ABSTRACT
Infant mortality rate (IMR) is an important indicator of progress toward health equity and socio-economic development. Despite progress, the US is ranked 45th among 192 countries in IMR, with non-Hispanic black IMR 2.2 times that of non-Hispanic white rates, and higher than average IMR in Native American populations. The Preconception Peer Educators (PPE) program of the U.S. DHHS Office of Minority Health Resource Center (OMHRC) aims to raise awareness about IMR disparities in African Americans, and to promote preconception health behaviors among women of childbearing age and sexually active men. Building upon this program, this report focuses on lessons learned from a capacity-building and participatory planning pilot program designed and implemented in 4 US cities by Health Equity Initiative in collaboration with the OMHRC to encourage multisectoral partnerships, and engage local leaders and organizations in participatory planning and infant mortality prevention.

Keywords: Capacity Building, Community Engagement, Child Health, Health Disparities, Health Communication, Health Equity, Infant Mortality, Maternal Health, Minority Health,

* The work discussed here was completed as part of R. Schiavo’s ongoing tenure at Health Equity Initiative. Dr. Schiavo’s current/other relevant affiliations are also included.

† Disclaimer: As of January 2014, Denisse Ormaza joined the U.S. DHHS Health Resources and Services Administration (HRSA), and as of October 2014, Isabel Estrada-Portales works for the National Institutes of Health. This article describes work initiated or completed with Dr. Estrada-Portales and Ms. Denisse Ormaza’s contribution while they were employed at the Office of Minority Health Resource Center. The opinions expressed in this article are the authors’ own and do not reflect the view of the National Institutes of Health, the Department of Health and Human Services, or the United States government.
INTRODUCTION

Infant mortality rate (IMR) is widely considered a critical measure of the health and well-being of a nation as it is reflective of “maternal health, quality and access to medical care, socioeconomic conditions, and public health practices” (MacDorman, Mathews, Mohangoo, & Zeitlin, 2014, p. 2). IMR is also a major indicator of progress toward health equity and socioeconomic development. Despite progress, IMR in the United States continues to lag behind other industrialized nations, with poor infant survival rates linked to birth defects, preterm births, sudden infant death syndrome, maternal health complications and unintentional injuries (Centers for Disease Control and Prevention [CDC], 2014b). With an IMR of 6.07 infant deaths per 1,000 live births (MacDorman et al., 2014), the United States ranks 31st among the 34 OECD (Organization for Economic Co-operation and Development) countries (Organization for Economic Co-operation and Development, 2014). IMR estimates by the UN Inter-agency Group for Child Mortality Estimation (UNICEF, WHO, World Bank, UN DESA Population Division) placed the United States 45th among 192 countries (UN Inter-agency Group for Child Mortality Estimation, 2014). Although historic differences in IMR among US non-Hispanic black women and non-Hispanic white women have narrowed, the non-Hispanic black IMR is 2.2 times the non-Hispanic white IMR (CDC, 2014a).

In 2007, the Office of Minority Health (OMH) of the Department of Health and Human Services (DHHS) launched A Healthy Baby Begins with You—a national campaign to raise awareness of infant mortality, its root causes and its disproportionate burden among African-Americans, and to encourage the adoption of preconception health-related behaviors among women of childbearing age and sexually active men. Preconception health behaviors are a set of recommended behaviors ranging from eating healthy, exercising, smoking control, chronic stress management, to undergoing genetic counseling, that have been associated with improved birth outcomes (Schiavo, Gonzalez-Flores, Ramesh, & Estrada-Portales, 2011). Preconception care, “a comprehensive program that identifies and reduces reproductive risks before conception” (Jack & Culpepper, 1990, p. 1147), has been associated with infant mortality prevention (Burns, 2005).

