SUNRISERS: An Introduction to the Child Death Review Case Reporting System

Heather Dykstra & Esther Shaw
National Center for Child Death Review
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State of the States in 2003
(Before the CDR Case Reporting System)

• 44 states had a case report tool (electronic or paper)
• 39 states published an annual report with findings and recommendations
  – 18 states had legislation that requires a report on child death
• However, there was no consistency among any state case report tools or state reports
CDR Case Reporting System: A New Case Reporting System

- Funded by the Maternal and Child Health Bureau, HRSA, HHS
- A 30 person workgroup of 18 states over two years, analyzed 32 existing state case report forms
  - Developed standard data elements, data dictionary, 33 standardized reports
  - Piloted in 17 states for 18-24 months
Purpose of the System

• To systematically collect, analyze and report on:
  – Child, family, supervisor, and perpetrator information
  – Investigation actions
  – Services needed, provided, or referred
  – Risk factors by cause of death
  – Recommendations and actions taken to prevent deaths
  – Factors affecting the quality of the case review
Participants of the CDR Case Reporting System

As of May 2009

n=50,241 cases
Data Highlights
As of April 2009

• Includes over 50,000 cases from 27 participating states
• Includes deaths, near deaths, and stillborns from 1995 to 2009
  – Deaths account for 99.2% of cases
• 59% of cases are males
• 65% of cases are white and 24% are African-Americans. 15% are children of Hispanic or Latino origin.
Data Highlights

As of April 2009

- 54% of cases are infants, while 18% are teens between ages of 15-18.
- Leading manner of death (per death certificate) is natural (55%).
- Except for infants, accidents are the leading manner of death for all other age groups.
Data Highlights

As of April 2009

• CDR teams report that 30% of all deaths are preventable.
• 55% of teens are considered probably preventable, while only 16% of infants.
• Accidental manner deaths had the highest percentage of preventability (71%), followed by homicides (67%), and suicides (53%).
How Do Teams Use Their Data?

• State teams use findings to develop action plans based on their recommendations.
• Local teams and states use their reports to keep or increase CDR funding.
• National groups use state and local CDR findings to advocate for national policy and practice changes.
The Paper Form

- 14 pages of questions
- On average, 6 pages are not filled out per case (detailed info on cause)
System Features

• Web-based
• Real time data
• Easy to track/monitor cases from local to state level
• Comprehensive and prevention focused
• Can enter, search, print, and download data
• 33 standardized reports
• Approximately 275 questions (1,700 data variables)
• Can migrate old data into it
• National Center provides all training and help desk support
• It’s free
Security

• Secured login to website
• Data transmission is protected by 128-bit secured sockets layer (SSL)
  – Strongest commercially available
• Firewalls protect the servers where the data is stored
• MPHI maintains a Data Center
Permissions

• Local level users can only enter and view case report data for their team
• State level users can enter and view case report data for all teams in that state
• National Center staff can view ONLY de-identified data across all states
  – Data are de-identified by HIPAA standards
Confidentiality

• Data is owned by the state and local team
• All data entered should be in compliance with your state laws
• The Receiver of the data, the Michigan Public Health Institute, is not subject to the Freedom of Information Act (FOIA)
Data Dissemination

- Currently developing a formal data dissemination plan to guide the release of an aggregated, de-identified multi-state dataset
- Available fall of 2009
The Child Death Review Case Reporting System

From Case Review to Data to Action

Step 1: Complete case review of child death.


Step 3: Send Report through Web, to servers at MPHI

Step 4: Servers sort and store data and permit access according to state requirements.

Step 5: State and local teams and national CDR download standardized reports and/or download data to create custom reports.

Step 6: Reports and data are used to advocate for actions to prevent child deaths and to keep children healthy, safe and protected.
Entering Data into System
(Online survey of System users, conducted winter 2008. 138 survey respondents)

• Takes on average 15-19 minutes to enter a case
• Most users partially fill out form before CDR meeting, attend meeting, and complete entry after the meeting
• Over 70% of users reported the System ‘Excellent’ or ‘Very Good’
Report Tool

CDR Case Reporting System Training Site:
http://training.cdrdata.org/default.html
# Welcome Adams County, Pennsylvania

Why do children die in Pennsylvania? Which deaths might have been prevented?

These questions are the motivating force behind the PA Child Death Review Program. A child death review is a multi-agency, multi-disciplinary process that routinely and systematically examines the circumstances surrounding child deaths in a given geographical area and a given age group.

The PA Child Death Review Team is comprised of pediatricians, forensic pathologists, coroners/medical examiners, representatives from PA Departments of Health, Public Welfare, Community Affairs, the Attorney General’s office, social services and law enforcement. The aggregate information will be shared with legislators and state policy makers in order to concentrate funding and program priorities on appropriate prevention strategies.

The Pennsylvania Child Death Review Program has 44 local teams representing 48 counties reviewing over 90% of child deaths in Pennsylvania (Feb 2002).

