FSG REIMAGINING SOCIAL CHANGE

Healthy Birth Outcomes through Cross-Sector Collaboration

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Our teams work across all sectors by partnering with leading foundations, businesses, nonprofits, and governments in every region of the globe. We seek to reimagine social change by identifying ways to maximize the impact of existing resources, amplifying the work of others to help advance knowledge and practice, and inspiring change agents around the world to achieve greater impact.

As part of our nonprofit mission, FSG also directly supports learning communities, such as the Collective Impact Forum, the Shared Value Initiative, and the Impact Hiring Initiative to provide the tools and relationships that change agents need to be successful.

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Introduction

Improving birth outcomes means acknowledging and addressing the larger system at play

In the United States, a black baby is more than twice as likely to die before his or her first birthday as a white baby.[1] In some states, the black infant mortality rate can be up to three times higher than that for white infants.[2] Moreover, black mothers are three and a half times more likely than white mothers to die from pregnancy-related causes.[3] On their own, these inequities deserve attention. However, poor birth outcomes in the United States are further accentuated by our position relative to the rest of the industrialized world—the U.S. overall ranks near the bottom of the Organisation for Economic Co-operation and Development (OECD) countries in infant mortality, at 29 out of 35.[4]

In order to improve birth outcomes in the U.S., we must acknowledge that infant mortality and other adverse outcomes are not only a result of biology and medical care, but also of a woman's access to social, educational, environmental, and economic opportunities throughout her life. These non-clinical factors—*social determinants of health*—demand multiple interventions and require multiple actors to shift their attention.

Over the past 10 years, the field of maternal and child health has increasingly focused on addressing these complex systems through long-term multi-sector collaborations aimed at aligning many actors towards the same goal. By coordinating resources from funders, health care system leaders, researchers, community members, community-based organizations, governments, and others, we can begin to change the laws, policies, practices, and environmental factors that affect birth outcomes.

Many states, cities, and communities have been exploring multi-sector collaborations as a way to increase the number of healthy births. In 2012, the federal Maternal and Child Health Bureau (within the Health Resource and Service Administration of the U.S. Department of Health and Human Services) launched the first group of state-level Collaborative Improvement and Innovation Networks (CoIINs)[5] focused on infant mortality and maternal health. This effort was expanded to include all of the states in 2014 and resulted in a toolkit that summarized their key insights.[6] The Association of Maternal and Child Health Programs created a compendium of best practices that provides policy

1 Int. J. Environ. Res. Public Health 2017, 14, 727; doi:10.3390/ijerph14070727.

2 State Variations in Infant Mortality by Race and Hispanic Origin of Mother, 2013–2015, https://www.cdc.gov/nchs/data/databriefs/db295_table.pdf.

3 CDC Pregnancy Mortality Surveillance System, https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pmss.html.

4 The Organisation for Economic Co-operation and Development (OECD) is an intergovernmental economic organization comprised of 35 of the world's most developed nations, including Japan, the United Kingdom, Australia, Italy, and Canada. The only OECD countries with infant mortality rates worse than the U.S. are the Slovak Republic, Latvia, Chile, Mexico, Turkey, and Korea. https://www.americashealthrankings.org/learn/reports/2016-annual-report/comparison-with-other-nations.

5 https://mchb.hrsa.gov/maternal-child-health-initiatives/collaborative-improvement-innovation-networks-coiins.

6 Toolkit: https://www.nichq.org/infant-mortality-prevention-toolkit.

GLOSSARY

Infant Mortality: The death of an infant before his or her first birthday.

Low Birth Weight: An infant born weighing less than 2,500 grams is considered low birth weight. The infant mortality rate for low birth weight infants is about 25 times that of the infant mortality rate for normal weight babies. Strongly correlated with preterm birth, low birth weight infants are more likely to have challenges with the heart, liver, and lungs and increased risk of infection, as well as increased risk for diseases later in life.

Preterm Birth: The birth of an infant before 37 weeks of pregnancy. This is the main driver of the disparate infant mortality rates between black and white infants, accounting for 54 percent of the disparity. Among infants that survive, preterm birth is associated with increased risk of developmental delay and disability.

Small for Gestational Age: Small for gestational age (SGA) babies are smaller than usual for the number of weeks of pregnancy. SGA babies may have complications such as decreased oxygen levels, low blood sugar, or difficulty maintaining a normal body temperature.

and program options for states and also a companion toolkit to support comprehensive initiatives aimed at improving birth outcomes.[7] There are many examples of local initiatives putting these principles into practice. The collaborative efforts StartStrong and Cradle Cincinnati have reported substantial improvement in Cincinnati and Hamilton County, Ohio birth outcomes by using a systems-level and multi-sector approach.[8] And even more recently, a family and child wellbeing initiative in Baltimore, B'more for Healthy Babies, recently published a report of the impressive infant health outcomes of their multi-sector collaboration.[9]

FSG had the opportunity to work with two initiatives who have engaged in such work: the Fresno County Preterm Birth Initiative (PTBi) and the Staten Island Perinatal Initiative. Like many other U.S. cities, Fresno and Staten Island face high rates of infant mortality, preterm birth, and other adverse birth outcomes, and disproportionate negative outcomes for women of color and/or those who are low-income. In 2015, both initiatives partnered with FSG to leverage the use of collective impact, an approach to cross-sector collaborative partnership that engages multiple actors in a system to address a specific social problem at scale.[10]

This paper documents the shared lessons learned from both initiatives. While collective impact looks different in the two communities due to unique local contexts, there were similarities in how the initiatives defined scope, facilitated community ownership through an equity lens, leveraged relationships and trust, and managed the pace of change.

Our FSG team is extremely appreciative of the unique opportunities to support the Fresno and Staten Island initiatives. These two projects deepened our understanding of maternal and child health issues and provided excellent opportunities to leverage collective impact best practices and experiment with innovative approaches to drive community change. This paper is dedicated to our former clients: the University of California, San Francisco's Preterm Birth Initiative and the Staten Island Foundation; to the two steering committees of dedicated community leaders who lead these initiatives; and, most importantly, to the mothers and families of Fresno and Staten Island. Without their investment, commitment, and perseverance, this work would not have been possible.

