Let's Make It Easy While Getting the Most from Your Hard Work on Child Death Review Reporting

February 4, 2009

MCHB Webcast
3:00 - 4:30 p.m., Eastern time
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Welcome

Thank you to Arizona, Hawaii, Michigan and online survey respondents.

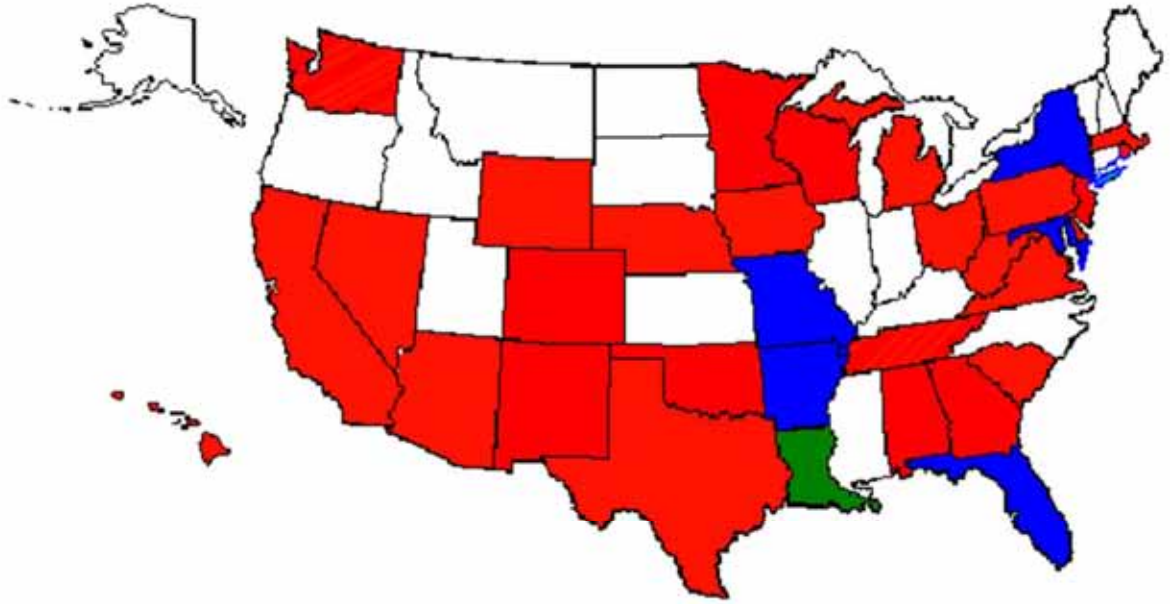
Thank you to Mary Overpeck for your input in developing this web cast.

Overview of Webcast

- Why the Report Tool is Important to CDR Users
- Why Data Quality is Important
- Review of Selected Problem Questions, particularly focusing on:
  - Section I, Acts of Omission and Commission
  - Section J, Services
  - Section K, Prevention
- Report Tool's Standardized Reports

Using the CDR Case Reporting System

(As of January 2009)



