What is PH surveillance?

- General definition
  - Ongoing systematic assessment of health of a community, including timely 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

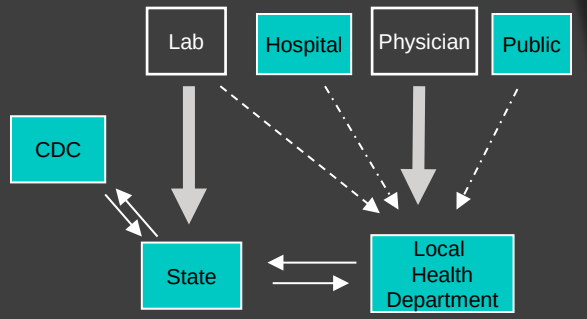
- Guide public health action
- Measure burden of disease
- Monitor disease trends
- Guide planning, implementation and evaluation of public health programs
- Evaluate public policy
- Detect changes in health practices
- Prioritize health resources
- Describe clinical course of disease
- Provide basis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

Where do surveillance data generally come from?

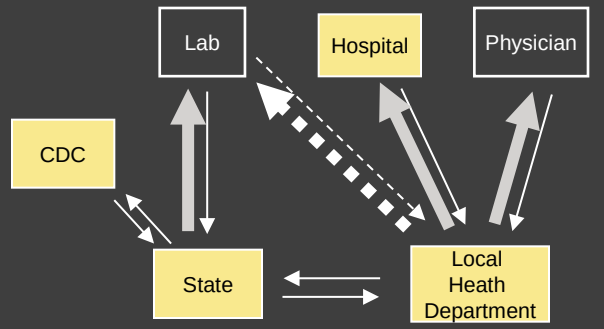


Type of surveillance studies

- 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

- 2008: 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
- Potential data sources
  - Law enforcement
  - Child advocacy centers

Next steps

- Enter into partnership with LE and CACs
- Link datasets
- Analyze data
- Disseminate results

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Recognition of a Need

- Independent agencies recognized a need for more sensitive CM data.
- Child death review identified high numbers of fatalities with a maltreatment component
- No single agency has jurisdictional responsibility for all CM – victimization rates depend on agency
  - Limited cross-discipline assessments of CM
- Need for a focus on prevention
- Formally designated as an issue of public health importance

Key components in establishing CM surveillance in Alaska

- Point person with both PH and EPI training
  - To get to the point you have to sell the product (CPS, DPH)
- Construction of a multidisciplinary development team (Children's Justice Act Task Force)
  - Advocate to help navigate agency
  - Public health is a "new" partner
- Data sharing…understanding
- Focus on prevention not early intervention