7 Compendium: http://www.amchp.org/AboutTitleV/Resources/Documents/AMCHP Birth Outcomes Compendium.pdf; Companion Toolkit: http://www.amchp.org/programsandtopics/womens-health/Focus%20Areas/infantmortality/Pages/default.aspx.

8 bi3, *StartStrong: Transforming the System of Care to Reduce Infant Mortality*, December 2017: http://bi3.org/wp-content/uploads/2017/12/bi3_StartStrong_ThoughtLeadership_WhitePaper-121217.pdf.

9 The Annie E. Casey Foundation, *B'More for Healthy Babies: A Collaborative Funding Model to Reduce Infant Mortality in Baltimore*, 2018: http://www.aecf.org/resources/bmore-for-healthy-babies/.

10 http://collectiveimpactforum.org/what-collective-impact.

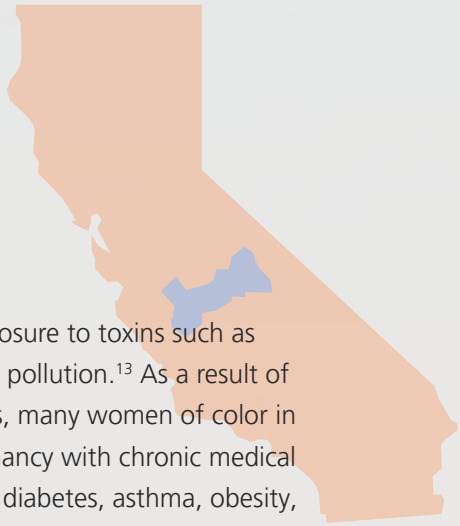
Reflections from Fresno and Staten Island

4 key lessons for cross-sector collaborations seeking to address infant health outcomes

While Fresno and Staten Island are distinctly different communities, their experiences with collective impact revealed compelling insights for cross-sector collaborative efforts that are working to address birth outcomes across the country. FSG supported these communities in launching their initiatives in 2015. Although these initiatives are three years old, they are both considered nascent due to the long-term nature of the work. Impact on the actual rates of infant mortality, preterm birth, and low birth weight as a result of these cross-sector collaborative efforts is yet to be assessed.

Here we highlight four key lessons for cross-sector collaborations seeking to address infant health outcomes. These lessons are drawn from our work helping to launch the initiatives in Fresno and Staten Island and from the specific experiences of those involved.

FRESNO COUNTY, CALIFORNIA



The context:

At the time the Fresno collective impact effort was first in development, Fresno County had among the highest preterm birth and infant mortality rates in California, with over 1,500 babies born preterm on an annual basis. A significant percentage of women in Fresno are low-income, and almost 70 percent of all births in Fresno are covered by Medi-Cal.[11] Social determinants of health play a strong role in driving health inequities in Fresno. The high rates of poverty and unemployment mean that low-income women of color in Fresno lack access to affordable fresh food, safe housing, clean drinking water, and transportation.[12] Fresno is the most polluted county in the state, meaning that women living there also face high environmental exposure to toxins such as toxic air and water pollution.[13] As a result of these social factors, many women of color in Fresno enter pregnancy with chronic medical conditions such as diabetes, asthma, obesity, and heart disease—all risk factors for preterm birth.[14] The coalescing of those social factors in the experience of black and Native American women means that they face the highest *rates* of preterm birth, low birth weight babies, and infant mortality (see Figure 1).[15] Latina women account for over 60 percent of all births in Fresno County, and as a result experience the highest *total number* of preterm births, even though their rate of preterm birth is among the lowest.

11 Watkins, J., Carpenter, W. *Medi-Cal births for 2007-2011: birth counts by county and aid category*. California Department of Health Care Services, Sacramento, CA, July 2014, and Kidsdata.org birth data, accessed June 11, 2018.

12 FSG Interviews

13 FSG Interviews

14 FSG Interviews

15 African American Infant Mortality in Fresno County (2015). Central Valley Health Policy Institute, Central California Center for Health and Human Services, College of Health and Human Services, California State University, Fresno.

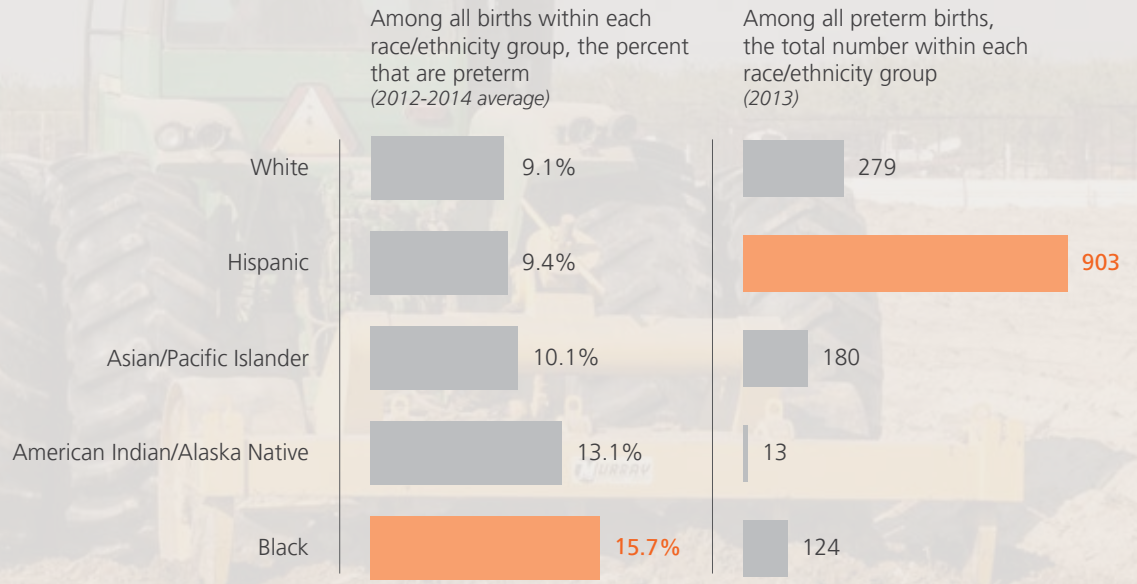
The initiative:

