Changing Systems That Influence Birth Outcomes in Marginalized Zip Codes

Jack E. Turman Jr, PhD,[a,c] Nancy L. Swigonski, MD, MPH, MBA, FAAP[b,c]

Indiana's government is prioritizing the reduction of the state's persistently high infant mortality levels. Despite improvements in overall state and Black infant mortality rates, high rates persist within Indianapolis zip codes, characterized by multigenerational poverty and underrepresented minorities (Table 1). These rates occur in the presence of high-quality health care and home-visiting programs working to address the leading causes of infant death (birth defects, preterm birth and low birth weight, maternal pregnancy complications, and sudden unexpected infant death).[1] Numerous studies, however, link infant mortality to underlying root causes associated with the social determinants of health (SDOH).[2–4] Addressing the SDOH requires sustainable improvements in social systems that influence women's health and birth outcomes. Our work complements the work of health care by building the capacity of individuals and organizations within targeted zip codes to remove social inequities that impact birth outcomes.

Our work with families motivated and informed our approach. First, many families have experienced infant mortality across multiple generations. Second, even with public communication campaigns focused on prenatal care, safe sleep practice, and women's health, many residents are unaware of the leading and root causes of poor birth outcomes. Third, residents are not aware of the linkages between social demographics and poor birth outcomes. Fourth, neighborhood networks within communities are often insular; likewise, policy-making networks are insular. There is a need to merge community and policy networks to facilitate dialogue and share realities and solution strategies. Finally, women from the community possess untapped leadership potential and valuable community insight. Unfortunately, they lack a seat at maternal and child health (MCH) decision-making tables. These individuals are needed to help design and implement solutions that address root social, economic, or cultural causes of infant mortality.

A recent scoping review revealed the lack of programs focused on changing social systems to improve infant mortality rates in marginalized communities.[4] Healthy People (HP) 2030 establishes the objectives to improve our nation's health outcomes over the next decade. Social systems that influence health outcomes are in HP section 2030 on SDOH.[5] We used the HP 2030 SDOH to guide the development of our advocacy goals and objectives and the associated actions to address root causes of infant mortality (Table 2).

METHODS AND PROCESS

Addressing changes in social systems that influence birth outcomes requires an interdisciplinary team of

[a]*Departments of Social and Behavioral Sciences and* [b]*Health Policy and Management, Richard M. Fairbanks School of Public Health and* [c]*Department of Pediatrics, School of Medicine, Indiana University, Indianapolis, Indiana*

Dr Swigonski designed and implemented the work associated with early childhood education programs; Dr Turman designed and implemented the Grassroots Maternal and Child Health Leadership Training Initiative; and both authors worked on writing this manuscript from its conceptualization to its completion and approved the final manuscript as submitted.

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Address correspondence to Nancy L. Swigonski, MD, MPH, MBA, FAAP, Department of Pediatrics, School of Medicine, Indiana University, 410 W 10th St, Suite 2000, Indianapolis, IN 46202. E-mail: nswigons@iu.edu

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TABLE 1 Indiana Urban Zip Codes With Persistently High Infant Mortality Rates, 2014–2018

Indiana Zip Code Marion County (Indianapolis)	Total IMR (2014–2018)	Non-Hispanic Black IMR (2014–2018)
46202	21.7	31.9
46218	11.2	15.7
46235	13.4	14.7
46226	11.5	14
46229	11.2	12.7

Data provided by the Indiana State Department of Health.

pediatricians, social-behavioral scientists, and community members. This approach is one proven strategy to improve social and economic systems underlying health outcomes.[6,7] The authors (pediatrician and professor of social and behavioral sciences) initiated and implemented this effort. The development of goals and objectives were established in partnership with community members and organizations that share a passion for social systems change. The wide array of partners that worked with us in these efforts and their roles are listed in Table 3. Academic partners received a salary for their efforts. Most community members volunteered their time as employees of organizations whose mission aligned with the goals of building social systems in marginalized communities and/or addressing infant mortality. Early childhood education providers (ECEPs) volunteered and received help meeting licensing requirements for safe sleep and family engagement.

