NATIONAL CFRP
20 YEARS
Center for Fatality Review & Prevention

EFFECTIVE REVIEW OF NATURAL INFANT DEATHS

North Carolina Child Fatality Prevention Summit 2023

KEY FUNDING PARTNER

FEDERAL ACKNOWLEDGEMENT

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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, list-serv, 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.

ABOUT THE NATIONAL CENTER

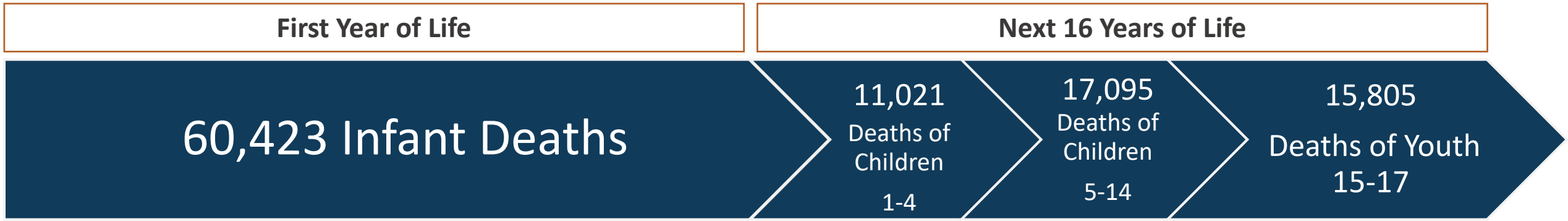
THE CASE FOR REVIEW

Natural Infant Deaths

Infant and Child Deaths from 2019-2021

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.



Source: Centers for Disease Control and Prevention, National Vital Statistics System, CDC WONDER On-line Database. Accessed from http://wonder.cdc.gov/ucd-icd10-expanded.html, March 20, 2023.

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.

Source: National Center for Health Statistics, February 23, 2023. *Infant Health.* Centers for Disease Control and Prevention. Retrieved from https://www.cdc.gov/nchs/fastats/infant-health.htm, March 20, 2023.

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

CHILD DEATH REVIEW CYCLE OF IMPROVEMENT

A CATALYST FOR PREVENTION

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.

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.

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.

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

Centers for Disease Control and Prevention. (December 16, 2022). *What are birth defects?* Retrieved from https://www.cdc.gov/ncbddd/birthdefects/facts.html#causes, March 20, 2023.

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

Source: Centers for Disease Control and Prevention. November 1, 2022. *Some factors associated with preterm birth.* Division of Reproductive Health. https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pdf/preterm-birth/Pre-term-Factors-Infographic.pdf

THE RIGHT QUESTIONS: IDENTIFYING RISKS AND GAPS

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.

Prevention Activities

Hand-off prevention recommendations to partners and evaluate implementation.

Review Findings

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

Write Recommendations

Use that same group of partners to write prevention recommendations, ensuring equity considerations are identified.