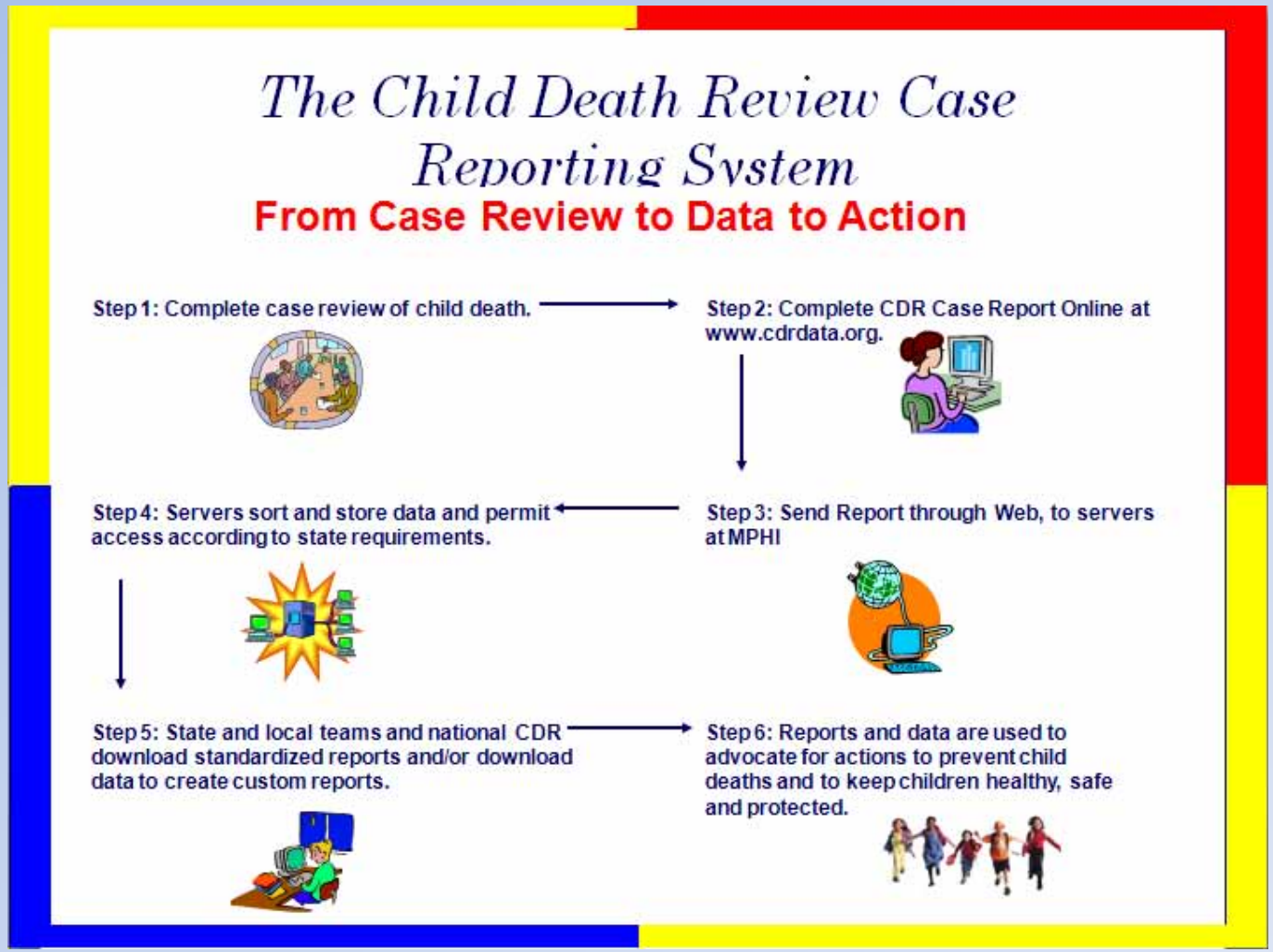
Considering
Participating
In Process

n = over 45,000 records in System

Why is the Report Tool Important to CDR Users?

- Ensure results lead to CDR Goals of improved Services and Prevention
- Report Tool elements were selected for what teams need to share with service and prevention programs in states and counties
- Data is Part of the Process

Why is the Report Tool Important to CDR Users?



CDR Results: Ohio Annual Report*

- 51 of 88 counties reported local prevention initiatives resulting from CDR

- Participating agency boards report increase in cooperation and understanding to:
  - ✓ Identify gaps in services
  - ✓ Improve service barrier access
  - ✓ Maximize use of existing services
  - ✓ Increase collaboration

* Ohio Eighth Annual CDR Report, 2008

Why is Data Quality Important?

Information on circumstances of deaths and involvement of service agencies is needed to:

- Accurately guide prevention initiatives
- Provide consistent evidence for service agencies and their governing boards

Survey on CDR Case Reporting System

- Online survey was conducted in winter 2008
- 138 participants responded from 18 states

This webcast is based partially on questions and issued raised from this survey.

Data Quality Issues with Report Tool

Case Definition

A. Child Information
B. Primary Caregiver(s) Information
C. Supervisor Information
D. Incident Information
E. Investigation Information
F. Official Manner and Primary Cause of Death
G. Detailed Information by Cause of Death
H. Other Circumstances of Incident
I. Acts of Omission or Commission
J. Services to Family and Community as a Result of Death
K. Prevention Initiatives Resulting from the Review
L. The Review Meeting
M. Narrative
N. Form Completed by:

Print This Section

Save and Exit

NATIONAL CENTER FOR CHILD DEATH REVIEW

KEEPING KIDS ALIVE

Understanding How and Why Children Die & Taking Actions to Prevent Child Deaths

Child Death Review Case Reporting System

Case Report 2.0

Effective January 2008

Instructions:

This case report is a component of the web-based CDR Case Reporting System. It can be used alone as a paper instrument, but its full potential is reached when the data from this form is entered into the *CDR Case Reporting System*. This system is available to states from the National Center for Child Death Review and requires a data use agreement for state and local data entry. System functions include data entry, case report editing and printing, data download and standardized reports.

