

A Response to the Crisis of Infant Mortality in Wisconsin

Recommendations

**Statewide Advisory Committee on Eliminating
Racial and Ethnic Disparities in Birth Outcomes**

July 2009

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BACKGROUND

2004 was a watershed year for infant mortality in Wisconsin. Wisconsin met the Healthy People 2010 goal of 4.5 infant deaths per 1,000 live births for white infants. However, 19.2 per 1,000 African American infants died, resulting in a black-white infant mortality disparity ratio of 4.3. This statistic is nearly twice the US ratio.

The awareness of these stark statistics resulted in a number of advocacy initiatives within the state, involving public and private partners. By December of 2006, the Statewide Advisory Committee on Eliminating Racial and Ethnic Disparities in Birth Outcomes was established to advise the Department of Health Services in the implementation of the initiative's original *Framework for Action*. The Secretary of the Department and the State Health Officer invited representatives of 40 organizations to "foster effective collaboration among a broad array of partners, to serve as ambassadors, help to raise awareness, identify resources, and facilitate action at all levels of the community."

The committee formed as a response to the crisis of infant mortality for the entire state of Wisconsin; however, the initial focus of these recommendations is to improve birth outcomes among African American infants in Milwaukee, Racine, Kenosha, and Beloit, where the highest number and rates of infant deaths occur.

This report summarizes the committee's progress-to-date and the recommendations of the 4 workgroups, formed for the purpose of advancing activities related to the *Framework for Action* regarding the following: communication and outreach; data; evidence-based practices; and policy and funding.

These recommendations also further the goals and objectives of the *2008-2011 Framework for Action*:

- 1) to build and strengthen community capacity, including building public will to change policy, allocate resources, and create and support collaborative, community-based initiatives;
- 2) to expand access to, and increase the availability of, high-quality services; and
- 3) to improve accountability.
www.dhs.wisconsin.gov/healthbirths/

THE CRISIS CONTINUES

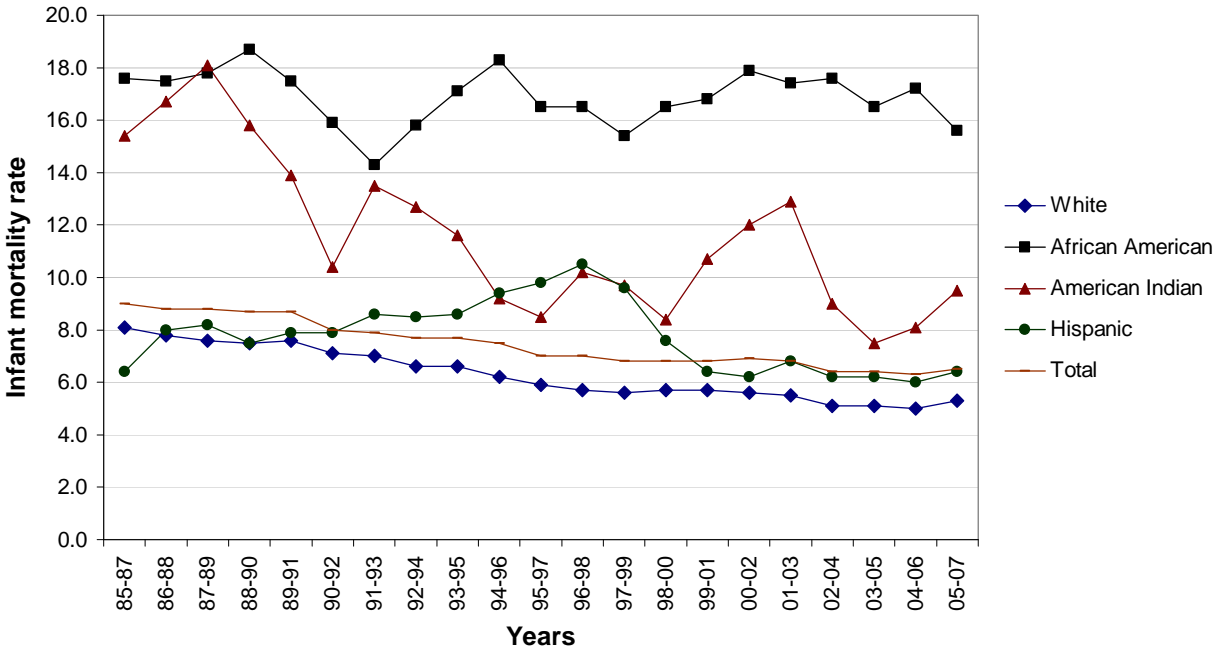
During the most recent reporting period, 2005-2007, Wisconsin's overall infant mortality rate, at 6.5 infant deaths per 1,000 live births, fell short of the Healthy People 2010 objective. The infant mortality rate for the United States in 2005 was 6.9 deaths per 1,000 live births.

