EFFECTIVE REVIEW OF
NATURAL INFANT DEATHS

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Agenda

Infant Death Review and Prevention Strategies

THE CASE FOR REVIEW OF INFANT DEATHS
Reasons to cultivate strong reviews of natural infant deaths.

PLANNING NATURAL INFANT DEATH REVIEWS
Laying a foundation and building confidence in reviews of natural infant deaths.

CONCEPTUALIZING PREVENTION
Thinking about findings and prevention strategies for local teams.
Technical Assistance and Training
On-site, virtual and/or recorded assistance, customized for each jurisdiction, is provided to CDR and FIMR teams.

National Fatality Review-Case Reporting System
Support the NFR-CRS which is used in 48 states and provides jurisdictions with real-time access to their fatality review data.

Resources
Training modules, webinars, written products, newsletters, listserv, website and more.

Communication with Fatality Review Teams
Regular communication via listserv, newsletters and regional coalitions.

Connection with National Partners
Develop or enhance connections with national organizations, including federal and non-federal partners.
THE CASE FOR REVIEW

Natural Infant Deaths
A National Snapshot

- There were 104,344 deaths of youth and children <18 in the US from 2019-2021.
- More than half of those death occurred before the 1st birthday.

First Year of Life

60,423 Infant Deaths

Next 16 Years of Life

11,021 Deaths of Children 1-4

17,095 Deaths of Children 5-14

15,805 Deaths of Youth 15-17

Leading Causes of Infant Death

Which of these deaths seem “preventable?”

CONGENITAL MALFORMATIONS
Most common include heart, lung, or brain conditions and other genetic conditions.

PRETERM BIRTH AND LOW BIRTH WEIGHT
Birth prior to 37 weeks gestation or less than 5 lbs. 8 oz.

SUDDEN INFANT DEATH SYNDROME
SIDS is a diagnosis of exclusion and does not include known asphyxia or overlay.

INFANT DEATHS AND PREVENTABILITY

Moving Beyond Injury Prevention

• Natural deaths may not always seem preventable; that doesn’t mean reviewing them won’t support prevention efforts.
• Most infant deaths are due to natural causes.
• They may be medically complicated or more difficult to review due to records/expertise.
• Reviewing these cases can give us unique insights into problems in our communities.
“Infant mortality is the most sensitive index we possess of social welfare …”
–Sir Arthur Newsholme
PLANNING NATURAL INFANT DEATH REVIEWS

Strategies to Maximize Impact and Understanding
Changes in Community Systems

A mechanism for changing systems that interface with families. Child death review illuminates where systems are successful in working together as well as opportunities for improvement.

Community Action

The Community Action team receives the recommendations from the review team and is charged with developing and implementing plans leading to positive change within the community.

Data Gathering

Multidisciplinary data on the context in which the child and family lived should be documented to uncover disparities in how families are offered resources, access services, and navigate systems.

Case Review

Tell the story. Have each team member share what they know about the death including history with the child and family, how the agency responded to the death, and any delivery of services to the family or community.
PLANNING REVIEWS OF NATURAL INFANT DEATHS

Strategize for Effectiveness, Equity, and Prevention

- Review multiple natural infant deaths together at the same review
- Consider new or additional case records
- Consider new or ad hoc team members
- Examine crosscutting risk and protective factors
Additional & Ad Hoc Members

Equipping your team with subject matter expertise

- Obstetrician/Gynecologist
- Midwife
- Doula
- Neonatologist
- Pediatrician
- ER Staff
- Family practice providers
- Social workers
- Home visitors
- Maternal/infant public health representatives
ADDITIONAL RECORDS

Consider that the team may need different or new information

- Prenatal records
- Labor and delivery records
- NICU records
- Home visiting records
- Hospital social work notes
IDENTIFY PROTECTIVE FACTORS

Identifying strengths and what went well highlights assets in systems and families

- Family level strengths may focus on parenting or health practices, social supports, or utilization of services
- Systems-level strengths may focus on effective collaboration, service provision, or quality care
SOME RISK FACTORS FOR BIRTH DEFECTS

Most birth defects are caused by a complex mix of factors we don’t understand.