For more information contact:
**Vick Zittle**, Program Director  
**Yvonne McCalla**, Program Assistant

**PA Chapter, American Academy of Pediatrics**  
919 Conestoga Road, Bldg 2, Suite 307  
Rosemont, PA 19010

Phone: 800-316-9776  
Fax: 610-520-9177
A. Child Information

1. Child's Name:
   - First: [Blank]
   - Middle: [Blank]
   - Last: [Blank]

2. Date of Birth: [Blank] (i.e. MM/DD/YYYY)

3. Date of Death: [Blank] (i.e. MM/DD/YYYY)
B. Primary Caregiver(s)

1. Primary Caregiver
   One Two
   ○ Self
   ○ □ Biological parent
   ○ □ Adoptive parent
   ○ □ Step parent
   ○ □ Foster parent
   ○ □ Mother’s partner
   ○ □ Father’s partner
   ○ □ Grandparent
   ○ □ Sibling
   ○ □ Other relative
   ○ □ Friend
   ○ □ Institutional staff
   ○ □ Other
   ○ □ Unknown

2. Caregiver(s) Age in Years:
   One Two
   □ □ Years
   □ □ Unknown
Manner & Cause

F. Official Manner and Primary Cause of Death

1. Official manner of death from the death certificate:
   - Natural
   - Accident
   - Suicide
   - Homicide
   - Undetermined
   - Pending
   - Unknown

2. Primary cause of death:
   - Unknown
   - From an injury (external) cause
     - Motor vehicle and other transport
     - Fire, burn or electrocution
     - Drowning
     - Asphyxia
     - Weapon, including person’s body part
     - Animal bite or attack
     - Fall or crush
     - Poisoning, Overdose or Acute Intoxication
     - Exposure
     - Undetermined
     - Other
   - From a medical cause
     - Asthma
     - Cancer
     - Cardiovascular
     - Congenital anomaly
     - HIV/AIDS
     - Influenza
     - Low birth weight
     - Malnutrition/Dehydration
     - Neurological/seizure disorder
     - Pneumonia
     - Prematurity
     - SIDS
L. The Review Meeting Process

1. Date of first review meeting: ___________ (i.e. MM/DD/YYYY)

2. Number of review meetings for this case: ___________

3. Is review complete?
   - No
   - Yes

4. Agencies at review:
   - Medical examiner/forensic
   - Law enforcement
   - Prosecutor/district attorney
   - Public health
   - CPS
   - Other social services
   - Physician
   - Hospital
   - Other health care
   - Fire
   - EMS
   - Education
   - Mental health
   - Substance abuse
   - Court
   - Child advocate
   - Others

5. Factors that prevented an effective review:
   - Confidentiality issues among members prevented full exchange of information.
   - HIPAA regulations prevented access to or exchange of information.
Search Features

Search for Last Name
Search for Case Number
Search for Date of Death
Search for Manner of Death
Search for Cause of Death
Search for Date of Entry
Search for Entry Incomplete
Search for Prevention Updates
View All Cases
Return to Main Menu

Search for Last Name
If you are not sure of the spelling for a last name example, entering 'st' will return all cases where
Enter Last Name (or partial): rob
### Selection Criteria

- All cases
- Cases marked as complete for data entry
- Year of Review
- Year of Death

#### Infant/Child Information
1. Demographics (Ethnicity/Race and Age Group by Sex)
2. Infant Death Information
3. Manner and Cause of Death by Age Group

#### Incident Information
4. Investigation Information

#### Motor Vehicle and Other Transport
5. Motor Vehicle and Other Transport Death Demographics
6. Vehicle Type Involved in Incident and Position of Child
7. Risk Factors of Young Drivers (Ages 14-21) Involved in the Crash
8. Motor Vehicle Protective Measures
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Footnote: Columns do not add up to total deaths because the factors are not mutually exclusive. If factor is unknown, it is not included in these counts. Portable cribs may inadvertently be counted as not in a crib or bassinet since they are typically coded as "other". Unsafe bedding or toys include pillow, comforter, stuffed toy, and other toy.
Download Your Data

Download All Sections
All Tables (zip File)

Download a Section
Table 1Ctsa - Case Definition
Table 3INF - Section A
Table 1GRV - Section B
Table 1SUP - Section C
Table 1HDO - Section D
Table 1HIV - Section E
Table 1CAU - Section F_G12
Table 1HCH - Section G1
Table 1SR - Section G2
Table 1DIR - Section G3
Table 1SUF - Section G4
Table 1SDO - Section G5
Table 1WPA - Section G6
Table 1BIF - Section G7
Table 1PA - Section G8
Table 1PCU - Section G9
Table 1REP - Section G10
Table 1MDT - Section G11
Table 1CAL - Section H
Table 1ACT - Section I_1-27
Table 1ACT2 - Section I_28-32
Table 1PRV - Section J_K
Table 1REV - Section L_M_N
Help

Contact Information for the National MCH Center for Child Death Review:

2440 Woodlake Circle, Suite 150
Chester, MI 48044

Phone: 1-800-666-2434
Fax: (313) 324-7305
Email: info@childdeathreview.org

Maintaining Your Account:
Change your Password
Edit your Contact Information

Supporting Documents:
- Child Death Review Program Manual
- Guide for Effective Child Death Reviews
- Child Death Review Case Report Form
- Internet Database User Manual
- Internet Database User Manual for State Administrators
- Internet Database Error Report Form
- Data Dictionary
- Data Codebook for Download
- Macro to Import Data into Microsoft Access

For Administrators:
Accounts Administration
Thank You

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www.childdeathreview.org

info@childdeathreview.org

1-800-656-2434