The purpose of this form is to collect comprehensive information from multiple agencies participating in a child death review. It can be partially filled out before a meeting. The form documents the circumstances involved in the death, investigative actions, services provided or needed, key risk factors and actions recommended and/or taken by the CDR team to prevent other deaths.

While this data collection form is an important part of the child death review process, the form should not be the central focus of the review meeting. Experienced users have found that it works best to assign a person to record data while the team discussions are occurring. Persons should not attempt to answer every single question in a step by step manner as part of the team discussion.

It is not expected that teams will have answers to all of the questions related to a death. However, over time teams begin understanding the importance of data collection and bring necessary information to the meeting. They find that the percentage of unknowns and unanswered questions decreases as the team becomes more familiar with the form.

The form contains three types of questions: (1) Those that users should only select one response represented by a circle; (2) Those in which users can select several responses represented by a square; and (3) Those in which users enter text. This last type is depicted by 'specify' or 'describe'.

Most questions have a selection for unknown (U/K). A question should be marked 'unknown' if an attempt was made to find the answer, but no clear or satisfactory response was obtained; questions should be left blank (unanswered) if no attempt was made to find the answer. 'N/A' stands for 'Not Applicable' and should be used if the question is not applicable. For example, use N/A for 'level of education' if child is an infant.

This edition is Version 2.0, effective January 2008. Additional paper forms can be ordered from the National Center at no charge. Users interested in participating in the web-based case reporting system for data entry and reporting should contact the National Center for Child Death Review.

Phone: 1-800-656-2434 Email: info@childdeathreview.org Website: www.childdeathreview.org Data entry website: https://cdrdata.org/

This form was developed by a work group of over 30 persons, representing 18 states and the Maternal and Child Bureau of HRSA/HHS.

1

General Points (All Sections)

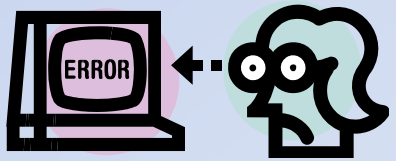
Having Problems with a Report Tool Question?

1. Read the question and response options carefully.
2. Consult your Data Dictionary!
3. Contact your State Administrator and/or the National Center.

General Points (ctd)

Data Quality Issues with Report Tool:

- Data Omission (Missing Data)
  - Failure to understand question
  - Information not available
- Data Inconsistency
  - Differences in definitions

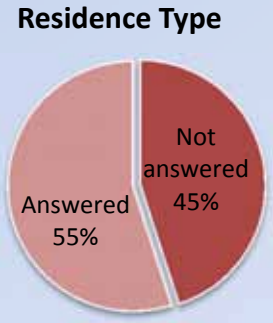


General Points (ctd)

- Confusion about use of “unknown” vs. leaving a question blank
  - Check “unknown” if you tried to find the information to answer the question, but no clear or satisfactory response was obtained.
  - Leave question blank (unanswered) if no attempt was made to find the answer or question is not applicable.
- Limit the use of the “other, specify”
- Be sure to run any definitions or “rules” by your State Coordinator

Section A – Child Information

- A9 & A10, Residence
  - Residence information is often left blank. Please try to complete this important question.
  - For newborns who never left the hospital, residence is primary caregiver's.



- A22, History of Substance Abuse
  - For tobacco abuse of child, please select "Other, specify" and state "tobacco" in text box.

Sections A, B and C – Child, Caregiver and Supervisor

- A23, B11,B12, C10, History of Maltreatment
  - For unsubstantiated referrals, please select 'Yes' regarding history, unless the referral was found to be completely falsified.

- A23-26, C10, History of Maltreatment & CPS
  - This data is also not getting reported consistently. Your DHS representative should be bringing this information to meetings.