Of note, the multifocal efforts in infant mortality reduction in our state preclude the attribution of drops in infant mortality to any one effort, including ours. In addition, the frequency of infant deaths and infant sleep-related deaths in any one zip code is low, so rates in individual years are unstable for statistical analysis. We are tracking aggregated zip code–specific rates over time to allow for future assessment of trends of infant mortality outcomes. In the meantime, we report advocacy-related process and outcome measures as steps toward infant mortality rate (IMR) change.

TABLE 2 Advocacy Goals and Objectives Associated With SDOH

	HP Social Determinant	Advocacy Action to Decrease Risk Factors
Goal 1: assist local organizations that serve and interact with neighborhood women, infants and families to build infrastructure and programming over 2 y that support healthy pregnancies and infants.		
Objective 1.1: at least 12 early childhood education programs per year will grow their infrastructure and programming to address local infant mortality reduction.	Education	Support high-quality early childhood education and development.
		Provide linkages for educational opportunities for employees.
	Economic stability	Support child care as local, small business.
		Increase employment opportunities for neighborhood women.
Objective 1.2: a network of health and social service providers and community members working for the FIMR-CAT will implement health literacy programming and skill building to improve the adoption of safe sleep practice in families from neighborhoods at high risk for deaths related to unsafe sleep.	Health and health care access	Promoting safe sleep health literacy among multiple settings and stakeholders.
Goal 2: connect GMCHLs skilled in policy advocacy and development with MCH decision-makers to improve local social systems that influence birth outcomes.		
Objective 2.1: within a 1 y period, train at least 12 GMCHLs from zip codes at high risk for infant mortality.	Social and community context	Build the knowledge and skills of grassroots women to participate in community leadership and civic action.
	Economic stability	Connect grassroots women to employment, internship, and education opportunities to improve their personal financial well-being.
Objective 2.2: within a 2 y period, GMCHLs will have collaborated with organizational or political leaders to implement a new social system that reduces the risk of infant mortality in a marginalized population.	Social and community context	Develop a community-navigation program to serve reentry women with infants.
Objective 2.3: within a 2 y period, GMCHLs will advance a policy brief for consideration by local, state, or federal policy makers.	Social and community context	Write and submit policy briefs to state or federal lawmakers that address MCH priorities of targeted zip codes.

TABLE 3 Partnerships Formed to Meet Advocacy Goals

	Paid Status	Volunteer Status	Contribution
Goal 1: assistlocal organizations that serve and interact with neighborhood women, infants, and families to build infrastructure and programming over 2 y that support healthy pregnancies and infants (funding: Riley Children's Foundation, Kohl's Care grant)			
Team Members			
Pediatrician (30% effort)	X	—	Conceptualization, oversight, reporting.
Project manager (20% effort)	X	—	Oversee work, including recruitment, engagement, and data collection.
Academic–community liaisons × 2 (200% effort)	X	—	Recruit ECE providers, analysis of needs, training, collecting data, develop collaborations, develop network of ECE providers.
ECE providerss (n = 63)	—	X	Participate in state quality program; provide safe sleep education and materials to families; provide and expand infant care.
FIMR-CAT workgroup members (n = 44)	—	X	Reach out and provide safe sleep education and training.
Data manager (10% effort)	X	—	Develop databases, data reports.
Goal 2: connect GMCHLs skilled in policy advocacy and development with MCH decision-makers to improve local social systems that influence birth outcomes (funding: Riley Children's Foundation, Indiana State Department of Health, AmeriCorps, private philanthropist)			
Team Members			
Professor of public health (40% effort)	X	—	Conceptualization, oversight, development of curriculum, evaluation, reporting.
Project manager (100% effort)	X	—	Daily management of each objective.
Undergraduate and graduate student research assistants (anthropology, sociology, art, public health) (20% effort, n = 4)[a]	X	—	Teach narrative storytelling, teach policy advocacy, develop media projects, mentor women in leadership projects.
Director of IUPUI Arts and Humanities Institute Documentary Film Project (25% effort)	X	—	Oversee development and distribution of media, creating a national documentary regarding GMCHL efforts.
Department of Corrections staff (n = 3)	—	X	Help create and implement a community transition program for incarcerated women.
Indiana Institute for Working Families staff and intern (n = 1)	X (intern)	X (staff)	Develop and teach policy advocacy skills, mentor women in advocacy action.
Indianapolis Healthy Start social worker	—	X	Oversee program serving incarcerated women.
Nursing faculty member (30% effort)	X	—	Develop materials for leadership training curriculum.
Nursing faculty member	—	X	Mentor GMCHLs in leadership projects.
Retired WHO public health nurse	—	X	Mentor GMCHLs in policy leadership projects.