An integral component of this campaign, the Preconception Peer Educators (PPE) program of the Office of Minority Health Resource Center (OMHRC), a federally funded project of the OMH, aims to (1) reach the college population with tailored health messages and encourage preconception health behaviors; (2) train students as PPEs using a curriculum that includes health disparities and minority health, infant mortality, African-American health status, preconception health, chronic stress; and (3) arm PPES with tools and materials to train peers and conduct community outreach within their cities and neighborhoods by also connecting with local organizations (US Department of Health and Human Services, Office of Minority Health, 2013; Schiavo, Gonzalez-Flores, Ramesh, & Estrada-Portales, 2011). To date, the OMHRC has trained more than 1,500 PPEs at campuses across the US (US Department of Health and Human Services, Office of Minority Health, 2013). This paper describes a pilot project that was designed to build upon the PPE program experience and community outreach efforts by creating local capacity, ownership and future directions for a sustained focus on infant mortality prevention within four U.S. cities.
Why a Multisectoral and Participatory Approach to Infant Mortality Programming

In recent years, participatory approaches to research and intervention design, where communities are actively engaged with diverse partners, including but not limited to academic institutions, local businesses, and hospitals, are being recognized as effective contributors to health equity (Fawcett, Schultz, Watson-Thompson, Fox, & Bremby, 2010; Minkler, 2010; University of Michigan School of Public Health, 2011), health-promoting public policy (Minkler et al., 2008), community-driven social change (University of Michigan School of Public Health, 2011), and health improvement (Bailey, 2010). Community-based research is already a well-established collaborative research approach that equitably involves community members, organizational representatives, researchers and other partners in contributing their unique strengths and shared responsibilities to gain and integrate knowledge to improve the health and well-being of communities (Israel, Schulz, Parker, & Becker, 1998).

In going beyond community-based or participatory research, participatory planning is a multilevel, integrated approach to community, patient and public engagement as well as intervention design. This approach capitalizes on the unique attributes and cultural awareness of different communities and organizations to create consensus on health and social issues, and to design, implement, and evaluate effective interventions via the contribution of all participants. The concept of participatory planning is an essential component of several strategic planning and communication efforts and models (Johns Hopkins Center for Communication Programs, n.d.; Schiavo, 2013; UNICEF, 2015; World Health Organization [WHO], 2012; Malekpour, deHaan, and Brown, 2013; Forester, 1999), especially in developing nations and vulnerable population settings. Furthermore, sharing expertise and resources allows partners to “access new markets, spur innovation, and achieve greater outcomes” (CDC, n.d., p. 1).

As health disparities are complex and multifactorial issues, the active engagement of multiple organizations and levels of society is essential for the effectiveness of all interventions. In fact, a preliminary assessment of the PPE Program showed that 73% of PPEs regarded community engagement as a key success factor in community outreach on infant mortality issues (Schiavo et al., 2011). Yet, for partnerships to succeed, they need to rely on the participation and buy-in of all potential partners for key goals, processes, and action steps. Other authors have discussed the importance of a systematic approach to partnership development as related to agenda-setting, partner satisfaction, and program continuity (CDC, n.d.; Schiavo, 2013). The project described here was initiated to (1) integrate PPE community outreach efforts within local communities; (2) involve local leaders and organizations in infant mortality prevention programming; (3) enable sustainability of ongoing and future efforts by engaging local players; and most important, to (4) facilitate the development of multisectoral strategies for infant mortality prevention at the local level. The project was designed and implemented by Health Equity Initiative (HEI) (www.healthequityinitiative.org), which also facilitated the workshop and participatory planning process, in collaboration with and funds from the OMHRC. Figure 1 is a description of the process.
Overview of the Process

The project was initiated in four cities: Nashville, Tennessee; Los Angeles, California; Charlotte, North Carolina; and Jacksonville, Florida, which were chosen due to the high burden of infant mortality among African Americans. In 2013, Nashville recorded an IMR of 11.5 among African-Americans in a county where the IMR among non-Hispanic whites was 5.9 and the total IMR was 7.71 (Tennessee Department of Health, 2013). Also in 2013, the African-American infant death rate in Los Angeles County, CA was 9.8, over double the total infant death rate of 4.6 (Los Angeles County Department of Public Health, 2013). In Mecklenburg County, where Charlotte is located, the African-American IMR was 10.2, when compared to an IMR of 4.5 among non-Hispanic whites and a total IMR of 6.2 (North Carolina State Center for Health Statistics, 2013). Similarly, Duval County, of which Jacksonville is county seat, saw an IMR of 11.7 in black babies, double that of non-Hispanic whites (5.8) in 2011 (Florida Department of Health, 2012). Moreover, all of the four cities had ongoing, active PPE programs over the past few years. Participants were recruited by the OMHRC and its local partners, and were contacted by HEI prior to the project’s kick-off for input on local needs, potential lists of attendees, and other information on relevant ongoing activities and programs.