Sections B and C – Caregiver and Supervisor Information

- From Survey, respondents noted that answers to Section B and C questions were:

  "often hard to obtain"

  "details are very often not known or not known to nearly the degree the questions ask"

During CDR Review, you should be able to answer these questions. Use these sections as a quality assurance for review.

Section B (ctd)

- B5, Caregiver(s) Income Level
  - Often difficult to obtain but it is a marker for socioeconomic status (SES).

  Income level categorized as “high” or “low” is a subjective response based on the local team’s decision.

Section C (ctd)

- C1, Did Child have Supervision
  - Answer this question carefully. Consider all response options.
    - For example, infant sleeping in room next to parents. Even though child was asleep at time of incident and parents were in the next room, the child was still "supervised."

Section C (ctd)

- C4, Primary Person Responsible for Supervision
  - You can only select one response.
  - If newborn infant dies in a hospital shortly after birth, in most circumstances, hospital staff should be listed as supervisor.

Section D – Incident Information

- Please answer Section D questions, even if case is a natural death.
  - For natural deaths, consider the 'incident' as the acute event leading to the death. For a child with a chronic illness, the incident date may be the same as the date of death with no acute event occurring.
- D1, Date of Incident
  - For newborns that do not leave the hospital, select 'same as date of death.'

Section D (ctd)

- D2, Time of day that Incident Occurred
  - Reminder that this is the time incident occurred, not the time of death (but the incident could be same as death).

- D4, Place of Incident
  - Please note that this is a “check that all apply” question.
  - Reminder that question asks for place of incident and not place where child was pronounced dead.
  - For children that die of natural causes, with no acute event leading to the death, the incident place is usually the same as the place of death.

Section E – Investigation Information

- E1, Death Referred To
  - There is a difference between a medical examiner and a coroner. Please be sure you are selecting the correct one.
- E4, Scene Investigation
  - Mark the agencies that conducted an investigation at the death scene, not the agencies present or from whom there are records.

Section E (ctd)

- E8, Investigation Find Evidence of Prior Abuse
  - If no investigation was conducted, leave question blank.
- E10, Death in Licensed Setting, Action Taken
  - If infant dies in hospital, leave question blank.

Section F - Manner and Cause of Death

- F1, Manner of Death
  - Choose the **manner** of death from the death certificate.
- F2, Cause of Death
  - Use the **cause** of death from the death certificate that will take you to the section in G with the richest picture of the case. This should be a cause that is listed on the death certificate but may not necessarily be the first or last cause listed.
- If the team does not agree with the designations on the death certificate, this can be captured in Section L.

Section F (ctd)

- F2, Cause of Death
  - For infant deaths in which the ME declared both manner and cause to be undetermined, please check ‘Undetermined if injury or medical cause.’

Section G1 - Motor Vehicle

- G1a, Vehicle
  - ‘Bicycle’ is an option for vehicles involved in incident. Treat a bicycle as a vehicle for the remainder of this section (d,g,h).
  - If child is a pedestrian, child’s vehicle should be marked ‘None.’
- G1b, Position of Child
  - Children boarding or blading are considered ‘pedestrians.’

Section G1 – Motor Vehicle (ctd)

- G1c-d, Cause of Incident & Collision Type
  - For single vehicle rollovers, check ‘Rollover’ in G1c. If vehicle rolled and hit a ditch, mark ‘Other event’ in G1d.
- G1g, Drivers Involved
  - Please try to answer driver license status for all involved drivers.
  - If age of driver is unknown, you may enter ‘999’ to indicate unknown age.
  - If age of driver is roughly known, you may enter your approximate age estimate.

Section G4 – Asphyxia & Section G6 - Weapon

- Suicide by Hanging
  - Choose either cause of death = Asphyxia and Strangulation (Section G4) or cause of death = Weapon and Rope (Section G6), but be consistent within your state.

Section G6 – Weapon Including Person's Body Part

- Physical Abuse is recorded in Section G6 if it is the cause of death.
  - If Physical Abuse is not the cause of death, use Section I to record the abuse in Question I3.

Section G9 – Poisoning, Overdose or Acute Intoxication

- G9f, What is the difference between Accidental Overdose or Acute Intoxication?
  - Accidental overdose: Unintentionally administering medication above recommended safe dosage levels. Also includes children ingesting/exposed to agents (including nonpharmaceutical agents) without knowledge of adverse consequences.
  - Acute Intoxication: Refers to agents taken as a result of recreational use or addiction. It excludes suicide.