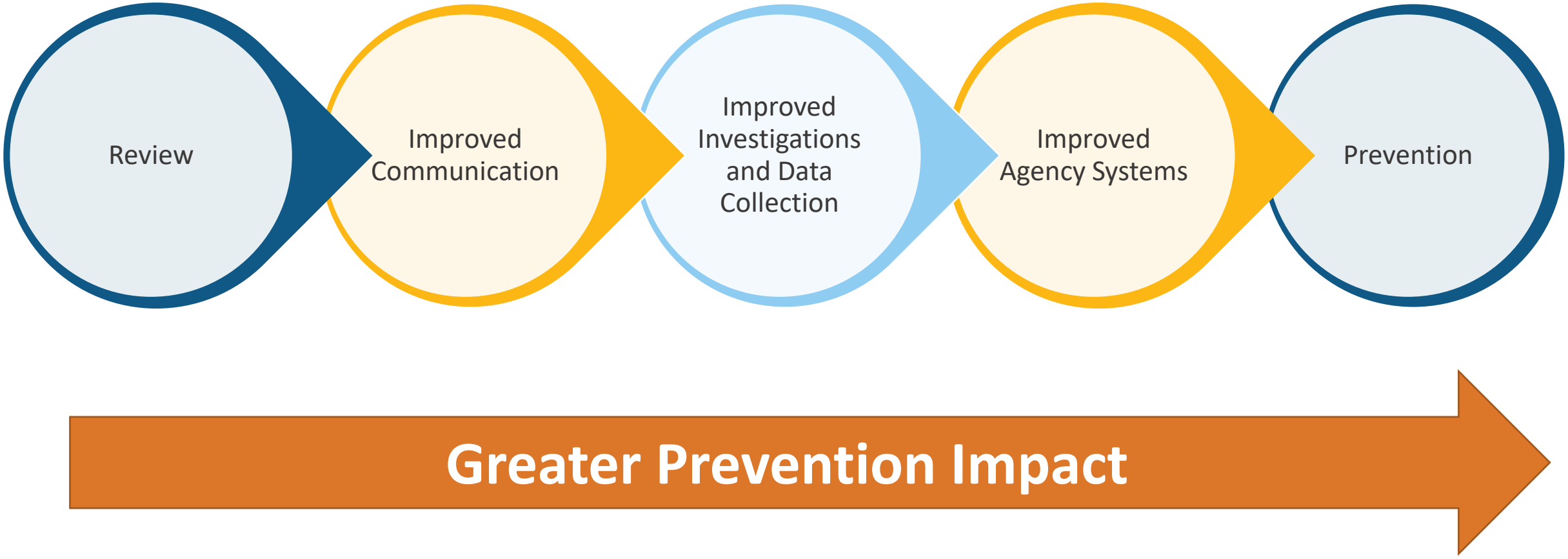
FACTS ABOUT THE CASE

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



USING FATALITY REVIEW DATA

Key Audiences and Avenues to Improve Communities

PROGRAMS

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

POLICY

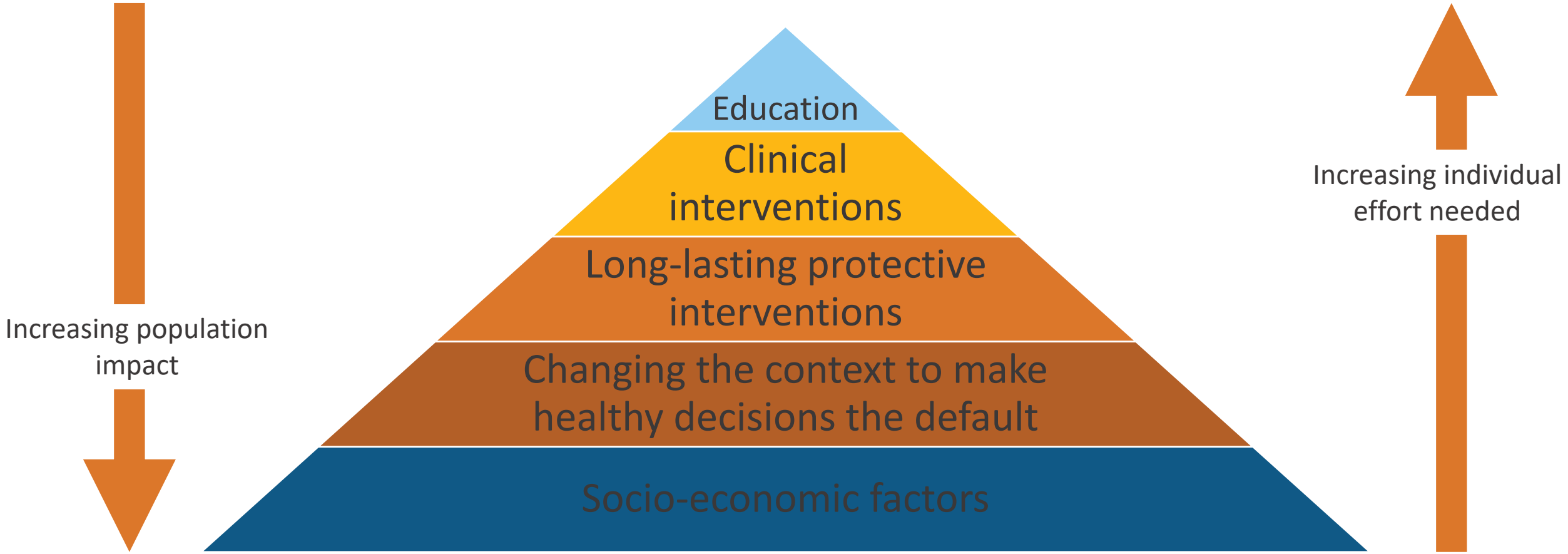
Policymakers need the insights of fatality review to inform policies that affect families.