ECE, early childhood educator) ; IUPUI, Indiana University–Purdue University Indianapolis; WHO, World Health Organization; —, not applicable.
[a] A faculty member in each liberal arts discipline volunteered to mentor each liberal arts student.

Overview of Goal 1: Build Infrastructure and Programming Within Local Organizations That Serve Neighborhood Women, Infants, and Families

Our first objective under this goal was to help at least 12 early childhood education programs/year grow their infrastructure and programming as a vehicle to promote infant safety and healthy development. This objective's focus on ECEPs emerged from the findings of a needs assessment that identified a marked shortage of high-quality infant care. This shortage serves as a barrier for women seeking employment or education opportunities. Many women in low-income neighborhoods need access to high-quality infant care because they lack paid maternity leave, causing them to return to work soon after delivery. ECEP are small businesses and trusted community resources. Building the capacity of ECEP within these neighborhoods provides local employment opportunities, a safe place for infants, and a local source of infant health education to families.

However, ECEPs have few resources and multiple competing priorities and experience high levels of stress[8]

and low pay.[9] We developed partnerships with ECEPs (home-based, centers, faith-based) within the targeted zip codes. We also partnered with governmental and nongovernmental organizations involved with supporting child care licensure and quality efforts (eg, Indiana's Family and Social Services Administration, United Way of Central Indiana, historically Black churches). All parties participated in planning activities and implementation. A process map was generated with partnering organizations to develop communication strategies. A needs assessment and referral mechanism linked various partnerships and provided a feedback loop to ensure that needs were met. Each ECE site was assessed to examine their needs (training, materials, capital improvements) then provided with needed materials and referred to partner organizations to support improvement in their quality rating. Increases in quality rating are associated with increased payment for families receiving Child Care and Development Fund support. Participating ECEPs were required either to have or to add infant "seats" to their site and to accept Child Care and Development Fund vouchers.

Mortality associated with unsafe sleep practices accounts for 1 of 5 infant deaths in Indiana.[10] One focus of our efforts was to increase the health literacy of ECEPs so they could serve as role models for safe sleep for families. By law, ECEPs practice safe sleep within their setting, but, when asked, they rarely engaged families in a discussion around safe sleep. We provided a "welcome kit" (the Cribs for Kids[11] "survival kit," consisting of a sleep sack, pacifier, and educational materials) for each newly enrolled infant. We worked with ECEPs to integrate safe sleep discussions with their welcome kit when enrolling a family. In working with ECEPs, time constraints, staff turnover for training, and parent interaction opportunities were often challenges.

Success was defined as changes in systems within our partnering organizations and increases in ECEP licensure and quality ratings. We exceeded our goal of working with 12 ECEPs by partnering with >60 sites in 2 years. The largest need for quality rating improvement were safe sleep materials and developmental materials. Trained ECEP sites can now welcome their new infants with the Cribs for Kids[11] welcome kit and talk with parents about infant sleeping arrangements, weaving in safe sleep advice and strategies used at their sites. Our efforts resulted in quality improvement in local ECEPs: 14 sites who were previously unlicensed became licensed, 39 sites improved their quality ratings by 1 to 2 levels, and 10 sites (referred for unsafe sleep practices) received safe sleep materials and training. Our development of networks between support organizations and ECEPs allows continued collaboration and shared learning because communication strategies and referral strategies are embedded between the organizations. We continue to advocate for the importance of ECE programs in fostering not only infant but also community development and overall health.

Our second objective for this goal was to facilitate a network of health and social service providers and community members volunteering for the county's Fetal and Infant Mortality Review Community Action Team (FIMR-CAT) to implement education and skill building to improve the adoption of safe sleep practice in families from targeted zip codes. A Safe Sleep Work Group (SSWG) was formed and led by the pediatrician who wrote this article. Recruitment to the SSWG was initially through the FIMR-CAT membership (numerous local health and social service providers). The SSWG was then subdivided into working groups that targeted particular demographics (fathers, new mothers, youth, and grandparents or kinship care). To ensure diversity within each workgroup, members recruited community members to serve on these subcommittees.