Section G12 – Other, Undetermined or Unknown Cause

- Section G12 is only completed if Cause of Death (F2) is one of the following:
  - External injury is Undetermined, Other or Unknown cause
  - Undetermined if injury or medical cause
  - Unknown cause of death

- Section G12 is not intended to be used for the Narrative (Section M).

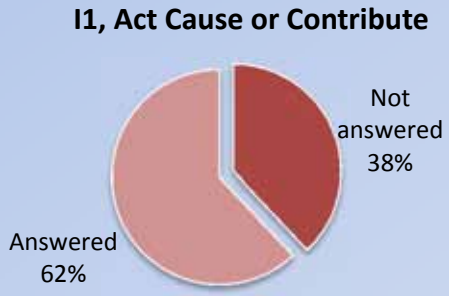
Section H – Other Circumstances of Incident

- H1a,d – Incident & Usual Sleep Place
  - Port-a-crib or Pack ‘n Play should be marked as “Crib”. (Current Data Dictionary needs to be amended.)

  - If child was sleeping in a twin bed, select “Adult bed” and then specify “Twin” in the follow up question.

Section I – Acts of Omission and Commission

- This section should be considered for the majority of deaths, excluding natural deaths.



- I1, Act Cause or Contribute to Death
  - An act of homicide or suicide would be a ***cause*** of death.
  - An act such as failing to supervise a child may ***contribute*** to the death.

Section I – Acts of Omission and Commission

- I3, What Act Caused or Contributed to Death
  - This question is the one place on the form where you can provide more information for suicides, homicides, child abuse and neglect.
  - Check poor absent supervision if you believe it was a factor, but did not rise to the level of abuse or neglect.
  - “Suicide” leads you to I28 and I29 (detailed suicide risk factor questions).
  - “Other negligence” captures acts such as vehicular homicide from drunk driving, negligent manslaughter, etc.

Caused or Contributed?

Examples:

Caused: Abuse-Mother's boyfriend beat an infant to death.

Contributed: Neglect-Mother knew boyfriend was abusive to child.

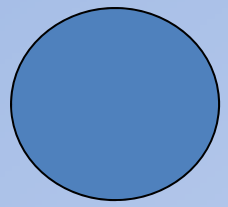
Caused: Suicide- Teen shot himself with a firearm

Contributed: Other negligence or supervision-Father knew son was suicidal but kept loaded and unlocked weapons in house.

Caused: Neglect-Mother would not seek medical attention for infant.

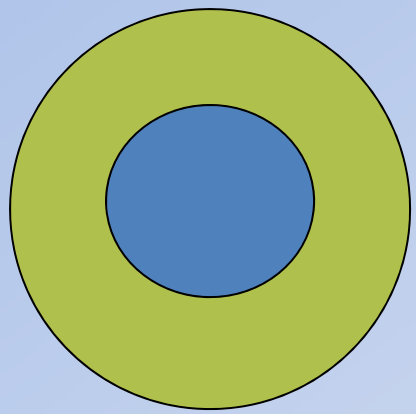
Contributed: Religious practices-Mother's religious beliefs opposed traditional medicine.

Section I 11



Chronic with Child

Versus



Pattern in Family

Section J – Services to Family and Community

- 53% of our survey respondents “Always” try to complete this section.

- Respondents indicated they frequently don’t have this information; however, these questions should generate a conversation among the team.
  - Only 23% said they had more than 60% of the information needed to complete this section.

Section K – Prevention Initiatives Resulting from the Review

- 52% of survey respondents say they 'Always' try to complete this section. Only 32% said they had more than 60% of the information they needed to complete this section.
- K1 "Could the death have been prevented" is frequently used in analysis
  - During team review, this question can drive a useful conversation.
- Please do not include recommendations or actions already in place.

Section L – The Review Meeting Process

- Please try to complete L5 (Factors that Prevented Effective Review) and L6 (Review Meeting Outcomes) in order to evaluate changes needed to your review process.

- L6 is the place to record the team's disagreement with the official manner or cause of death.