In an effort to build local capacity on partnership development and management as well as to facilitate the design of consensus-driven action plans, a two-day interactive workshop was designed and facilitated by HEI. Eighty-seven attendees participated across the four cities, representing multiple sectors, such as local departments of health (DOHs), academic institutions, community-based organizations, community health clinics, students, local businesses, peer educators, and also included local PPEs who had been previously trained by the OMHRC. The first day of the workshop focused on Strategies to Develop Multisectoral Partnerships (Health
Equity Initiative [HEI], 2015; Schiavo, 2007, 2015). Key topics included dos and don'ts in building and managing successful partnerships; partnership evaluation parameters; how to assess the feasibility and cost-effectiveness of partnerships; understanding and managing roadblocks; how to develop partnership plans as part of strategic and communication plans; and relevant case studies. In addition, a Communication Resources Clinic was used to familiarize participants with existing tools and resources offered by the OMHRC and local partners, and to assess their potential use across different organizations.

On the second day of the workshop, participants developed and reached consensus on comprehensive partnership and action plans for infant mortality prevention to be implemented by the newly formed city-specific task force (N.B. In some cities the groups preferred to call themselves a “collaborative”). The development of all partnership/action plans relied on a systematic approach to participatory planning, which guided and encouraged participants’ ownership of its key elements. Partnership and action plans were integrated to reflect best practices in strategic planning and communication programming (Schiavo, 2013). The plan included the overall scope of the task force, as well as the key goals, objectives, strategies, and activities (Schiavo, 2013) that were identified and prioritized by participants as essential to infant mortality prevention. As per core principles of participatory planning (Mosse, 2001; University of Kansas, 2015), key activities as well as other elements of the action plan were identified and prioritized by an interactive process that emphasized the importance of “deferring to local groups’ knowledge” (Mosse, 2001, p. 385), including lessons learned from past or ongoing interventions, previous experiences, local stories, and/or other information that were shared and discussed by participants during the workshop. Throughout the process, the concern was with “deliberative and participatory practices: inquiring and learning together in the face of differences and conflicts, telling compelling stories and arguing together in negotiations, coming to see issues, relationships and options in new ways, thus arguing and acting together” (Forrester, 1999, p. IX). Not surprisingly, the action plans and related elements identified by participants on the basis of local knowledge and/or past or ongoing programs and lessons learned also reflect overall best practices and existing literature on similar topics (See Partnership Plans: Key Elements and Themes).

The action plan was integrated with principle elements of the partnership plan, including expected roles and responsibilities of all partners, benefits of partnership, organizational policies and preferences vis-à-vis the partnership, frequency and methods of communication, standard protocols for decision making and issue management, expected task force outcomes, and mutually-agreed upon evaluation parameters (Schiavo, 2013, p. 399). The latter included program and outcome-related evaluation parameters as well as indicators of partnership sustainability, which were designed to capture what would make partners stay engaged in the partnership. Finally, as part of the Communication Resources Clinic, participants identified the need for resources to evaluate ongoing efforts, brand the task force, and raise funds. Through its interactive workshop sessions, collaborative partnership plan development, and the Clinic, this project built capacity on strategies for multisectoral partnership development as well as setting goals and objectives for health disparities programming within a participatory model.