Disparities in Infant Mortality

Although the overall infant mortality rate in Wisconsin has declined during the past 20 years, these gains did not extend to all minority groups (Figure 1). For each racial and ethnic minority group in Wisconsin, the 2005-2007 infant death rate exceeded that of whites.

The risk of death during the first year of life was greatest for African American infants. Wisconsin has fallen from having one of the three best (lowest) African American infant mortality rates in the country in 1979-1981 to having one of the three worst (highest) African American infant mortality rates in 2003-2005.

Figure 1. Infant Mortality Rates (infant deaths per 1,000 live births) by Race/Ethnicity, Wisconsin, 1985-1987 to 2005-2007



The African American infant mortality rate in the state remains staggeringly high at 15.6 infant deaths per 1,000 live births, while the infant mortality rate for white infants in Wisconsin (5.3 per 1,000 live births) is close to the Healthy People 2010 target of 4.5. An African American infant born in Wisconsin is *three times as likely* as a white infant to die before his or her first birthday. If African American infant mortality were reduced to the white infant mortality level in 2005-2007, 72 African American infant deaths would have been prevented during each of those 3 years.

Distribution of African American Infant Deaths in Wisconsin

The African American infant deaths in Wisconsin occur mostly in the Southeastern region of the state. In 2005-2007, 91% of all African American infant deaths occurred to infants living in the Southeastern part of the state, with 76% of all African American deaths in the state occurring within the City

of Milwaukee. More than one-third of these deaths in the City of Milwaukee were associated with 6 specific zip codes.

Prematurity and Low Birthweight

The leading causes of death among African American infants are factors associated with prematurity (less than 37 weeks gestational age), low birthweight (less than 2,500 g or 5.5 lb), and Sudden Infant Death Syndrome (SIDS). Approximately 70% of African American infant deaths occur in premature or low birthweight births. The leading cause of death for white infants is congenital malformations (birth defects).

Overall in Wisconsin in 2007, 11% of infants were born prematurely (with a gestation of less than 37 weeks). The proportion of African American infants born prematurely was much higher at 17%. Similarly the proportion of African American infants born low birthweight (less than 2,500 grams) was much higher (14%) than the overall

percentage of Wisconsin infants born low birthweight in the same year (7%).

Infant mortality is recognized as an important indicator of the overall health status of a society, and stark disparities in this outcome continue to exist in Wisconsin. If the disparity in infant mortality could be eliminated, at least one African American infant would be saved every week in the state.

NATIONAL PERSPECTIVE

Disparities in birth outcomes are evident across the nation, but most states are in the early stages of developing responses to identified disparities. During the past several years, federal agencies have awarded states technical assistance grants to develop strategies to reduce racial and ethnic disparities in birth outcomes. Four general areas of approaches are used: community development and coalition building; data collection and dissemination; public awareness; and care delivery and quality assurance. Key findings among the states are the need to acknowledge both the role of racism in unequal birth outcomes and also the underlying social and economic determinants of health. Wisconsin is currently 1 of 6 states participating in a Kellogg Foundation-funded collaborative on the elimination of disparities in infant mortality.

PROMISING PRACTICES

Although research on the effectiveness of approaches to reducing racial and ethnic disparities in health outcomes is limited, promising practices exist. The following approaches have been found to be effective in improving the quality of care for racial/ethnic minorities, and thus birth outcomes, and have guided the recommendations of this committee.