Alaska CM surveillance goals

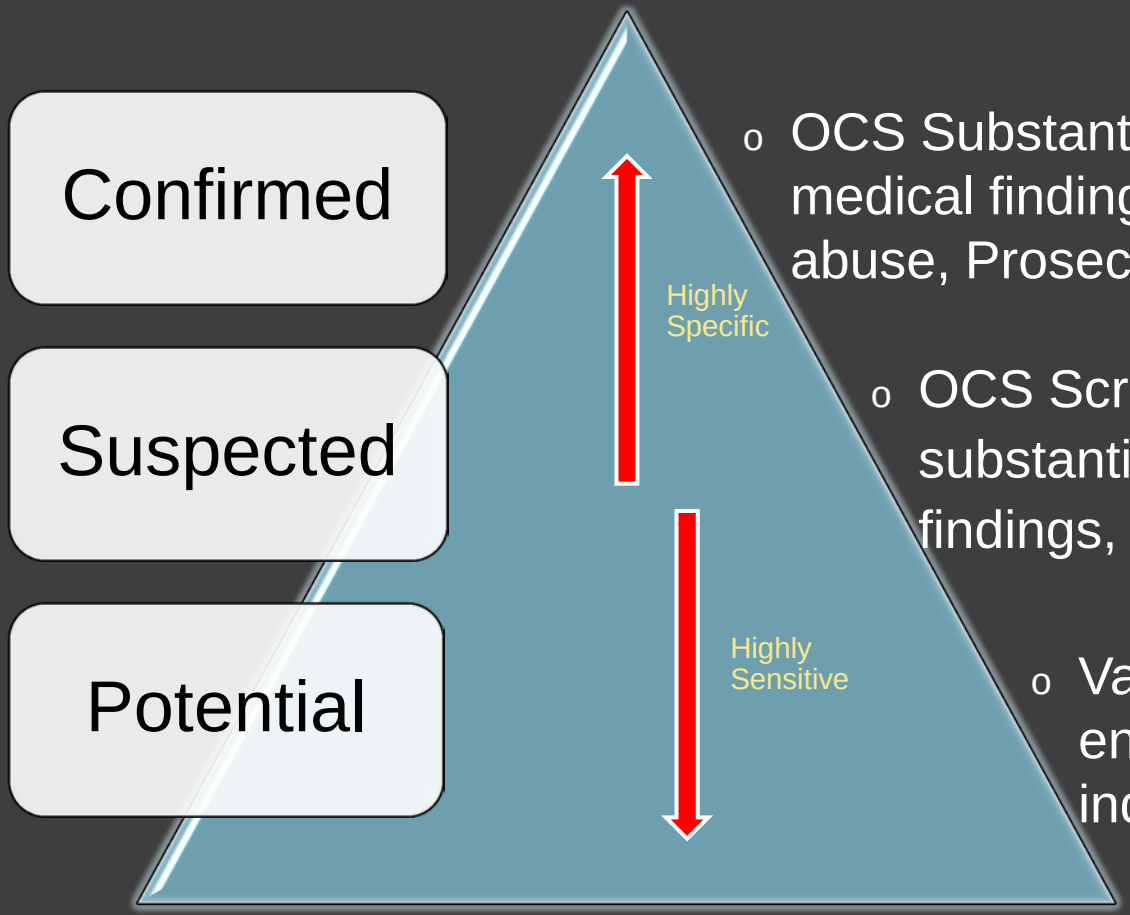
- Ongoing systematic collection and unification of existing data
- Apply public health tiered definitions (working algorithms)
- Measure a more inclusive assessment of the problem over time (resistant to policy changes and staffing)
- Identification of risk/protective factors & offer recommendations
  - Target populations and evaluate interventions
  - Move from programs the “feel right” to those that “show impact”

Key partnerships

- Child Protection – both reports received and outcome
  - Strong relationship: PH focusing on preventing abuse could potentially reduce case loads for CPS
- Law enforcement – both reports and outcome
- Child Advocacy Centers
- Medical providers
- Child Death Review – scaled each child death CM

