INNOVATIONS IN CHILD MALTREATMENT SURVEILLANCE:

Using Data to Move Towards Prevention

Essentials for Childhood
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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

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:**


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 other’s 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 all CM: limited cross-discipline assessments of CM
- Need for a focus on prevention
Establishing surveillance in AK: Key components

SCAN

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
Key partnerships

- CPS
- Maltreatment Surveillance
- Law enforcement
- CACs
- Medical community
- Public Health
- CDR
Interactive systems framework

- Individual agency data
- Agency impact on maltreatment increased
- State wide impact assessments and evaluations with recommendations
- Data implemented to action statewide
- State/local comprehensive child maltreatment reports
- Alaska SCAN data linkage with multiple agency data
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/syndromic 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**
  - OCS Substantiation, Abnormal medical finding, Disclosure of abuse, Prosecution

- **Probable**
  - OCS Screen In P1 or P2 or substantiated P3, inconclusive findings, partial discloser, charges filed

- **Potential**
  - Valid reports to OCS, Law enforcement, CACs, ICD codes indicative of abuse

- **Highly Specific**
- **Highly Sensitive**
Making Surveillance work

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

log-Linear Trend Test, p=0.013

log-Linear Trend Test, p=0.952

Rate per 1,000 live AK births

Year

2005  2006  2007  2008  2009  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)

Unique “Any” Maltreatment

Unique Sexual Abuse

Unique Physical Abuse
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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