- **Multifaceted interventions.** Adverse influences from multiple arenas must be addressed simultaneously, including social, environmental, psychological, behavioral, and biological factors.
- Interventions need to take an **ecological approach**, and address individual factors (such as smoking, and other behavioral risks), interpersonal factors (including partner and family relationships, social support networks), institutional and community factors (neighborhood, racism, pollution), policy factors (working conditions, leave time, and receipt of public benefits), and life course factors (maternal birth weight, inter-pregnancy interval, pre-existing medical conditions).
- Interventions should focus on **social risk factor modification** rather than classic medical risk treatment, using a “wrap-around” model that includes early entry into prenatal care; case management for psychosocial or situational needs; behavioral health coordination to address mental health risks; smoking cessation; and access to related resources (WIC, employment resources, housing, etc.).
- Interventions must be **informed by community stakeholders**, including the use of community-based participatory research, involving community members, leaders and organizations, as well as service providers and university-based researchers, to define problems and to jointly identify and implement responses.

STATEWIDE ADVISORY COMMITTEE WORKGROUPS

Each of the 4 workgroups was charged with specific tasks, and each employed different strategies to accomplish their work.

Communication and Outreach

The Communication and Outreach workgroup was charged with providing guidance to the Department in its efforts to raise awareness of racial and ethnic disparities in birth outcomes and to promote culturally-appropriate messages. The workgroup reviewed successful public awareness campaigns in other states and provided advice to Wisconsin's campaign, *ABCs for Healthy Babies*, funded by the Minority Health and Tobacco Programs in 2008. The guidance included where and how to engage community organizations and community members in conducting focus groups with mothers, fathers, and grandmothers in Beloit, Kenosha, Madison/Dane County, Milwaukee, and Racine. The success of this work resulted in Wisconsin's receipt of a 2-year, federally-funded social marketing grant, in Milwaukee and Racine, called *ABCs for Healthy Families*.

Data

The Data Workgroup was charged with selecting key indicators for tracking progress in eliminating racial and ethnic disparities in birth outcomes; identifying and monitoring statewide and local trends; and communicating key data findings for effective interventions.

As an initial step in choosing indicators for tracking, the workgroup identified a large pool of potential indicators related to infant mortality and/or low birth weight that were associated with: community supports and risks (such as, *high school graduation rate* or *poverty rate*); program and clinical interventions (such as, *early entry into WIC* or *disease management*); and population characteristics, including maternal social and demographic characteristics (such as, *educational level* or *maternal age*), and maternal health status and behavioral risks (such as, *maternal history of previous poor birth outcome* or *smoking during pregnancy*).

The next step in narrowing the selection of the indicators was to draft a preliminary report, based on the format and methods of the UW Population Health Institute's "Health of Wisconsin Report Card." WIC program data from the CDC Pregnancy Nutrition Surveillance System were also examined. A selection of key findings from this preliminary report helped the workgroup focus on those indicators critical for tracking progress in eliminating disparities in birth outcomes:

- In 2006, infants born to African American mothers were more than twice as likely to have low birth weights (13.5%) than those infants born to white mothers (6.2%)
- In 2005-2006, the percent of infants born prematurely varied by race and ethnicity, ranging from 10% of white births to 18% of African American births
- Two-thirds of the WIC participants in Wisconsin, who gave birth during 2005, were not enrolled in WIC during their first trimester of pregnancy

Finally, the workgroup reviewed the work of the Evidence-based Practices workgroup to identify clinical or maternal health status indicators. In addition, Medicaid and vital statistics (birth certificate) were identified as 2 readily available data sources for these indicators.

Evidence-based Practices

The Evidence-based Practices workgroup was charged with exploring medical and non-medical interventions that have the potential to reduce disparities in birth outcomes.

Leading causes of infant mortality differ between African American and white infants. Examination of these differences reveals that many of Wisconsin's infant deaths are preventable.

Three outcomes were identified as being both potentially preventable and having a major impact upon the disparity in infant mortality:

- Low birthweight and preterm births
- Maternal complications of pregnancy
- Sudden unexpected infant deaths (SUID), including SIDS (sudden infant death syndrome)

A list of known medical and non-medical interventions was created, and workgroup members choose topics for review based upon their personal and professional interests.