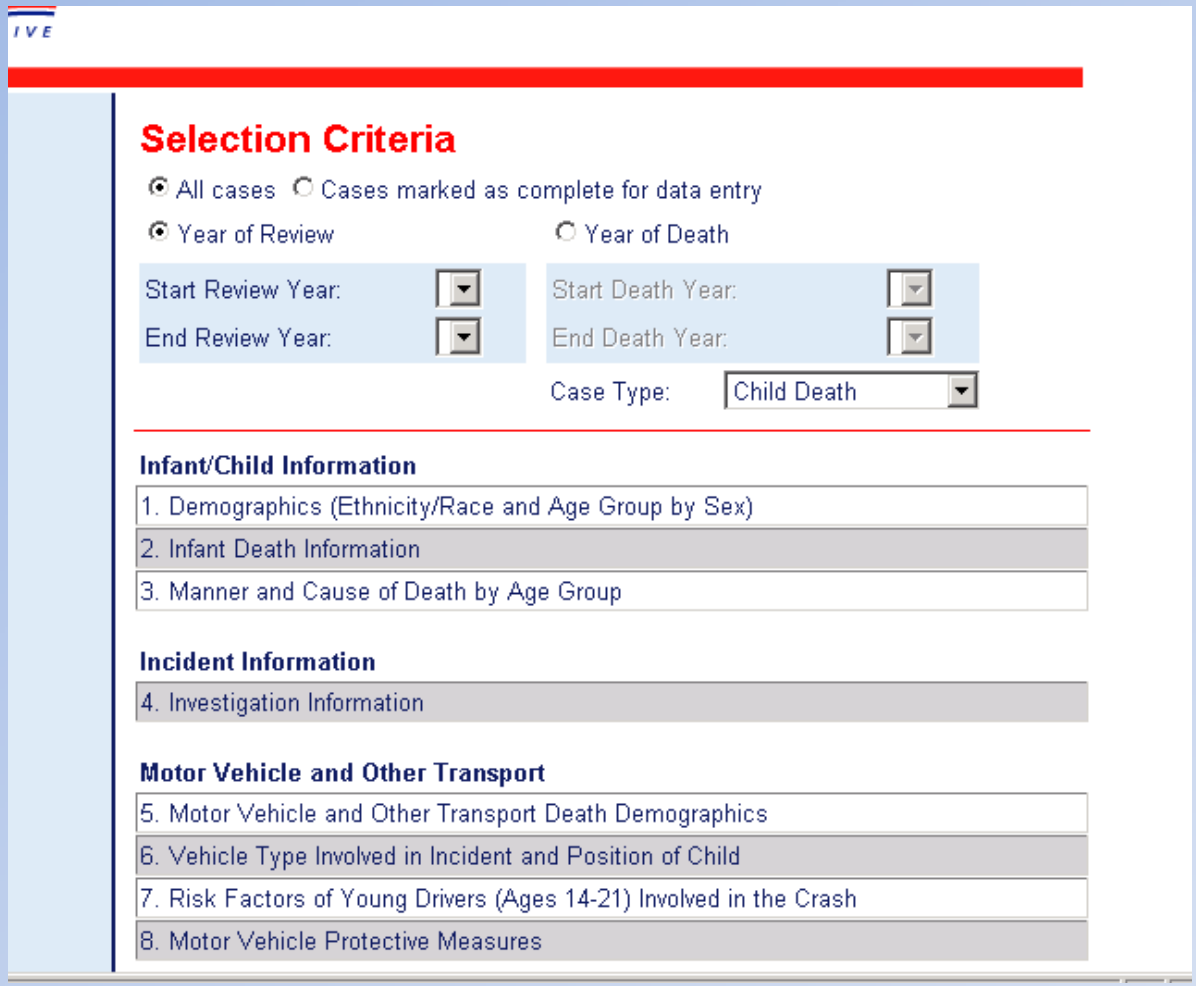
Section M – Narrative

- The responses don't always tell the complete story. Often, even a short narrative here goes a long way to communicate what happened in the case.
- Do not record identifying information in the narrative (names, addresses).
- Exclude information already provided elsewhere in the form.

This Is Your Data!

The Standardized Reports give many of the summary statistics that allow you to give feedback to your collaborating agencies and prevention workers.

This Is Your Data!



Standardized Reports

- Select reports with multiple filters
- 33 reports are readily available

General Definitions

- Opiates (A22,B10,C9,9a,I18)
  - Morphine, methadone, heroin, codeine and oxycodone among a host of others. You may have to look them up online to see if it was an opiate pain killer. Methadone is now being widely prescribed for pain so you may check 'pain killer – opiate' and methadone for the same overdose.