No----------Yes

Public Health Case Designation



- 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

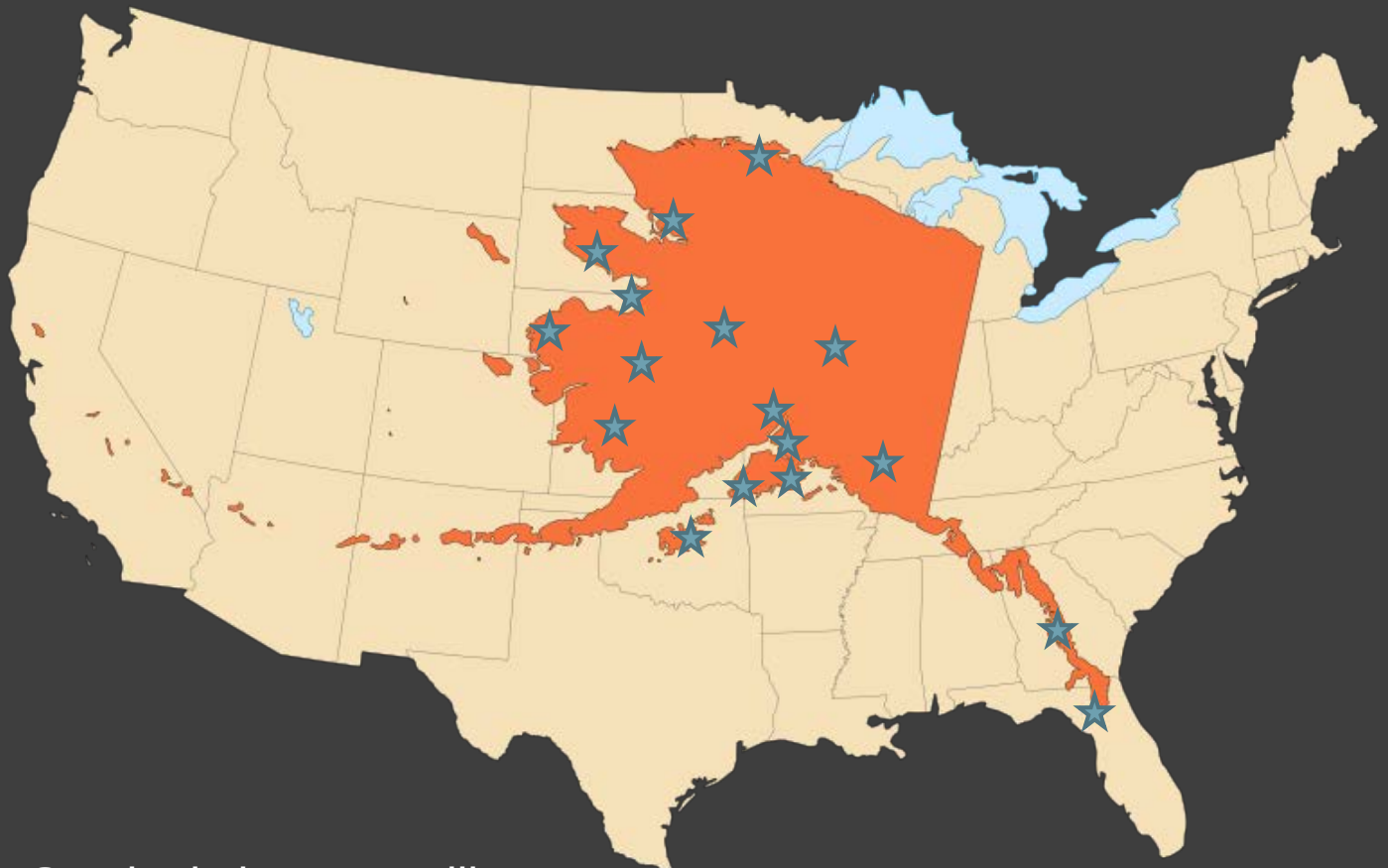
Counting CM

- Surveillance in AK of morbidity now uses a sentinel/syndromic approach (focus on consistency rather than complete case attainment)
- Every three years a complete statewide assessment conducted to determine overall magnitude*

- Allows surveillance to be timely and reliable!!!
  - Crucial for informing decision makers and evaluation

* To be implemented. We recognized that that we were mixing surveillance with complete case ascertainment which impacted the timeliness of the data substantially.

Making CM Surveillance work



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

Detecting maltreatment-related fatalities

Source years: 1992 – 2005 (Infants)	Count	Rate per 1k live births
Death Certificate (DC)	22	0.15
DC + Suspected	74	0.52
DC + Suspected + Potential	133	0.93

35% Abuse

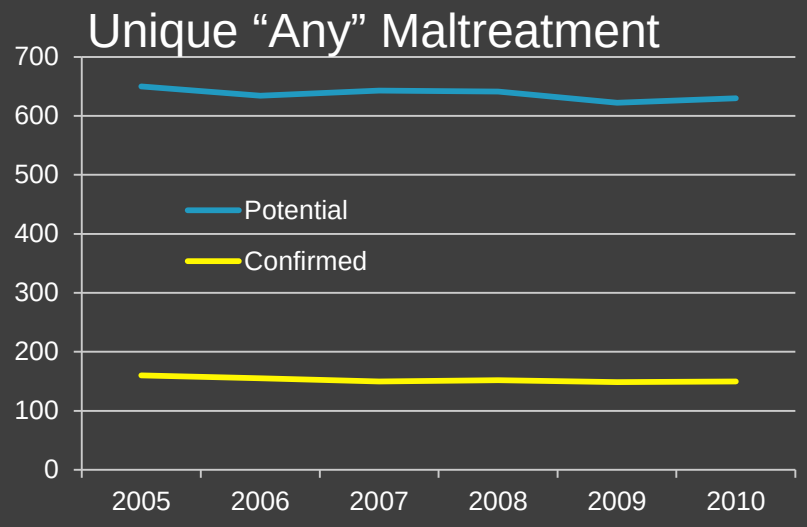
- Shaken baby/impact syndrome
- Blunt force trauma
- Vehicular manslaughter with DUI and Unrestrained child