A thorough and detailed methodology, based upon the California Health Benefits Review Program, was created to standardize the task of gathering evidence; however, the workgroup settled on a simplified systematic methodology utilizing the Evidence-Based Public Health Portal, an extension of the Ebling Library at the University of Wisconsin.

Workgroup members researched each of the agreed-upon topics, looking specifically for the best available evidence to support interventions directly related to reducing disparities in birth outcomes. Where high-level (randomized controlled trials) evidence was lacking, recommendations from professional organizations were examined, and best and promising practices were reviewed.

All draft reports were reviewed by at least 2 members, and subsequently were made available to the entire workgroup for review and comment.

The following individual reports will be available at a later date:

- Anemia
- Alcohol and other drug use
- Bacterial vaginosis
- Breastfeeding

- Chronic diseases
- Community health worker / Doula / Home visitor
- Domestic violence
- Fatherhood
- Gestational diabetes mellitus
- Group B beta strep
- Health literacy / Patient education
- HIV
- Hypertension of pregnancy
- Immunizations
- Interpregnancy interval
- Malnutrition / Underweight
- Mental health / Depression
- Oral health
- Preconception / Interconception health
- Preterm labor awareness and fetal movement recognition
- 17 alpha-hydroxyprogesterone (17-P) for previous preterm birth
- Racism
- Sexually transmitted infections
- Sudden unexpected infant death / Sudden infant death syndrome
- Substance abuse
- Tobacco
- Unintended pregnancy
- Urinary tract infections

Policy and Funding

The charge to the Policy and Funding workgroup was to identify short and long-term policy and funding strategies that address the social, educational, and economic inequities in Wisconsin linked to racial and ethnic disparities in birth outcomes.

At the outset, the workgroup discussed the need to define the scope of their work; to consider leveraging opportunities for both policy changes and funding; to take an upstream (primary prevention) approach to

birth outcomes; and to focus on recommendations that would make a measurable difference.

In their deliberations, several themes continually emerged, namely better coordination of the existing services and resources to meet the needs of families; gaining community-wide buy-in to take an upstream approach to birth outcomes; political will and community stakeholder leadership; and the need for a health and social services system that recognizes and supports the partnership.

RECOMMENDATIONS

The committee is aware that the following 16 recommendations provide a general direction for the department and its partners. Specific action steps will depend on individual community needs and the availability of federal, state, and private sector funding.

Communication and Outreach

- 1. Commitment to continuous engagement of the community**
State and local governments, educational institutions, non-profit and private sectors, including faith-based organizations, must remain committed to fostering awareness of racial and ethnic disparities in birth outcomes among the general public.

Create a willingness to act, a “grass roots” movement, by meeting and consulting with community members. Continuously engage the African American community for meaningful solutions.

New community partnerships are needed to respond to the needs of high-risk families, including social support for pregnant women and breastfeeding mothers; stress reduction; jobs for

fathers so they can provide material and emotional support; and equitable and respectful treatment in the health care setting.

- 2. Sustain and expand social marketing and policy changes**

Seek ways to expand and sustain the *ABCs for Healthy Families* social marketing campaign beyond Milwaukee and Racine, focusing on the life-course perspective, and the “Partnership to Eliminate Disparities in Infant Mortality Action Learning Collaborative,” focusing on the link between racism and infant mortality and the role of men and fathers, in Milwaukee.

- 3. Medicaid collaboration**

Align with the Medicaid program to expand partnerships and outreach efforts with agencies, providers, and consumers in southern and southeastern Wisconsin.

Data

Track the following measures by race and ethnicity and geographic locations on an annual basis

- 4. Birth outcome measures**
 - Low birthweight
 - Gestational age / prematurity
- 5. Community supports and risks**
 - Poverty status
 - High school completion rate
 - Employment status
- 6. Maternal health status**
 - One chronic condition (hypertension or diabetes)
 - One behavior risk factor (tobacco)

Evidence-based Practices (specific recommendations are provided by topic area and will be released at a later date)

7. High-quality health care for girls and women throughout their life span

The preconception period is a unique opportunity to improve the overall health of the teen / woman prior to pregnancy. However, because so many adolescents and women experience unintended pregnancies, each visit to a provider (especially well-woman visits) serves as an opportunity to provide preventive counseling, recommendations, and services related to good birth outcomes and overall health of the woman.