General Definitions

- "Chronic with child" versus "pattern in family or with perpetrator" (I11)
  - *Chronic with child* refers to a pattern of ongoing acts of abuse or negligence inflicted specifically on this child. A *pattern in family or with perpetrator* refers to a pattern of ongoing acts of abuse or negligence inflicted on one or more members of a family or household. An isolated incident refers to a single event with no documentation of similar prior incidents.

- Funeral Arrangements (J1)
  - This captures if the funeral arrangements were provided as a service to the family, not if the child had a funeral.

Thank You

The Child Death Review Case Reporting System is supported in part by Grant No. 1 U93 MC 00225-01 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services

www.childdeathreview.org

info@childdeathreview.org

1-800-656-2434

Archived at MCHCOM.Com

Questions and Answers from live Webcast

General Questions

"Should we be putting in data on a death not reviewed by our team?"

"Am I supposed to fill out a report for each death in my county?"

"At what gestational age do we not need to review a case? (For example, 22 weeks gestation)"

Response: Please contact your State Coordinator for guidance as to what cases your team should and should not be reviewing. In general, teams only enter cases into the CDR Case Reporting System that have been reviewed.

"Who sends me the death certificate and how am I supposed to know what deaths have occurred in my county?"

Response: The vital records agency collects and maintains death certificates. This person could be from the health department or the county clerk's office. Please contact your State Coordinator for assistance in obtaining death certificates.

Questions and Answers from live Webcast (ctd)

General Questions (ctd)

"This is an expensive and time consuming process. Has there been any discussion of funding for Child Fatality Review?"

"With budget reductions and program slashes around the nation, how safe do you feel the Database system is from being eliminated or of reduced capacity?"

Response: The CDR Case Reporting System has received funding until December 2011, and at present the National Center does not anticipate any budget reductions. We anticipate federal legislation to be introduced in 2009 to support funding to states for CDR-so please stay tuned!

"We are currently transitioning to this system from our old proprietary system. What are the most common and/or troublesome problems that states usually face when first implementing this system?"

Response: Some of the areas that new teams struggle with include: selection of only one supervisor; completion of Section I (Acts of Omission and Commission); and length of the report form. Generally though, states find the system very easy to use. States are also concerned with submitting identifiable data to the National Center. We are only able to access de-identified data and this is covered in the data use agreements we have with your state.

Questions and Answers from live Webcast (ctd)

General Questions (ctd)

"When will we get new data dictionaries?"

Response: Minor modifications (clarifying backover vs rollover, Pack and Play should be marked as "crib") to the Data Dictionary will be available in the next month. The Data Dictionary was significantly revised with the release of Version 2.0 (January 2008) and is available online in the CDR Case Reporting under the Help utility.

Section A

"Is tobacco abuse of a child, the parent or caregiver smoking in the home?"

Response: No. Tobacco abuse of caregiver should be marked in Section B, Question 10, "Caregiver have substance abuse history" – select "other" and write in "tobacco." Teams will need to decide if caregiver smoking in the home should be considered tobacco abuse. Question A19 should only be marked if child had history of substance abuse. If the cause of death was "SIDS" or "Undetermined Cause Under Age One", then Section G5a asks "if Child was exposed to 2nd hand smoke."

Questions and Answers from live Webcast (ctd)

Section A (ctd)

"If a child died of prematurity, is that considered a 'chronic disease'?" (Question A20)

Response: The answer is probably 'no' for most cases since prematurity is more of a perinatal condition. If the child was born premature and 18 months later died, and it was felt that prematurity was the cause of the death, then your team might decide to select prematurity as a chronic disease.

Section B

"Often times we have parents' income but are not sure what defines 'low' income." (Question B5)

Response: The National Center recognizes that this is a subjective question and is really up to your team's discretion. Per the Data Dictionary, income level is based on the local context and costs of living in the community. For some individuals, living in a very affluent community, 'low' may mean 'middle' for many of us. If a family is on public assistance, that would certainly help to identify the family as low income. The question is meant to be marker to identify poor people versus people that are middle class versus people that are wealthy.

Questions and Answers from live Webcast (ctd)

Section D

"Please give an example of 'incident' in a natural death."

