

# Overview of CDC's Sudden, Unexpected Infant Death Initiative

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## Presentation outline

- Background
- Research
- Sudden Unexpected Infant Death Initiative & Activities
- Accomplishments
- New projects and future plans

## Background

## Sudden Infant Death Syndrome (SIDS)

“sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history.”

\* Willinger M, James LS, Catz C. *Pediatr Pathol* 1991.

## Sudden, Unexpected Infant Deaths (SUID)

- SIDS
- Suffocation (asphyxiated by soft bedding, pillow, waterbed mattress)
- Overlaying (rolling on top of or against baby while sleeping)
- Wedging between mattress and wall, bed frame, furniture
- Strangulation between bed railings
- Homicide, hypo or hyperthermia, metabolic disorders, poisoning

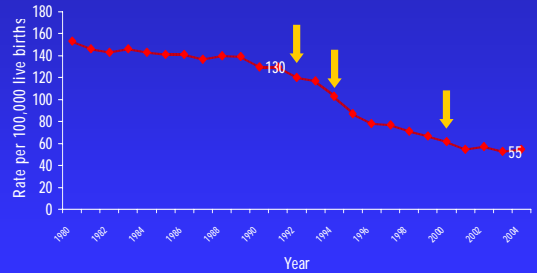
## Characteristics of SIDS

- Occurs suddenly without warning, often during periods of sleep
- Cause unknown after thorough investigation
  - Not due to suffocation, aspiration, abuse or neglect
- Peak incidence at 2 to 4 months of age

## Modifiable Risk Factors

- Smoking and substance abuse
  - Prenatal maternal
  - Postnatal exposure cigarette smoke
- Prone (face down) and side sleeping
- Soft sleep surfaces and loose bedding
- Overheating
- Bed sharing with:
  - intoxicated individual
  - caregiver who smokes
  - other than a parent

## Mortality rates due to SIDS, U.S., 1980-2004



## Concerned about SIDS & other SUID?

- SIDS:
  - Leading cause of postneonatal mortality
- Accidental suffocation & strangulation in bed
  - Rates have tripled in last decade
  - 4.1 to 12.5 deaths per 100,000 live-births from 1994 to 2004
- SUID rates comparable to birth defects
  - 4600 SUID deaths/year, 2500 SIDS

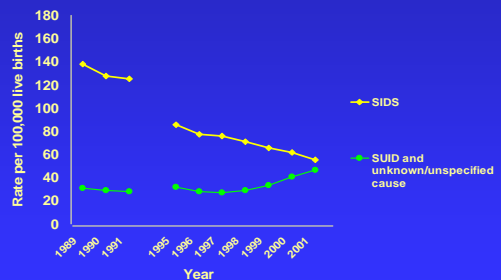
## Research

## CDC Research

- Decline in SIDS is offset by increasing rates of:
  - Cause unknown/unspecified
  - Other SUID (suffocation, wedging, overlaying, poisoning)
- This change in classification can be explained by:
  - How investigations are conducted
  - How diagnoses are made

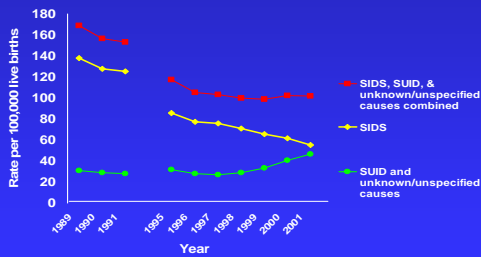
\* Shapiro-Mendoza CK, Tomashek KM, et. al., Am J Epidemiol, 2006.

## Infant Mortality Rates due to SIDS, SUID\* & Unknown/Unspecified Causes, US, 1989-2001



\* SUID include accidental suffocation and strangulation in bed; other accidental suffocation and strangulation; and neglect, abandonment and other restraint-related syndromes.

## Infant Mortality Rates due to SIDS, SUID\* & Unknown/Unspecified Causes, US, 1989-2001



\* SUID include accidental suffocation and strangulation in bed; other accidental suffocation and strangulation; and neglect, abandonment and other maltreatment syndromes.