In early 2015, a group of leaders in Fresno County came together to launch a steering committee for a local initiative to reduce the rate of preterm birth in the county. The group included mothers with lived experience of adverse birth outcomes and representatives from the health care, public health, education, philanthropic, and nonprofit sectors, as well as the county's chamber of commerce. The steering committee has met monthly since April 2015. The vision and goal of the Fresno County Preterm Birth Initiative is to create a future in which all women in Fresno County are in the best possible health before, during, and after pregnancy so that their babies are more likely to be healthy at birth and beyond.[16] The effort is supported by the UCSF Preterm Birth Initiative, a 10-year philanthropic research initiative working across three California counties.[17] One of the initiative's aims is to evaluate collective impact as a community-level intervention to improve equity in birth outcomes. Existing public health and academic partnerships, like the one with UCSF, greatly facilitated the launch of the initiative.

16 http://www.ptbifresno.org/.

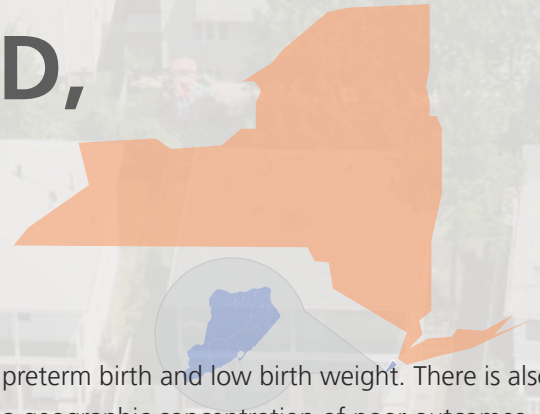
17 http://pretermbirth.ucsf.edu/ptbi-california.

FIGURE 1. RISK AND BURDEN OF PRETERM BIRTH IN FRESNO COUNTY BY RACE/ETHNICITY



Sources: National Center for Health Statistics, final natality data. Retrieved September 14, 2017, from www.marchofdimes.org/peristats; California Summit on Preterm Birth (March 18, 2015), CADPH, March of Dimes; California Dept. of Public Health, Center for Health Statistics, Birth Statistical Master Files; Centers for Disease Control & Prevention, Natality data on CDC WONDER; Martin, J. A., et al. (2015). Births: Final data for 2013. National Vital Statistics Reports, 64(1) (Mar. 2015). Retrieved from: https://www.kidsdata.org June 10, 2018.

STATEN ISLAND, NEW YORK



The context:

Staten Island, the southernmost of New York City's five boroughs, faces significant disparities in birth outcomes based on race and geography. The infant mortality rate for black babies is over four times higher than that of white babies.[18] Black infants represent only 13 percent of total births, but 36 percent of infant deaths. These infant mortality rates are worse than rates in lower- and middle-income countries around the world, including Botswana, Libya, Sri Lanka, Thailand, and Venezuela. Racial disparities are also present in other birth outcomes, such as preterm birth and low birth weight. There is also a geographic concentration of poor outcomes on the North Shore of Staten Island, an area with higher proportions of lower-income women and women of color (see Figure 2).[19] Service providers pointed to social determinants of health such as homelessness and housing instability, lack of access to healthy food in food deserts, lack of public transportation, and domestic abuse as sources of maternal and infant health challenges.

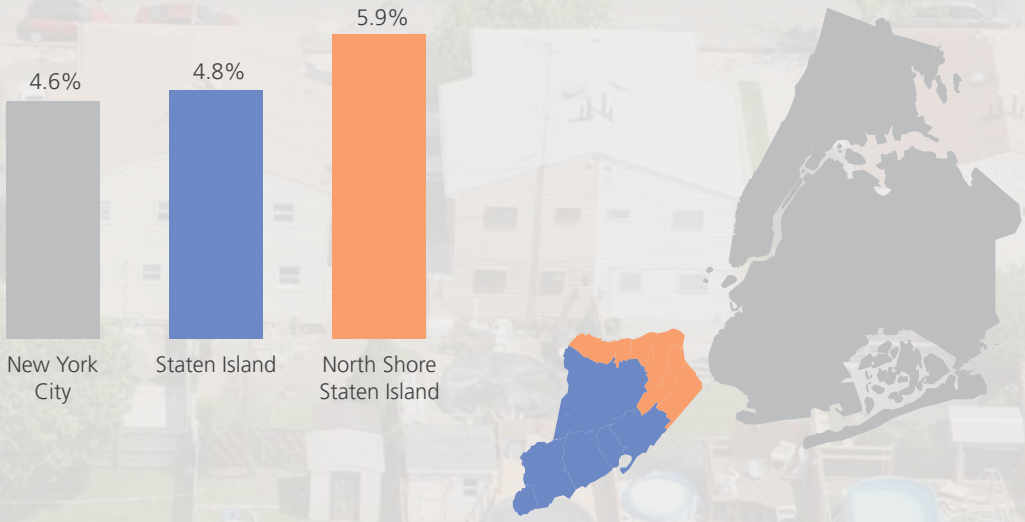
18 New York State Department of Health; data for 2011–2013; FSG analysis.

19 New York State Department of Health; New York City Bureau of Vital Statistics; Centers for Disease Control.

The initiative:

The Staten Island Perinatal Network began in October 2015 as a coalition dedicated to improving birth outcomes for women and families in Staten Island using a collective impact approach. The network's goal is to improve community conditions and create lasting improvements in the health and well-being of babies and families in Staten Island. The network has a specific focus on the neighborhoods and population groups experiencing the worst birth outcomes, including black and Latino families and those who live on the North Shore of Staten Island. Within five years, they aim to decrease the overall infant mortality rate by 15 percent and reduce the disparity between black and white infant mortality rates by 25 percent.

FIGURE 2. INFANT DEATHS PER 1,000 BIRTHS (2013)



Sources: New York State Department of Health; New York City Bureau of Vital Statistics; Center for Disease Control.