Each group targeted messages and skills-building sessions for their demographic group. For example, the men's group had a crib demonstration in barbershops. Grandparents seemed particularly confused about the use of sleep sacks instead of blankets, so life-size dolls were used for demonstration and hands-on practice. All sessions were held in local community venues in conjunction with local organizations. Success was determined by the number of community members receiving training through the Cribs for Kids' national Safe Sleep Ambassador program.[11] Safe Sleep Ambassadors complete online or in-person training and must pass a posttest to become an ambassador. Ambassadors make a pledge to reach out to at least 5 other members of the community. Challenges included reaching the largest number of people while allowing the hands-on practice and one-on-one conversations to address questions.

We developed an easy-to-use, cloud-based data collection system to gather data on populations and zip codes reached. In 2019, the SSWG reached >6000 community members (an average of 500 per month) and participated in 55 events, of which 67% were in the targeted zip codes. For sustainable impact, we trained 70 community members to become Safe Sleep Ambassadors, each of whom has pledged to reach out to their social networks. We also adapted the curriculum for youth and worked with a local school to train 145 elementary and middle school youth.

Overview of Goal 2: Connect Grassroots Maternal and Child Health Leaders Skilled in Policy Advocacy and Development With MCH Decision-makers to Improve Local Social Systems That Influence Birth Outcomes

Our first objective for this goal was to build and train a system of at least 12 grassroots maternal and child health leaders (GMCHLs) from targeted zip codes within 1 year. Across the globe, GMCHLs are critical for changing social systems to improve MCH outcomes because of their lived experiences within marginalized communities and their reality-based solution strategies to address root causes.[12] We recruited women for the GMCHL initiative from targeted zip codes through social service agencies, Department of Corrections, affordable housing communities, and faith-based organizations. All participants are >18 years of age, live within a targeted zip code, demonstrated leadership potential within the source that referred them to our program, and expressed an interest in addressing infant mortality. Most of the women experienced infant loss directly or indirectly (sister, aunt, daughter), or experienced another adverse birth outcome. Each GMCHL goes through an initial 12 hours of training,[13] followed by extensive mentoring in narrative storytelling wherein they write about their MCH experience. Once these steps are completed, they begin working on their community leadership project with intensive mentoring by our team. Each GMCHL provides 12 hours of community leadership per month and receives a monthly $300 gift card for her efforts. We adhered to the Kellogg Report on Grassroots Leadership Development[14] and fostered each woman's personal development while training and mentoring her in community development and advocacy.

Fourteen women completed our training curriculum[13] and wrote and successfully presented their personal narrative and ideas for community change in public settings. These 14 women are now active as GMCHLs. Each woman has met at least 1 personal goal established at the outset of the program. At the onset of the program, 8 women were unemployed; now, all women are either employed with full- or part-time work, advancing their formal education, or advancing their education in funded internship or learning opportunities (AmeriCorps, Indiana Institute for Working Families, IU Public Policy Institute).

Our second objective for this goal was that, over a 2 year period, GMCHLs will have collaborated with organizational or political leaders to implement a new social system that influences the risk of infant mortality in a marginalized population. Indiana is one of only 13 states with a prison nursery. The GMCHLs identified the need for a community-navigation system for women as they are released with an infant with little knowledge or skill in accessing the programs available for them. A GMCHL, who was formerly incarcerated and released with her infant, worked with a Master of Public Health intern to develop a community-navigation program to serve these women. Challenges included getting access to data about incarcerated women preparing for release and their issues with community reintegration, organizing resources available to women transitioning from prison to community, and technology issues connecting community members to incarcerated women. Our success was defined by the design and implementation of the community-navigation program.

This work resulted in the Mothers on the Rise program. The program provides 6 months of service to incarcerated (state prison or an alternative sentencing facility) women with infants, 3 months prerelease and 3 months post release. A key ingredient is the provision of 3 months of high-quality child care on release. This program received national attention for its unique focus on a peer mentoring approach to women transitioning from prison to community while parenting an infant. National coverage in US News and World Report[15] and the national *Radio Health Journal*[16] has helped raise awareness of the importance of this work.