• Smoking
• Drinking alcohol
• Drug use
• Certain medical conditions, including obesity or uncontrolled diabetes during or pre-pregnancy
• Fevers or elevated body temperatures in pregnancy
• Having someone in your family with a birth defect
• Being born to someone >34 years of age

SOME RISK FACTORS FOR PREMATURITY

Birth prior to 37 weeks gestation

• Low family income
• Young or advanced age at time of pregnancy
• First pregnancy as a teen
• Poor nutrition
• Anxiety/Depression
• Physical abuse
• Long work hours/extended standing
• Environmental exposures

• Black race
• Infection (placenta, UTI)
• Prior pre-term delivery
• Twins or higher order pregnancy
• Abnormal cervical/uterine anatomy
• Placental abnormalities
• Under or overweight
• Fetal abnormalities
• Short inter-pregnancy interval

• Chronic health issues in and prior to pregnancy
  – Hypertension
  – Diabetes
  – Clotting disorders
• Tobacco and alcohol use
• Substance abuse
• Inadequate prenatal care
• Stress

Infant Death Reviews

- Are there appropriate services for this family in the community?
- Were they able to access these services?
- Was the medical standard of care met in this case?
- Was there bias in the service-delivery context that affected the family?
- Was there a lack of knowledge that contributed?
- Were bereavement services available?
- Was genetic testing indicated/conducted?
- Was domestic violence present?
- Was substance use/abuse present?
- Were there mental health issues at play in this case?
- Were there environmental exposures that lead to preterm delivery?
CONCEPTUALIZING PREVENTION

Natural Infant Deaths
THE SHIFT TO FINDINGS
Moving From Recommendations to Findings

Create Findings
Objective facts about the case that identify key risk and protective factors.

Review Findings
Assemble a broad group of partners to review findings to identify opportunities for prevention.

Prevention Activities
Hand-off prevention recommendations to partners and evaluate implementation.

Write Recommendations
Use that same group of partners to write prevention recommendations, ensuring equity considerations are identified.
FACTS ABOUT THE CASE

DEFINING FINDINGS

• Objective facts that are tied to key risk and protective factors.
• Focus on how systems interacted and are identified for every case.
• Findings should be used to write formal prevention recommendations.
• Broad categories of findings include: characteristics of the child, characteristics of the parents and/or caregivers, physical environment, social environment, agency practices, collaboration across systems, social determinants of health/equity and unique characteristics of each system.
Fatality Review Outcomes

The Spectrum of Success

Review → Improved Communication → Improved Investigations and Data Collection → Improved Agency Systems → Prevention

Greater Prevention Impact
Fatality review data can inform service delivery, program improvement, and intervention design.

Policymakers need the insights of fatality review to inform policies that affect families.

Communities should contribute to and benefit from findings and recommendations to improve safety and wellbeing.
Spectrum of Prevention

Individual effort balanced with population impact

Education

Clinical interventions

Long-lasting protective interventions

Changing the context to make healthy decisions the default

Socio-economic factors

Increasing individual effort needed

Increasing population impact

Focusing Recommendations
Fatality Reviews of Natural Deaths of Infants

Social Determinants of Health
Conditions where people are born, live, learn, work, play, worship, and age affect a wide range of health outcomes and risks.

Community Systems
Improved and equitable coordination between systems makes communities safer for everyone.

Service Access and Delivery
Ensuring available, high-quality well-woman, prenatal, and perinatal care and effective referral processes supports better infant outcomes.

Unmet Needs Before and During Pregnancy
Meeting financial, material, medical, educational, community support, and safety needs supports healthier pregnancies and babies. This includes the services/response after the death.
Focus on Advancing Equity

Consider differences in how families interact with health and community systems

“The way our health, economic, and education systems are built negatively affects some families and their babies more than others, even before birth, into their first years of life and beyond. Together we can ensure the health and wellbeing of every mom, birthing person, and baby.”

-March of Dimes

https://ignitingimpacttogether.marchofdimes.org/
ALIGNING RECOMMENDATIONS

Strategic Alignment for Collective Impact

- Identify opportunities to elevate ongoing strategies
- Partner with champions in perinatal health
Prevention Examples