Lesson One:

Defining the scope and boundaries of the initiative is difficult, but necessary

What is the challenge?

At first glance, infant birth outcomes might seem like solely a clinical or medical issue. And while health care is an important factor, outcomes are also affected by social determinants of health (e.g., education and income) and structural barriers (e.g., racism and sexism) that must likewise be addressed to see improvement. It may be daunting or ineffective to take on an agenda that is too broad, so initiatives must prioritize areas of focus. However, initiatives should take care to ensure that a variety of groups can see themselves and their priorities in the initiative so that essential partners and stakeholders stay engaged. Moreover, the initiative must be broad enough to encompass some of the social determinants of health.

What can I do about this?

- ✓ Identify top strategic priorities to begin making progress
- ✓ Consider phasing in working groups to build up the initiative slowly
- ✓ Ensure that partners see themselves reflected in the initiative's vision
- ✓ Adopt a life-course approach that includes all factors influencing health and wellbeing

"The clarity we put in place in 2015 with our common agenda still guides us today."

– Sandra Flores, Program Director,
Fresno County Preterm Birth Initiative

1. Identify top strategic priorities to begin making progress

Resist the urge to take on an agenda that is too broad. Consider consensus-building activities or voting with polls and surveys to select two to four topic areas that are embraced by the community, have momentum, and are likely to have impact. Remember that the strategic priorities you select at the beginning of an initiative can evolve over time.

IN PRACTICE

The process of narrowing the scope of focus was difficult in both Fresno and Staten Island. The groups expressed their concerns that promoting healthy births is too complex to limit the number of working groups to three in Fresno or five in Staten Island. However, steering committee members in both initiatives recognized that it was important to start with a manageable number of working groups because each one takes significant effort, time, and resources to initiate and sustain. They determined where the energy was for the steering committees and the community by voting on focus areas. The steering committees also acknowledged that the topics selected could change as their local context changes and as additional needs or priorities are identified. The Staten Island team used data to illuminate the greatest disparities and then selected certain populations and regions to focus on based on that information. Each working group also set criteria to use when selecting focus areas. For instance, the "social determinants of health" working group evaluated whether potential focus areas were relevant and the extent to which they could be influenced.

2. Consider phasing in working groups to build up the initiative slowly

Working groups take a lot of time and energy to set up and it can take a while to figure out who should be included. Starting with one or two allows the team to learn from the successes and challenges of one before starting the next. Consider which working group topic has the most energy and momentum to move forward and bring together those stakeholders to start to identify opportunities for moving the work forward. As the working group progresses, document key challenges and best practices so that subsequent working groups can build from the lessons learned. The first working group can be used to help build capacity and leadership and leverage the support of those involved to move the next working groups forward.

IN PRACTICE

In Fresno, the team started with one working group and then added a new one after several months. Launching working groups required identifying new stakeholders from the community, including mothers with lived experience, reviewing data, and selecting a set of solutions or projects for implementation—a process that requires significant time and investment. In Fresno, this pace allowed the backbone team and steering committee to learn from the early failures and successes of each working group and to effectively build the initiative over time.

3. Ensure that partners see themselves reflected in the initiative's vision

An important consideration to keep in mind when choosing focus areas is that partners must be able to see how they and their priorities are relevant to the topic areas selected. To prevent partners from losing interest, ensure co-creation and ownership of the vision for the work from the beginning, so that even if a partner does not see their issue represented directly they still understand how their work fits into the overall effort. It can also be helpful to clarify upfront that there may be a narrowing of scope so participants are not caught off guard by the process.

IN PRACTICE

After the team in Staten Island narrowed their focus, some partners lost energy or commitment because their specific topic was not selected. Leaders then needed to connect with people one on one to encourage them to remain part of the partnership, reminding them of the broader vision. The backbone leader invested significant time in working with representatives of the groups whose priorities were not reflected in the initial strategies in order to identify a way for them to contribute in a meaningful way. It was important to emphasize that the initial selection of priorities was a place to start, in order to gain traction and momentum, and that the work would evolve over time.

4. Adopt a life-course approach that includes all factors influencing health and wellbeing

Ensure that the topics selected go beyond the clinical care a woman receives while she is pregnant. Non-clinical factors such as lack of access to stable income or adequate housing affect women long before they are pregnant and put their future children at risk of experiencing poor birth outcomes. As such, it is essential to think about a woman's overall health and wellbeing in a holistic way from her own birth and childhood through adulthood before and after pregnancy.

IN PRACTICE

The impacts of social determinants of health came up during steering committee discussions in both Fresno and Staten Island. In Fresno, issues of transportation and nutrition (lack of access to healthy food despite being the "bread basket" of the country) were identified as priorities. In Staten Island, homelessness and lack of access to adequate housing were also identified as priorities. Despite the fact that the collaborative efforts in Fresno and Staten Island work in very different communities, both identified the need to improve women's health and the many factors that impact her health before, during, and after pregnancy.

Lesson Two:

Active community leadership and ownership is required

What is the challenge?

Women of color and women living in poverty make up the primary populations facing disproportionate rates of adverse birth outcomes, and so should be involved in and leading the efforts that seek to improve these outcomes. Nonetheless, the voices and experiences of these women are often overlooked by the current health care system and by the people who seek to improve it.

Community engagement is an essential component of cross-sector collaborative efforts, but too often these efforts are limited to collecting input and feedback from people with lived experience rather than creating opportunities for them to co-create their own solutions.

Because the individuals driving the effort often do not have the same experiences as those at higher risk for poor birth outcomes, critical perspectives that could contribute to effective solutions are not considered. Many initiatives struggle with how to support authentic representation of and leadership by mothers and their families, and many people who lead these efforts are inexperienced in or uncomfortable with having open and honest conversations about race, racism, discrimination, and the effects of these systemic barriers on women's and infants' health. Yet, these experiences are essential to consider. Recent studies have shown that chronic worry about racial discrimination may contribute to racial preterm birth disparities, and may play a role in the black/white disparities that are found even among those of higher income and education levels.[20]

Community engagement must move from gathering or disseminating information to creating opportunities for leadership by the wider community, particularly those who are most affected. This requires examining the ways in which power dynamics work in a local community and creating community-level decision-making structures for the initiatives.