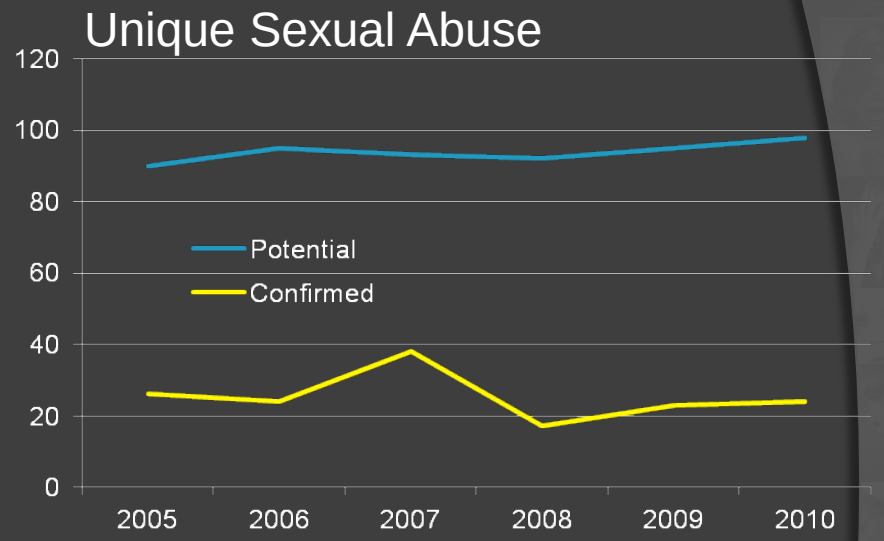
65% Neglect

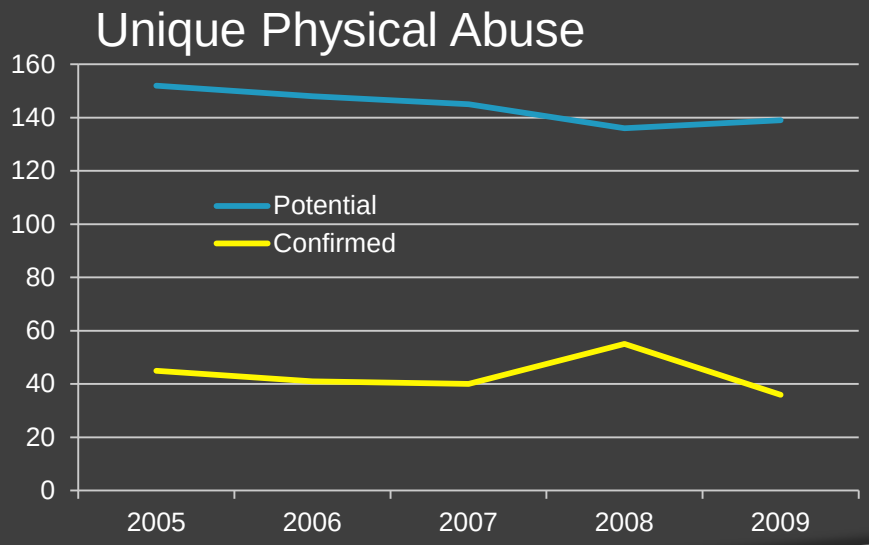
- Untreated life threatening illness/infection
- Abandonment of live newborn
- Loaded gun left out accessible to unsupervised child

*findings consistent with other research from multiple states, Michigan, Missouri, Rhode Island..

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







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.

So who uses this data and how

- 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 efficiently, population based numbers are imperative (remove anecdotal prevention efforts to science based – target efforts)
- Relationships are more about understanding roles and purpose, opposed to redefining jobs (reservation/concerns upfront)
  - 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.
- 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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