Response: If a child dies from a fatal asthmatic episode, the incident date would be the date of the onset of the asthma attack leading to the death. For example, if the child had an acute asthma attack at school, you would have a lot of information about the incident in terms of where the asthma attack occurred.

"What should 'Child's activity at time of incident' be if child died at birth or lived only a few days?" (Question D12)

Response: Per the Data Dictionary, for natural deaths, determine if the child's activity contributed to the onset of an acute incident leading to death. For children that died at birth or lived only a few days, please leave the question blank.

Questions and Answers from live Webcast (ctd)

Section F

"What if the death certificate leaves official manner of death blank but manner of death makes it obvious that it is a natural cause? Can you put 'Natural' though this isn't on the death certificate officially? Or do we request to amend the death certificate?" (Question F1)

Response: It is not uncommon for this to be blank on a death certificate. Please ask your State Coordinator for guidance. From the National Center's perspective, it is not problematic to enter 'Natural' for manner if the situation was clear cut. However, if manner was not obvious, then you may want to leave the question blank. You should also ask your medical examiner or coroner for their opinion.

"What category would maternal substance abuse leading to premature birth/death be classified as in Section F?" (Question F1,F2)

Response: For manner, select the official manner of death from the death certificate. For cause, you would probably select 'prematurity' or 'other perinatal conditions'. Some may have the death listed as accidental due to perinatal intoxication. As with many of the form's questions, theirs is no right or wrong answer, and you should use your team's discretion.

Questions and Answers from live Webcast (ctd)

Section F (ctd)

"If the death certificate says 'respiratory arrest,' how does that get us to the SIDS section?" (Question F2)

Response: Because the death certificate can list more than one cause of death, it is up to your team deliberation to choose the cause of death that would take you to Section G (Cause) that would offer the most information in regards to prevention. If the death certificate was marked with both 'respiratory arrest' and 'SIDS,' then it is the team's decision to mark the most appropriate cause in Question F2 (medical condition).

The System will take users to the SIDS section (Section G5) only when 'SIDS' is marked in Question F2.

Questions and Answers from live Webcast (ctd)

Section G1 (Motor Vehicle)

"Is 'rolled over' child in driveway the same as vehicle rolled over and into ditch?" (Question G1c)

Response: If a child is backed over by a vehicle in a driveway, select 'Back over' in Question G1c. If a child is in a vehicle accident where a vehicle turns over on its side or roof, then select "Rollover" in Question G1c.

Section H (Other Circumstances)

"Does crib count if they are in the NICU at death?" (Question H1)

Response: Yes, if an infant is in an ICU bed then select 'crib.'

Questions and Answers from live Webcast (ctd)

Section I (Acts of Omission or Commission)

"How do you answer Question I1 for a teenager who is riding with a drinking teenager?"

Response: This depends on your team's deliberation. A team could select that the crash was the direct cause and the drunken driver was the contributing cause. Or if the team felt that the driver was so incapacitated that he/she completely caused the accident to occur, the team could select the drunk driver as the direct cause.

Section J (Services)

"Our team feels itself is a Review team, not an Intervention team. They would not want to put any effort into finding this info, even if it was available."

Response: Section J is not just about interventions for the actual case but about looking forward and thinking about improving services, which is an important part of prevention as well. Ask your team to think about services that may have been identified as a result of this death that you feel need to be put in place for your community for the future – an opportunity to think through improvements and services in the community to help families in the future.

Questions and Answers from live Webcast (ctd)

Section K (Prevention)

"Our recommendations rarely result from a specific case, rather, from an aggregate view. And the recommendations are made long after the cases are reviewed."

Response: The National Center recognizes this difficulty and will continue to think about ways to design a specific module that would better capture the recommendations and prevention initiatives your team has designed in the aggregate.

The System, under Search, does give you the ability to retrieve all cases that have been marked to 'add prevention actions at a later date.' This aids your ability to add prevention actions at a later date.

Standardized Reports

"Any plans for state level access to get reports by county instead of judicial district which can include several counties in some cases in our state?"

"Any plans to have reports that you can create - i.e. all children that drowned in one city or county or zip code?"

Response: Currently the Standardized Reports can be run by county or team type (e.g., judicial district) for users with Statewide permission levels . You can run any report you want if you download the data for different combinations of jurisdictions. Standardized reports are limited by the 33 types. If additional funding becomes available to support further modification of the System, then additional customization of the Standardized Reports may be available.