What can I do about this?

- ✓ Assemble diverse steering committees that include representatives from historically excluded communities as well as systems leaders
- ✓ Dedicate resources and attend to power dynamics to support authentic community participation
- ✓ Lead conversations about race, racism, equity, and preterm birth
- ✓ Disaggregate data by race, ethnicity, and income to uncover and highlight health disparities. Use images and simple language to make potentially dry data and statistics compelling

20 Braveman, P., Heck, K., Egerter, S., Dominguez, T.P., Rinki, C., Marchi, K.S., et al. (2017). Worry about racial discrimination: A missing piece of the puzzle of Black-White disparities in preterm birth? *PLoS ONE 12*(10): e0186151. https://doi.org/10.1371/journal.pone.0186151.

1. Assemble diverse steering committees that include representatives from historically excluded communities as well as systems leaders

Members of the community should be included on the steering committee, especially moms and families who have experienced adverse birth outcomes. Rich wisdom, knowledge, and leadership already exist in communities, and this must be valued and elevated by steering committees. Community members should be meaningfully included on the steering committee so they can help determine the strategic direction and implementation of the initiative. Consider forming a "parents' council" or a working group focused on community engagement to encourage ongoing dialogue, feedback, and input from community members at large. Leverage the rich assets that already exist in these communities when possible to build the parents' councils (e.g., trusted community providers, advocates, etc.). Engage the councils on an ongoing basis to provide input and feedback and to co-create solutions for the initiative.

> "The steering committee members are not as diverse as I would like them to be. They don't reflect the community we're trying to serve. Sometimes decisions are made based on research [rather than lived experience] and it's not the best logic for dealing with the community."
>
> – Shamise Quinn, Backbone Director, Staten Island Perinatal Network

2. Dedicate resources and attend to power dynamics to support authentic community participation

Set aside dedicated funding and resources to contribute to capacity-building of mothers to be community leaders, making sure that they feel prepared to participate in an unfamiliar environment. Pay attention to subtle or unconscious power dynamics in the group that can limit community members' full participation. Provide translators, if needed. Consider offsetting the economic burden of community members' participation by providing stipends, transportation and parking vouchers, child care, and meals in return for their time and knowledge. Moreover, it may be helpful to hold meetings in locations where community members may feel more comfortable (e.g., a local public library) rather than somewhere less familiar and less accessible (e.g., a foundation headquarters). It may also be helpful to coach people about what to expect at the meetings. Be conscious of the language used, removing jargon and stigmatizing language from materials and from the conversation. Honor the different forms of expertise and wisdom in the room.

IN PRACTICE

In Staten Island, much of the community engagement comes from the clients at the health center that manages the initiative. Staff members conduct regular focus groups with mothers who are clinic patients in order to keep a finger on the pulse for what families, especially black mothers and mothers-to-be, are experiencing. However, the team has expressed their concerns that the steering committee does not represent the community as robustly as it could. Efforts were made to get community member participation on the steering committee, in part by reaching out through faith-based communities. The steering committee included people in direct service roles, including members who ran food pantries and led community outreach, but the team found it difficult to incorporate many local mothers as regularly as they would have liked. Sometimes, the barriers that lead mothers to face a higher risk of preterm birth are the same ones that made it difficult to participate on a steering committee. For instance, the time of meetings may prevent attendance because these mothers may not be able to take time off from work. Or transportation could be a challenge. To overcome the latter, the health center organizing the effort provided transportation vouchers that allowed a mother with a young infant to attend. She and her baby became a welcome addition to the meetings and served as a grounding presence, reminding people why they were so committed to the work.

In Fresno, the initiative successfully created opportunities for mothers who were affected by preterm birth and infant mortality to serve on the steering committee and to participate in leading and governing the initiative. They made provisions for childcare and transportation and created meeting norms where all voices were respected and valued. These efforts required intentionality, planning, and resources. They also created a "mom's council" where mothers who had experienced preterm birth would discuss ideas and solutions.

3. Lead conversations about race, racism, equity, and preterm birth

Leaders of collaborative efforts that seek to improve birth outcomes should have an intentional focus on race, equity, and bias. Train steering committee members in race, equity, trauma, and stigma from the beginning, so they recognize the intersection of race, racism, and power dynamics. Explain the different types of racism and bias that affect birth outcomes—structural or institutional, interpersonal and internalized.[21] Share the importance of implicit bias to highlight that bias can still have impact even when individuals do not or would not espouse explicitly racist views. Acknowledge and explore the historical and recent actions and inactions that contributed to the current health disparities in communities of color. Acknowledge that many members may not have experience in these kinds of conversations and may be uncomfortable tackling subjects that they may consider controversial. Continue to build capacity to lead, facilitate, and participate in discussions about race and equity and the impact of racism, bias, and discrimination on adverse birth outcomes in your community. For some, it can be difficult to understand the important difference of attributing poor outcomes to the race of the mother (as if the poor outcomes are intrinsic to one's ethnicity or identity) versus the effect of both overt and subtle racism she might experience (experiences that are external to the mother and can be addressed). Be sure to allocate sufficient time for these conversations, which can be complex and highly charged. For more information about how racism is a social determinant of health that impacts birth outcomes, please see the Appendix.

IN PRACTICE

In both Fresno and Staten Island, stakeholders brought up issues of racism, sexism, and discrimination as some of the drivers of adverse birth outcomes. However, it was difficult to define solutions to such entrenched challenges, and many steering committee members were hesitant to have these discussions about race and equity openly.

In Fresno, the entire steering committee participated in training on the intersection of race and preterm birth to better identify strategies that address racial disparities. They also identified early on that addressing cultural competency in the health care system was a crucial area of investment. While the initiative is aware that addressing the experiences of racism that black women face in the health care system will not eliminate racism in Fresno, they know it is an important first step towards designing an approach to address health inequity. They are currently planning efforts to improve the cultural competency of prenatal health care providers as a result of this initiative.