## Why be concerned about change in SUID reporting?

- Many SUID are not investigated
- Of those investigated,
  - Non-standard practices of data collection for investigations
  - Inconsistent classification and reporting of SUID deaths
- If we want to reduce these infant deaths, we need valid and reliable data to support our research and prevention efforts

## Need for better SUID Investigations

Without a complete death scene investigation

- Difficult to determine cause and manner-of-death
  - Pathologist conducting autopsy at disadvantage
  - Evidence for child death review & for court cases limited

With a complete death scene investigation

- Improved classification and reporting of SUID leads to valid and reliable data
  - Monitor trends in SUID
  - Conduct research to identify risk factors
  - Design interventions to prevent SUID
  - Evaluate programs aimed at prevention

## SUID Initiative & Activities

### Goal of the SUID Initiative

- ❖ Standardize and improve data collected at death scene
- ❖ Promote consistent diagnosis of cause of death
- ❖ Improve national reporting of SUID estimates
- ❖ Prevent SUID by using improved data to identify those at risk

### SUID Initiative Main Activities

- ❖ Revised the 1996 death scene investigation form
- ❖ Developed training curriculum and materials
- ❖ Disseminate and promote the use of the SUID Reporting Form and the training curriculum and materials
- ❖ Pilot test a SUID case registry

## Revised the 1996 death scene investigation form

- Formed a national workgroup
- Convened to improve/revise the 1996 Sudden, Unexplained Infant Death Investigation Reporting Form (SUIDIRF) and guidelines 1996 SUIDIRF
  - Aim to make user-friendly
- Evaluated form and field testing was positive

## Developed training curriculum and materials

- Formed a national steering committee and work group
- How to conduct a death scene investigation
  - Step-by-step demonstration of scene re-enactment
  - How to interview grieving families and caregivers
- How to differentiate SIDS, suffocation, and other sudden deaths
  - How to classify SUID death
- How to fill out a death certificate

## Dissemination and promotion of SUIDI materials

- Conducting 5 regional train-the trainer academies
- Training multidisciplinary teams of 5 from each state
  - 250 individuals will be selected
  - 50 teams of 5 members
  - ME/C, LE, child advocate, college faculty member, and DSI
- Each team will conduct local training

## Accomplishments

- 4 national training academies to date
  - 237 faculty, staff, and state team trained as trainers
  - 10,000 trained to use SUID Reporting Form and training materials
- Endorsement of SUIDI training materials by:
  - Name Association of Medical Examiners
  - International Association of Coroners and Medical Examiners
  - American Board of Medicolegal Death Investigators
  - National Sheriff's Association
  - International Association of Chiefs of Police have all.

## Accomplishments

- Tennessee trained 871 Law Enforcement, 1136 EMS, 983 Fire personnel
- The Indiana Council on Infant Health and Survival recommends usage of the CDC protocols and reporting form
- Washington State developed plastic coated message cards
  - Cards remind investigators of the procedures to use at the scene and local resources.
- New Zealand, England, Canada, Australia, and France have all requested the training materials or and expressed interest
  - France and Australia have adopted a modified version of the SUIDI Form

## CDC's SUID Case Registry

### CDC's SUID Case Registry

- 1-year pilot study
- Population-based system (state)
- Retrospective data collection: 2004 & 2005
- Collaboration with National Violent Death Reporting System (NVDRS)
  - 7 states
- Collects info about the circumstances contributing to SUID death

### Principal Data Sources

- Death certificates
- SUID Investigation Reporting Form
- Coroner and medical examiner records
  - Autopsy Results
  - Chart Review
  - Lab work (toxicology, metabolic, X-Rays)
- Law enforcement reports
- Birth certificates

### Long-Term Implications of an ongoing-enhanced case registry

- Monitor trends at state and local levels
- Identify risk and protective factors
- Develop and evaluate strategies and interventions aimed at prevention
- Identify cases for research studies
  
- Mechanism for identify a comparison study population for analytic studies

### Summary of successes

- States want to continue data collection
  
- States formed new partnerships
  - Law enforcement, MEs, coroners
  - Vital Statistics
  - Support and advocacy groups
  - Child death Review
  
- State Commissioners of Health expressed interest and continued support

### Next Steps

### Next Steps

- Establish on-going case registry
  - Convene a national working group
  - Decide on minimum set of variables and sources
- Continue training efforts aimed at improving investigations and cause of death reporting
  - Target AI/AN populations
- Evaluate the impact/effectiveness of the training

## Acknowledgements

## Federal Partners

- Federal Bureau of Investigation
- National Institute of Justice
- Consumer Product Safety Commission
- Indian Health Service
- Department of Defense
- Health Resources and Services Administration
- National Institutes of Health
- National Center for Health Statistics
- Office of Minority Health, DHHS

## Non-Federal Partners

Professional medical associations	SIDS organizations and advocacy groups	Law enforcement agencies
National Association of Medical Examiners International Association of Forensic Nurses American Academy of Pediatrics American Medical Association	First Candle/ SIDS Alliance CJ Foundation for SIDS Association of SIDS and Infant Mortality Programs March of Dimes	National District Attorneys Association International Association of Chiefs of Police National Sheriff's Association

## Acknowledgement of substantial contributions of past team members:

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## CDC SUID Initiative Team

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<http://www.cdc.gov/SIDS.htm>



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## Thank you

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