(See individual topic reports: preconception / interconception / interpregnancy interval; unintended pregnancy; alcohol; substance abuse; malnutrition / underweight; oral health; immunizations; mental health / depression; tobacco)

8. Specialized prenatal care for adolescents and women of high-risk populations

It is likely that a different venue (other than individual clinic visits) will be necessary to offer successful prenatal care that is effective in eliminating racial disparities in healthy birth outcomes. An example is CenteringPregnancy[®], a model of group-centered prenatal care, shown in the literature to improve birth outcomes. Other examples may include more intensive screening, treatment, and then repeat testing for medical conditions (including urinary tract infections, bacterial vaginosis, and sexually transmitted infections), enhanced promotion of breastfeeding, and education regarding the signs and symptoms of preterm labor, as well as changes in fetal movement.

(See individual topic reports: anemia; bacterial vaginosis; chronic diseases;

gestational diabetes mellitus; group B beta strep; hypertension in pregnancy; STIs; UTIs; progesterone; SUID)

9. Hospital care to include additional services, education, and support

Hospital admission is often the initial or most intensive opportunity for care for high-risk mothers and infants. Examples of these interventions may include rapid HIV testing of mother and/or baby; patient education regarding safe sleep; and promotion of breastfeeding through encouragement and support.

(See individual topic reports: HIV testing; breastfeeding)

10. Empowerment, culturally appropriate choices, and life-course approach

Women must be empowered to act as partners in their own care and be provided with culturally appropriate choices, information, and educational materials of an individually determined literacy level to ensure effective patient-provider communication. Evidence is mounting that decreased stress across a lifespan would improve birth outcomes. The importance of the life-course perspective, with its inherent connection to racism and stress, cannot be over emphasized.

(See individual reports: racism; home visiting, doula, and community health workers; domestic violence; health literacy / patient education; preterm labor awareness and fetal movement recognition; fatherhood).

11. Financial incentives

Financial incentives for healthy births must be created in order to balance the increased cost of providing the additional services that are recommended, recognizing that the cost savings of good birth outcomes far outweighs the expense of providing the

care necessary to achieve such outcomes.

12. Additional research on racial and ethnic disparities in birth outcomes

Although the evidence is substantial and compelling, it is imperfect. The primary literature is often limited in quantity and/or quality and it is evident that no single intervention alone is sufficient.

Additional research is needed to find comprehensive, integrated solutions, including best practices, specific for populations at high risk for poor birth outcomes.

Policy and Funding

Based on their charge and assessment of the conditions needed to support healthy birth outcomes in southern and southeastern Wisconsin, the workgroup emphasizes the use of new and existing resources for region-specific public health plans that establish priorities determined by community stakeholders. Local leadership in this area is crucial.

13. Local community health improvements trusts

Create a community health improvement trust that is comprised of blended funding streams from health care, public health, community, and philanthropic sectors to help achieve shared community goals. The trust would serve 2 purposes: identify priorities for communities in greatest need and realign current dollars with a set of community-identified and agreed-upon priorities. Miami Dade has such a trust and its success is predicated on serving *all* families, not just those who are historically underserved. The focus of the entire community is on asset building and improving family resiliency.

14. Regional public health partnership plan

The regional public health partnership plan establishes a formal system for organizing an incorporating political will and community driven leadership. This model could align directly with the proposed Community Health Improvement Trust. This concept is based on the HUD-Milwaukee Continuum of Care to plan, prioritize, monitor, and evaluate emergency shelter, transitional housing, and permanent supportive housing projects designed to house and assist homeless individuals and families.

15. Pilot children's zone in Milwaukee

The Milwaukee Children's Zone is based on the model of the Harlem Children's Zone in New York City, and addresses issues of health, development, and safety for children and families across the life span. It would be a multi-year, comprehensive community-building initiative with a mission to create significant, positive opportunities for all children living in a high-need geographically determined area of Milwaukee by helping policymakers, parents, residents, teachers, and other stakeholders create a safe learning environment for youth. It is predicated on the belief that earlier, rather than late, intervention is more effective and less costly both in human and economic terms. This recommendation is timely given the Obama Administration's proposal for neighborhood initiatives.