21 Jones, C.P. (2000). Levels of racism: a theoretical framework and a gardener's tale. *American Journal of Public Health* (90), 1212–1215. http://ajph.aphapublications.org/doi/pdf/10.2105/AJPH.90.8.1212.

4. Disaggregate data by race, ethnicity, and income to uncover and highlight health disparities. Use images and simple language to make potentially dry data and statistics compelling

Other factors such as zip code or neighborhood can also be informative. Consider how to share data with members of the steering committee, working groups, and community in a way that helps them understand the personal, social, and economic impact of adverse birth outcomes. Translate statistics and data using images and infographics so that they have meaning for a broader audience. Be clear that addressing health disparities helps everyone, not just the communities who are most affected. Unaddressed disparities inevitably limit productivity, competitiveness, and growth, preventing the entire community from experiencing the full collective potential of all its members. There is a role for everyone to play in ensuring that families and communities are all well supported.

IN PRACTICE

The Staten Island team disaggregated their data by neighborhood and by race. Only then could they identify some of the most concerning health disparities (see Figure 3). For instance, the overall infant mortality rate for Staten Island is comparable to the average for the entire state and the rest of the U.S. However, when the team looked at the North Shore, a specific region comprised of six zip codes, the average infant mortality rate was 23% higher than the rest of the island. The differences in infant mortality rates by race are even more stark. Black babies in Staten Island are over four times more likely to die before their first birthday than white babies. Looking at the overall infant mortality rate in Staten Island without disaggregating the data would have masked this sobering reality.

Data about infant mortality rates can sometimes feel like it is not tangible or concrete. For instance, in Staten Island, one could present the standard statistics: The infant mortality rate for white babies is 2.8 per 1,000 live births, and the infant mortality rate for black babies is 13.1 per 1,000 live births. However, for many people, it is difficult to fully grasp the impact and gravity of the situation using dry statistical terminology. Instead, the Staten Island initiative presented data in a more visually compelling way in order to convey the stark disparities in mortality rates between black and white babies (see Figure 4).

FIGURE 3. DISAGGREGATING DATA CAN HIGHLIGHT CRITICAL DISPARITIES

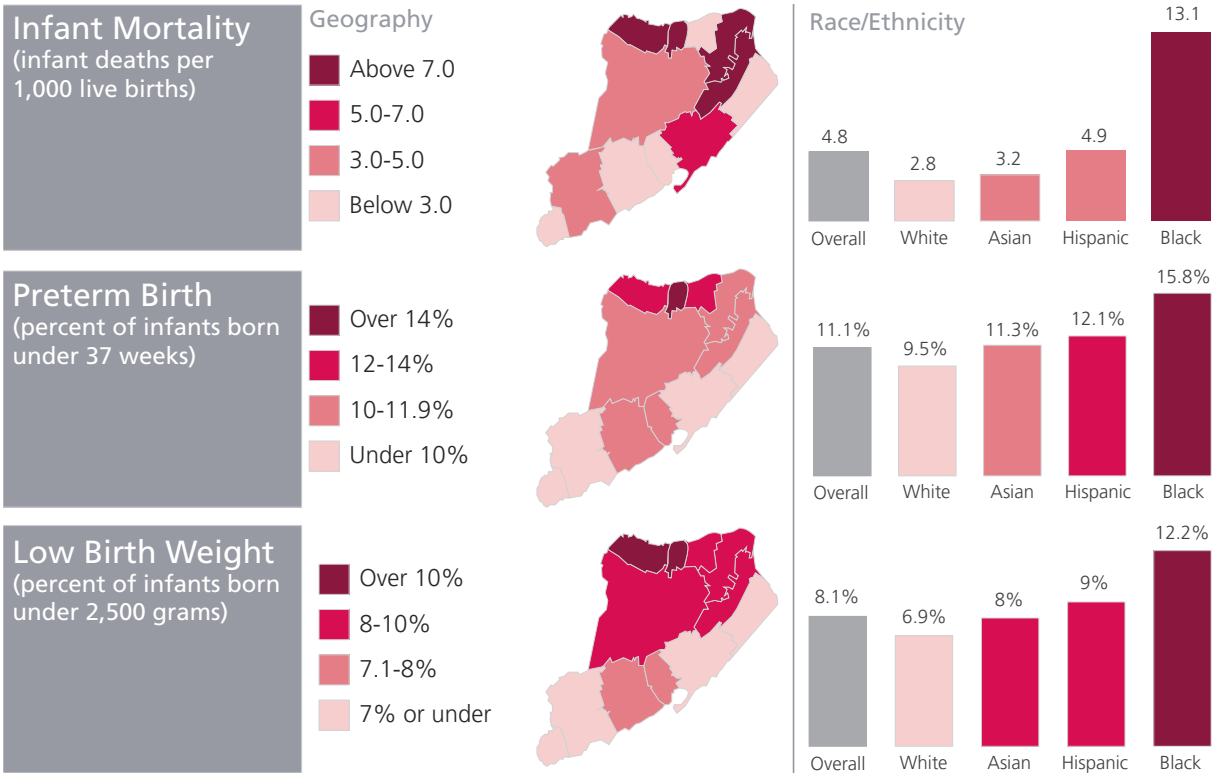
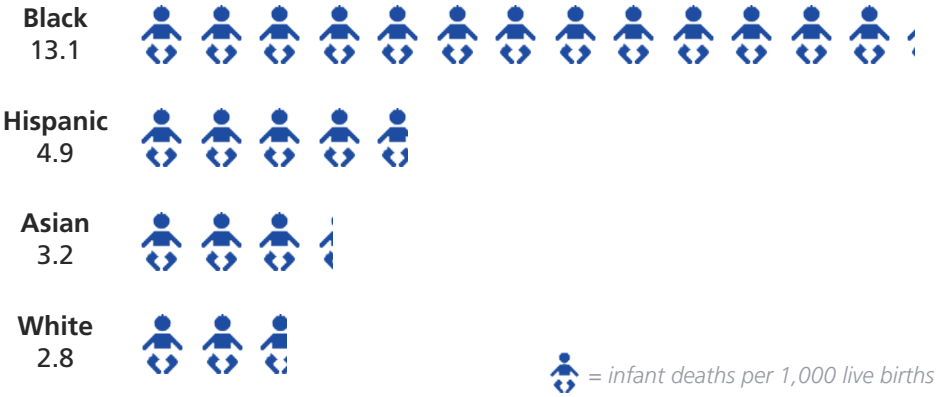