Our third objective for this goal was that, within a 2 year period, GMCHLs will advance a policy brief for consideration by local, state, or federal policymakers. The metrics of success included the creation of policy briefs reflective of community needs and the inclusion of GMCHLs at MCH decision-making tables. Challenges included getting audiences with policymakers and helping them understand the role and usefulness of GMCHLs. The GMCHLs provide a new perspective for policymakers and policy. We took several steps to ensure the voices of the GMCHLs would be heard. First, we hosted a week-long exhibition in the statehouse during the legislative session. This provided lawmakers and policy analysts with an introduction to the GMCHLs. This was followed by GMCHLs being asked to deliver a 3-hour talk regarding the social determinants to the MCH staff of the State Department of Health. It provided an opportunity for decision-makers to learn the realities of communities with persistent infant mortality. This opened the door for the GMCHLs to consult on the content and delivery of the state's Title V MCH assessment (the first time grassroots women participated in this effort).

The great skill of GMCHLs in telling their stories and their recommendations for social changes led them to being plenary speakers at the state's infant mortality summit, with >1500 attendees. This was the first time grassroots women served as plenary speakers. GMCHLs are now sitting at MCH decision-making tables across our city and state, including the state's fair housing board and a local public policy institute and working with the state's maternal mortality review board. Finally, the leaders' stories and action were helpful in the creation of the state's first legislative MCH caucus.

The GMCHLs have successfully completed and presented 2 policy briefs for state lawmakers. The first focuses on providing financial assistance and greater rights to grandparents raising their grandchildren. These grandparents in the targeted zip codes are often overlooked by policymakers. The second brief advocates for the elimination of sales tax on feminine hygiene products and diapers because there is a growing population of women with challenges affording these essential items. In only 2 years of existence, GMCHLs are being integrated with networks of policymakers, resulting in an important exchange of information across all parties that will help address infant mortality for marginalized communities.

LESSONS LEARNED

Pediatricians and their social science colleagues are well suited to inform policy makers about the impact of social inequities on birth outcomes and infant development; the personal stories and solution strategies of community members and organizations can greatly assist in these efforts. We learned important lessons that can help pediatricians in other communities lead these types of community-based advocacy efforts. First, it is important to purposefully bring together networks of policy makers, health care and social service providers with grassroots organizations and individuals to bring about micro (organizational level) and macro (state level) changes to improve systems that influence health disparities, such as infant mortality rates. Do not assume that there is meaningful dialogue occurring between these networks. Advocacy that is grounded in community-based realities emerges when these networks are merged. Second, bring a variety of scholars, disenfranchised community members, and atypical community organizations to the table for advocacy development and implementation. Scholars from liberal arts and arts, media, and design were excited to participate, and their work was critical for our success. Their ability to create communication strategies accelerated our work efforts. Likewise, the inclusion of formerly incarcerated individuals and ECEPs in marginalized neighborhoods led to the creation of novel outreach across the communities. Finally, there are free and helpful tools that provide detailed guidance to help a pediatrician organize advocacy efforts and policy action, such as those found in the Community Tool Box.[17]

CONCLUSIONS

We were successful in meeting our immediate advocacy goals aimed at changing systems that influence birth outcomes in marginalized zip codes. We are pleased that our state and county 2019 infant mortality and Black infant mortality rates are at historic lows.[18] Because the causes of infant mortality are complex, no one effort can claim success for these improvements. Our advocacy efforts, focused on root cause systems change, are vital to promoting the sustainability of recent improvements in our infant mortality rates.

Our approach provides pediatricians a framework to build teams that break down old, siloed efforts using a unified framework, local data, and community voices. The partnerships we brought to this effort or developed through the effort are helping sustain the actions of organizations and the GMCHL. The work is being integrated into agencies with responsibilities for improving pregnancy and infant health outcomes. We are still actively involved in this work and are expanding it across the state. To learn more about our GMCHL initiative, visit our Web site.[19] Ensuring health equity for all women and infants requires our diligence to break down the obstacles to opportunities experienced by marginalized communities to raise healthy infants.

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ABBREVIATIONS

ECEP: early childhood education provider
FIMR-CAT: Fetal and Infant Mortality Review Community Action Team
GMCHL: grassroots maternal and child health leader
HP: Healthy People
IMR: infant mortality rate
MCH: maternal and child health
SDOH: social determinants of health
SSWG: Safe Sleep Work Group

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