Partnership Plans: Key Elements and Themes

As the root causes for high infant mortality rates share some commonalities across different US settings, several recurring themes emerged in all four cities, which also resulted in
some shared objectives across plans. Examples include a sharp focus on raising awareness of infant mortality rates and preconception health as well as building capacity among healthcare providers, so they could adequately address preconception health at clinical visits. Yet, in each city, participants also prioritized city-specific objectives that reflected differing issues and local needs, such as the importance of increasing men’s participation (Nashville); stress management/coping (Los Angeles); and awareness of access to healthcare services (Jacksonville) (see Table 1). As part of this interactive process, participants discussed local community needs that had been assessed through formal and informal processes and consultations as part of past and ongoing interventions and/or their own experiences. Given the multisectoral nature of all participant groups at the different sites, multiple perspectives informed a discussion on what has worked or “failed in the past, and why,” (University of Kansas, 2015) so that the action plans could build upon past or ongoing experiences and address key issues. Such issues also resonate as critical areas in infant mortality prevention programming according to local reports on community health needs and/or drivers of infant mortality (Braveman, Nicholson, & Marchi, 2007; Harrington, Vallejo, Freiheit, Tunis, Fenyvesi, & Nang, 2013; Jacksonville Community Council Inc., 2008); other authors and relevant experiences (Schiavo, Gonzalez-Flores, Ramesh, & Estrada-Portales, 2011; U.S. Department of Health Human Services, 2007 and 2008); as well as many emerging, promising, and best practices in infant mortality prevention (Association of Maternal and Child Health Programs, n.d.).

Of great importance is the social mobilization-driven focus that inspired the development of all these plans. As discussed, across the four sites, the plans were designed to engage a broad range of audiences and to transcend common practices that too often see only the *usual suspects* (e.g. at-risk populations and their advocates) being actively interested in addressing health disparities. In addition to these *usual suspects*, participants identified several audiences to be engaged in partnership/action plans refinement, including policymakers, community members, healthcare providers, mass media, caretakers, professional associations including non-health-related associations, local businesses (retail, beauty, bank, etc.), local media, public and private schools of all levels, government agencies including non-health agencies, social service organizations, community-based organizations, school counselors, and social workers. As per the definition of “community” used by the project—“a variety of social, ethnic, cultural, or geographic associations, for example, a school, workplace, city, neighborhood, organized patient or professional group, or association of peer leaders” (Schiavo, 2013, p. 181)—the plans advocate for everyone in the city to work together and recognize that “if a black baby dies it’s everyone’s responsibility to make sure that it does not happen again” (Schiavo, 2013).

Table 1. Sample Recurring and City-specific Objectives of the four Plans

<table>
<thead>
<tr>
<th>Recurring Objectives</th>
<th>City-specific Objectives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Raise awareness of infant mortality rates/preconception health among broad audience</td>
<td>Develop economic and social support for the initiative <em>(Charlotte)</em></td>
</tr>
<tr>
<td>Build capacity of healthcare providers to address preconception health • Improve clinician-patient</td>
<td>Increase men’s participation in preconception health through increased attendance at preconception health and infant mortality community events <em>(Nashville)</em></td>
</tr>
<tr>
<td></td>
<td>Address <em>wellness</em> across the lifespan (age 8+), including</td>
</tr>
</tbody>
</table>
Developing Mutually Agreed upon Parameters for Partnership Sustainability

Recognizing that sustaining strong and equitable partnerships requires commitment and effective collaboration is key to long-term sustainability. Participants identified several themes as being critical to partnership success, as well as useful measures for partner satisfaction (see Table 2). These factors ranged from personal commitment and efficient use of time (“events are planned ahead of time” and “efficient project management techniques”), to transparent communication, observable results, and benefits for each partner (“my organization is benefiting from being involved in the task force”).

The project was complemented by the development of a few new resources to address participants’ needs across the four sites. These included Fundraising and Evaluation Kits to aid the efforts of the newly formed task forces. Sample fundraising resources include a fundraising letter, a statistical fact sheet, a list of potential funders and a sample phone script (Health Equity Initiative & Office of Minority Health Resource Center, 2012a), to assist with initial fundraising activities. Evaluation resources include tools to help measure and report on key activities and mutually agreed upon goals and objectives; assess member satisfaction; and identify success factors and opportunities for task force effectiveness (Health Equity Initiative & Office of Minority Health Resource Center, 2012b). Both these resources can be downloaded at the links within their respective citations in the References section of this paper.