FIGURE 4. USE IMAGES AND CREATIVE LANGUAGE TO BRING DATA ALIVE

The absolute number of infant deaths masks significant disparities in birth outcomes

For every 1,000 live infant births for each racial or ethnic group, on average, a different number of infants do not survive to their first birthday



Source: New York State Department of Health data for 2011-2013; FSG analysis

Lesson Three:

The depth of relationships and trust will sustain the initiative

What is the challenge?

An often-quoted saying on the benefit of joint effort is: "If you want to go fast, go alone. If you want to go far, go together." People may be wary of sharing important information, fear competition from the new effort, or question the motivations and sincerity of the initiative. Past initiatives may have already created fatigue with inefficient and ineffective efforts, mistrust due to broken promises, or hesitance to participate in yet another initiative that does not produce results despite lofty claims. Effective collaboration must be built on a foundation of authentic and trusting relationships, both among steering committee members and between the initiative and the wider community.

What can I do about this?

- ✓ Be aware of local context, listen with humility, and build trust
- ✓ Find opportunities to deepen relationships among steering committee members and be clear about expectations

"Frustration and reticence harbored by certain individuals and groups can turn into energy and passion for the work if you do the groundwork to show that you are here to help and here to stay. Thank you notes can go a long way. Build trust by staying accountable and following through. Don't be afraid to atone for past errors."

– Wendy Hussey, Program Director,
UCSF Preterm Birth Initiative

1. Be aware of local context, listen with humility, and build trust

Do your homework ahead of time to find out what past initiatives have tried before and who was involved, and uncover existing context and politics around your new initiative. Acknowledge the work that has already been done on the issue and what lessons were learned from those experiences. Try to meet with stakeholders in existing and previous efforts and build from their work, rather than starting from scratch and operating in a vacuum. When community members or leaders share their concerns, listen with curiosity and respect.

IN PRACTICE

In Fresno, the collaborative found that community members confused the initiative with other similar efforts. Many community members had tough and valid questions about why this initiative would be any different from other previous and current ones. The community engagement specialist had to spend time clarifying the goals and reach of the Preterm Birth Initiative (PTBi)—she mentioned that it took many one- to two-hour meetings with individual community leaders to identify and address concerns. She also spent time listening to why people were afraid or frustrated. One person directly expressed concern that the PTBi might be competing with them to take local government funding. By listening to the concerns and genuinely expressing empathy for past disappointments, the team in Fresno began to build more trust among community members.

2. Find opportunities to deepen relationships among steering committee members and be clear about expectations

The strength of relationships will provide a strong foundation for governance and leadership within the collaborative. The steering committee needs to feel that they are part of a team and can trust one another. Provide opportunities for steering committee members to spend time together productively, socializing and learning, inside and outside of meetings. Involve them with community engagement such as meeting with mothers and their families on a regular basis.

Make sure the scope, timeline, and expected outcomes from the initiative are clear to the community and other stakeholders so that everyone knows what to expect. Birth outcomes take a long time to influence, and the factors that have led to poor birth outcomes have been in place for some time. Therefore, it will take time to see substantial progress. Create clarifying messages that show the connections between your initiative and other similar efforts. Follow through with commitments and acknowledge and address previous disappointments.

IN PRACTICE

In Staten Island, significant effort was invested in building a rapport among the steering committee members, which included doing activities during meetings to help the team get to know each other as people. One activity involved the team creating journey maps to illustrate the experiences of mothers who experienced adverse birth outcomes.[22] The steering committee members all reviewed the maps and discussed emotional reactions, which moved them out of the technical realm and into the human element. Grounding people in the experience of what it could be like to have an adverse birth outcome helped orient those who were less familiar with the topic and developed a sense of urgency and purpose among steering committee members.

In Fresno, the team built in additional time during steering committee meetings to facilitate relationship-building. For instance, they held breakfasts and lunches together with no set agenda. In addition, steering committee members participated in a "human-centered design" process to familiarize themselves with the experiences of women and mothers during their reproductive life course in Fresno County. Steering committee members met with women and mothers of preterm infants who graciously welcomed them into their homes for two-hour interviews to share more about their experiences. Steering committee members also attended support groups for NICU families, young fathers, and teen mothers as a way to develop deep empathy for the experiences of mothers in Fresno County. This level of engagement not only increased their own empathy in designing the initiative's agenda, but also provided a great opportunity for relationship-building outside of meetings.

22 https://www.fsg.org/blog/systems-thinking-tool-journey-mapping.

Lesson Four:

True transformation of a system requires a long-term vision

What is the challenge?

Often collaborative efforts must balance the need to build the relationships, trust, and infrastructure necessary for the initiative to succeed with the need to make significant change on the infant mortality rate or preterm birth rate in a community in a relatively short time frame. There is often pressure to demonstrate results quickly in order to maintain and increase momentum. Not surprisingly, the slow pace of the work can be frustrating for people who have many demands on their time and yet recognize the gravity and urgency of the problem at hand. Moreover, funding for initiatives is often bound by a time horizon that is too short to lay the groundwork for substantive change.

What can I do about this?

- ✓ Encourage funders to take a longer view and identify long-term goals and objectives
- ✓ Identify "quick wins" that build momentum and capacity for the initiative

"The timeline is longer than you think. Be patient and let the initiative develop the ways it needs to in order to succeed. It is a long, arduous journey. This is not about clearing hurdles– this is about hiking up a mountain."