16. Expansion of medical and social science research and expertise to address disparities in birth outcomes

Translational, community-based research to help in the efforts to address racial and ethnic disparities in birth outcomes is needed.

NEXT STEPS

Communication and Outreach

- Support *ABCs for Health Families project*.
- Collaborate with Medicaid on provider and partner communication, consumer outreach, and in providing comprehensive care throughout the life-course.
- Engage with the Dane County investigation to explore similarities and differences between the 2 regions regarding infant mortality.

Data

- Collaborate with Medicaid and Evidence-based Practices Workgroup to create reports on selected indicators.
- Identify new and emerging data sources for tracking progress including PRAMS and FIMR.
- Seek more and better data sources, including by race and ethnicity, such as, additional indicators of maternal and obstetrical health status and community supports.

Evidence-based Practices

- Disseminate individual topic reports via the Healthy Birth Outcomes web site and through the Medicaid program.
- Provide guidance in the design of the Wisconsin Partnership Program's Special initiative to reduce disparities in birth outcomes.
- Keep the entire committee informed of the developments with the Medicaid program and the HMOs.

Policy and Funding

- Merge with the Kellogg Foundation sponsored *Partnership to Eliminate Disparities in Infant Mortality Action Learning Collaborative* team to create an action plan addressing the link between racism on infant mortality and to focus on the role of men and fathers in Milwaukee.
- Build broad-based partnerships; develop a policy and program platform to address African American male and father involvement; and solidify a community action coalition for advocacy and tracking.
- Seek participatory, social change solutions.
- Assure coordination of research at the state and local levels and that evaluation occurs.

APPENDICES

Statewide Advisory Committee on Eliminating Racial and Ethnic Disparities in Birth Outcomes—Participating Organizations

Abri Health Plan
Aurora Family Service
Aurora / Sinai Medical Center
Black Health Coalition of Wisconsin, Inc
Center for the Study of Cultural Diversity in Healthcare
Center for Tobacco Research and Intervention
Center for Urban Population Health
Children's Health Plan
Children's Hospital & Health Systems
City of Milwaukee Health Department
Columbia St. Mary's Hospital
Froedtert Hospital
Greater Milwaukee Committee
Greater Milwaukee Foundation
Ho Chunk Nation
Infant Death Center of Wisconsin
Managed Health Services
March of Dimes
Marquette University School of Nursing
MCH Advisory Committee
Medical College of Wisconsin
Milwaukee Family Services Integration Office
Milwaukee Health Services
Milwaukee Public Schools
New Concept Self Development Center
Oneida Community Health Center
Public Health, Madison-Dane County
Rock County Health Department
Safe Mom Safe Baby Project
Sokaogaon Chippewa Health Clinic
St. Croix Tribal Health
Strive Media
United Healthcare / Americachoice
UW Milwaukee College of Nursing
UW School of Medicine and Public Health
Western Healthy Babies Regional Action Team
Wheaton Franciscan / St. Joseph's
Wisconsin Department Children and Families
Wisconsin Department of Health Services
Wisconsin Hospital Association
Wisconsin Partnership Program
Wisconsin Primary Care Association
Wisconsin United Coalition of Mutual Assist. Assn.
Wise Women Gathering

Workgroup Members

Communication and Outreach

Co-chairs: Patricia McManus, Black Health Coalition of Wisconsin, and Claire Smith, DHCAA, DHS

- Bill Bazan, Wisconsin Hospital Association
- Georgia Cameron, DPH, DHS
- Jill Denson, Milwaukee Health Services
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- Stephanie Harrison, Wisconsin Primary Health Care Association
- Anne Harvieux, Infant Death Center of Wisconsin
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- Sue Miller, Abri Health Plan
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Evidence-Based Practices

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- Jennifer Stenger, Rock County Health Department
- Chris Van Mullem, Aurora Sinai / Samaritan Hospital
- Tina Watts, Safe Mom Safe Baby Project
- Janelle Wells, UW School of Medicine and Public Health

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- Patricia McManus, Black Health Coalition of Wisconsin
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- Pamela Pfeffer, March of Dimes
- Geof Swain, City of Milwaukee Health Department
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