PUBLIC

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

Spectrum of Prevention

Individual effort balanced with population impact



Frieden, T. R. (2010). *American journal of public health*.

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.

Service Access and Delivery

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

Community Systems

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

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."***

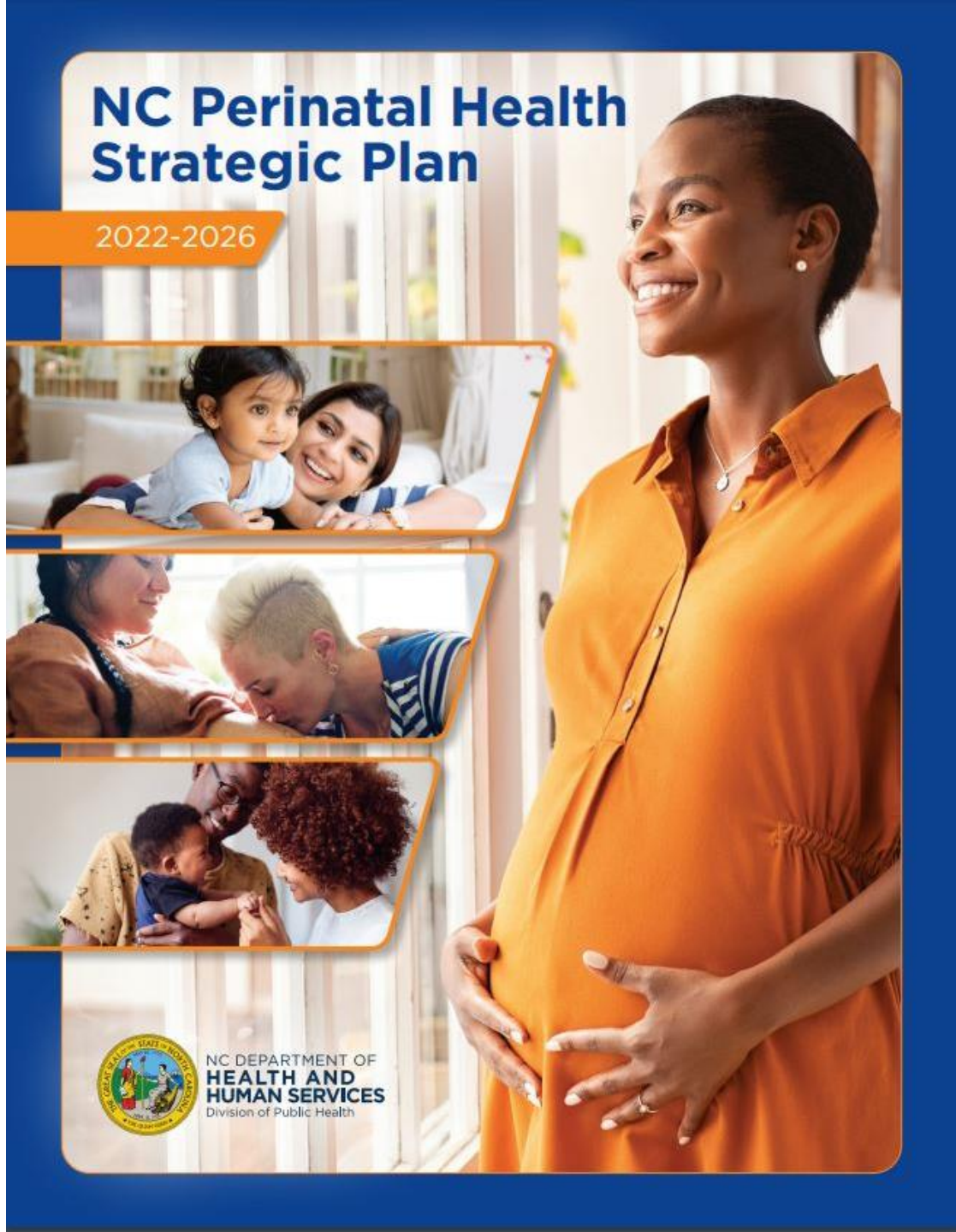
-March of Dimes

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

Questions?

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