– Sandra Flores, Program Director
Fresno County Preterm Birth Initiative

1. Encourage funders to take a longer view and identify long-term goals and objectives

It's often difficult to fully resolve pervasive social issues like infant mortality or preterm birth in two or even five years, given that the current situations have taken several decades or even longer to develop. Funders should make long-term investments to create long-term impact and identify goals and objectives to be completed in 10 or 15 years. Build the case for funders by showing progress in innovative ways. This may mean investing in communications to spread the word about events and highlight successes or new developments. Consider working closely with funders as partners so that there is more seamless co-development of strategy. Finally, funders must support more than just convening—there are also needs for resources for implementation and programming after the planning period ends.

IN PRACTICE

Funders in both Fresno and Staten Island started out with the premise that this work will require long-term investments. The work in Fresno is funded by a multi-year grant from UCSF's PTBi. The work in Staten Island was initially funded by a local community foundation and is currently funded by a government grant which is renewable on an annual basis.

In Fresno, much of the initial launch year was spent defining the strategic framework (or common agenda) and setting up the initial infrastructure for the effort.[23] At times, stakeholders acknowledged that their efforts were focused more on process rather than direct actions driving changes for the women, their families, and their communities. Two years into the effort, the Fresno team launched their third and final working group.

In Staten Island, the work stalled for about a year due to unforeseen human resource challenges; however, now the initiative has returned to operation and is moving forward.

Even though both efforts took a long time to get up to full speed, that investment of time has paid dividends in the number of stakeholders involved, the breadth of engagement across communities, and the promising approaches that are being adopted in both communities.

23 **https://www.fsg.org/tools-and-resources/collaborating-create-common-agenda**.

2. Identify "quick wins" that build momentum and capacity for the initiative

Stakeholders engaging in cross-sector collaborative efforts often want to see improvements in birth outcomes in the near future. But it takes a lot of hard work and effort to launch an initiative and even longer to see true systems change. Some short- and medium-term outcomes can be implemented with existing resources in a relatively short amount of time (three to six months) in order to build and sustain momentum and community engagement. For instance, the "quick win" of sharing best practices among providers and partners caring for pregnant women can spark innovation and inspire others. Early victories allow stakeholders to focus on building relationships and project infrastructure while also focusing on tangible, if small, changes for communities and populations facing adverse infant health outcomes. However, teams should avoid relying on quick "feel-good" solutions that weaken the system's chances of resolving the problem and should instead take care to invest in short- and medium-term work that ultimately builds capacity towards the longer-term vision. For instance, without proper planning for capacity-building and project management transfer, starting with external help (like a consultant) that speeds a process along can make sustaining the work more difficult after the consultant leaves. External support can help jumpstart a process, but without thoughtful planning for the transfer and ownership by the backbone, steering committee, and community members, the initiative could fall apart. This could create fatigue and disappointment at seeing yet another unsuccessful initiative, making it even more difficult to continue the work or start up another project in the future.

IN PRACTICE

Both Fresno and Staten Island identified some "quick wins" that could be accomplished with existing resources to bolster their efforts. In Fresno, as a result of the Preterm Birth Initiative, the city decided to start celebrating World Prematurity Day. One local mayor was on the steering committee and released a proclamation on that day. The city and county lit up government buildings in the purple color of the prematurity ribbon and several moms and families came to the event.

In Staten Island, a "fast pass" was implemented by providers involved in the initiative for women with young children to allow them to skip the line during prenatal care visits.

Conclusion

Multi-sector collaborations can change the structures that present barriers to healthy births

We hope this paper will provide valuable insights and action steps to all who are working to improve birth outcomes across the country. While the lessons and experiences taken from our work in Fresno and Staten Island are not representative of all initiatives, we hope other initiatives will also share their own lessons learned through platforms such as the Collective Impact Forum.[24] These types of multi-sector collaborations can change the structures and environments that present systemic barriers to healthy births for all families. Addressing disparities in adverse birth outcomes and improving our overall national infant mortality rate is critical for our country's ability to thrive. By exploring, testing, and learning together, we hope to improve health outcomes for all infants and mothers in the U.S. These babies we are seeking to save are our future students, engineers and artists, writers and nurses, teachers and entrepreneurs. An investment in them now is an investment in our future as a nation.

24 https://collectiveimpactforum.org.

Appendix:

Race and Racism as Social Determinants of Birth Outcomes

Communities of color, especially black women, face a disproportionate burden of adverse birth outcomes in the U.S., even beyond infant mortality. The preterm birth rate for black women is 1.6 times higher than the rate for white women, and the preterm birth-related infant mortality rate is three times higher.[25] Racism is one key structural barrier that is linked to these disparate outcomes.[26]

Racism exists on many levels, including interpersonal and institutional. Interpersonal racism "refers to prejudice and discrimination resulting in differential assumptions about the capabilities and motives of others according to their race."[27] In the health context, implicit or unconscious bias has led to disproportionate access to quality health care for communities of color. Studies have documented that black mothers-to-be are treated with disrespect, misdiagnosed, over- or under-prescribed medications, or have received unnecessary procedures without the mother's full awareness and consent. However, this type of overt interpersonal racism and discrimination is only the tip of the iceberg. Beneath the water are other forms of racism that are less visible. Institutionalized racism or structural racism refers to the ways that laws and systems perpetuate an environment in which people have different access to resources, services, power, and opportunities as a result of race. As we know, there are disparities by race in terms of access to housing, education, and employment—all social determinants of health—as well as differences by race in access to quality health care.

Racism and poverty are among many important sources of chronic stress among populations of color. There is a strong relationship between the chronic stressors of racism and poverty and adverse birth outcomes.[28] Studies have shown that exposure to chronic stress can impact many aspects of a person's biology, including the nervous system, the neuroendocrine system, the immune system, and cardiovascular functions.[29] Allostatic load describes the long-term impact that stressors have had on a person's biologic functions.[30] Think of allostatic load as a way of measuring the "cumulative wear and tear on the body's systems" that develops as a result of having to continuously adapt to environmental stressors.[31] Thus, exposure to discrimination, structural racism, and chronic stress from lack of access to opportunities and resources can all increase allostatic load. Research has demonstrated that black women have a higher allostatic load compared to black men and compared to white women.[32]

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