Table 2. Examples of Mutually Agreed Upon Measures for Partnership Success

| **Personal commitment** | to complete tasks on time and attend meetings regularly |
| **Organization and effective use of time,** | so that meetings have a clear agenda, are focused and result in decisions and progress; and that effective project management techniques are used to plan events and ensure progression of work |
| **Consensus building and ability to compromise** | on important decisions, which requires the willingness to be “open to different approaches” and “consider different ways of working” |
| **Transparency and effective communication,** | where all partners are “informed as often as [they] should about what goes on in the collaboration”, “communication is generally good”, and there are “no hidden agendas” |
| **Mutual benefits,** | including increased organizational visibility, networking opportunities, and support for complementary programs |
| **Observable results** | from the task force’s work, and overall program/task force growth |
DISCUSSION

Several common threads emerged across all four pilot cities. For example, participants in all four cities mentioned low awareness of infant mortality as a key issue. Since preconception health is not widely discussed in primary healthcare settings or at student health centers, all action plans consistently prioritized the importance of healthcare settings for future task force action. Most groups also agreed on the importance of broadening the efforts to involve those outside of the usual suspects (e.g. African American, public health organizations) in tackling disparities in IMR.

Participants also identified several challenges to task force sustainability, including the importance of integrating new efforts with the work of existing coalitions, addressing political issues that may undermine effective collaboration and inclusiveness, and enabling the continuity of the PPE program. Prioritizing investment and funding for infant mortality prevention was also cited across all four different groups as an important enabling factor. The development of mutually-agreed upon parameters to evaluate the success of the partnerships also pointed to many important factors that would contribute to task force sustainability and encourage long-standing participation of its members.

Despite differences in organizational purpose or mission as well as different levels of IMR knowledge and professional experience, participants effectively collaborated to create city-specific partnership plans. The involvement of each of the different sectors and disciplines was recognized to be vital in reaching out to different segments. For instance, local DOHs and academic centers were crucial in engaging students and local community based organizations. DOHs also provided much needed access to existing data and projects. Because of its high visibility, the OMHRC was instrumental in recruiting and securing attendees for the initial effort.

At the onset of partnership, interpersonal communications and in-person meetings emerged as best suited to discuss and assess local issues, brainstorm on potential solutions, and allow participants to ‘tune into’ partnership efforts. Notably, the project recognized the importance of integrating new and existing efforts and encouraged a sense of ownership among participants in reference to the implementation phase of all plans as well as the recruitment of new partners, and partnership assessment.

All of the above themes can help inform future capacity building and partnership development efforts by organizations and professionals from multiple sectors and disciplines that seek to establish, manage and/or assess different kinds of collaboratives to address health disparities. Building capacity for strategic partnership development and management as well as participatory planning is central to the success of partnership-driven efforts. Further emphasis on topics related to strategic partnership and participatory planning is needed as part of workforce development efforts, including in the fields of public health, healthcare, and community development. Several core skills and competencies in partnership development and management (e.g., assessment, communication, transformational and trans-organizational skills, team building, strategic planning, consensus building, partnership planning, participatory planning, and others) (Interprofessional Education Collaborative Expert Panel, 2011; Schiavo, 2013) were addressed by and/or informed this project, so that participants could review and discuss different concepts, case studies, and lessons learned on the art and science of strategic partnerships, and contribute their multiple perspectives to the development of city-specific plans for infant mortality prevention. Of relevance, an important aspect of the project was to engage participants on developing parameters not only to assess the intervention’s outcomes but also to measure
their future level of satisfaction with the collaborative and willingness to remain engaged with partners (see table 2).

Ultimately, organizations and leaders who seek to engage in similar efforts would be better off starting with creating a “culture of partnerships” within their own institutions by (1) encouraging a partnership-driven mindset and allowing time for consensus-building processes; (2) identifying partnership champions and establishing dedicated functions; (3) emphasizing the importance of teamwork, listening, negotiation skills, balancing different needs and organizational cultures, and sharing credit for success; (4) training key officers and staff members on strategic partnership development and management; and (5) sharing lessons learned and key results of partnership-driven efforts with other organizational departments, all partners, and other key stakeholders, so that best practices and the overall value of partnership can be further demonstrated (Schiavo, 2015 and 2013).

Finally, key findings from project assessment are included in the section below and provide further information that may offer useful insights for future capacity building efforts for the development of collaboratives and task forces.

Key Findings: Project Assessments

The capacity building and participatory planning process and related workshop were assessed via an anonymous questionnaire distributed in all four cities. The questionnaire focused on securing information on message recall on most important information participants learned from the workshop (regarding strategies to develop multisectoral partnerships), behavioral intentions, as well as participants’ assessment of the overall quality of the project. Forty-one percent (41%) of the participants completed the questionnaire. Of these, 45% were not PPEs and included local participants from academia, nonprofit organizations, departments of health, community health centers, businesses, and advocacy groups. Select key findings are summarized in Table 3. Quotes included in the table represent recurring themes that emerged across different answers.

### Table 3. Key Findings: Project Assessment

<table>
<thead>
<tr>
<th>What Participants Most Remembered Learning</th>
<th>What Participants/Partners Intend to Do After Kick-Off Meeting (Behavioral Intentions)</th>
<th>Average rating given by participants to capacity building/partnership plan development process</th>
</tr>
</thead>
<tbody>
<tr>
<td>• “How to select partners. How to assign responsibilities”</td>
<td>• “I plan to seek out contacts for partnership”</td>
<td>Quality of event: 4.44 (on a scale of 1 to 5 with 1 being “Very poor” and 5 being “Excellent”)</td>
</tr>
<tr>
<td>• “Developing goals and objectives that are measurable.”</td>
<td>• “Gathering baseline data on preconception health knowledge”</td>
<td>Relevance of information: 4.72 (on a scale of 1 to 5 with 1 being “Totally irrelevant” and 5 being “Extremely Relevant”)</td>
</tr>
<tr>
<td>• Identifying partners/task force members related to goals and objectives”</td>
<td>• “Contact current partners to reengage in preconception health”</td>
<td>Method of presentation: 4.29 (on a scale of 1 to 5 with 1</td>
</tr>
</tbody>
</table>
Key findings suggest several topics and features for consideration as part of future capacity building efforts for collaboratives and task forces. For example, future training efforts on partnership development and management should consider including methods for developing a comprehensive partnership plan; establishing measurable goals and objectives; selecting potential partners, as well as assigning responsibilities and encouraging accountability and buy-in among different groups, which were all cited by participants among the topics they most remembered learning from the workshop (see table 3).

Interactivity was a key feature of the overall workshop and emerged as an important theme within qualitative remarks by participants. Qualitative answers complement the quantitative assessment of the quality, relevance, and methods of the workshop (see table 3) and suggest that participants “enjoyed the interaction” and the “great use of time” during the workshop. “Interactive participation,” is an important feature of many participatory planning processes, and is designed to encourage participants to share and acquire new knowledge; relate to new information as it applies to one’s work; and “participate in joint analysis, which leads to locally formulated action plans.” It tends to involve “interdisciplinary methodologies that seek multiple perspectives and make use of systematic and structured learning processes.” Interactive participation should be considered for similar interventions as it may allow participant groups to “take control/ownership over local decisions…so, they have a stake in maintaining structures or practices” (Edwards-Jones, Davies, & Hussain, 2009, p. 166; Pretty, 1995).

CONCLUSIONS

As with other health disparities, multisectoral partnerships are emerging as a key strategic approach to combine multiple perspectives and expertise on infant mortality prevention programming. This pilot program provides valuable insights and a potential framework for similar capacity building efforts by public health, community development, and healthcare professionals and organizations in the fields of infant mortality prevention and, more broadly, health disparities, social innovation, and user-centered design. Across the four sites, participants also identified key categories for the assessment of this kind of effort: (1) infant mortality health-related outcomes; (2) partnership sustainability and growth; and (3) partner satisfaction vis-à-vis mutually agreed upon parameters. The project’s structured approach to capacity building and participatory planning can be reproduced in other settings, both within the United States and globally, and has implications for leaders and organizations that work on collaborative efforts to
address health disparities. As this or similar endeavors move forward, the development of local champions, along with sustained mentorship and support on key topics from this initial effort, are essential to long-term sustainability.

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HUMAN PARTICIPATION PROTECTION
Institutional review board approval was not needed for this project. Human subjects were not the focus of any research conducted. The unit of analysis was partnership development and sustainability rather than the individual. No personal identifiers or personal information were collected. There was no substantial risk for professionals who participated in this project.

REFERENCES


