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Infant Mortality CoIIN Case Study

Aligning Title V, Healthy Start, and Families to Increase New Mother Wellness in New Jersey

Introduction

Executive Summary

Family engagement plays an essential role in state Title V maternal and child health (MCH) programs. Family members volunteer, advise and/or are employed by state Title V MCH, and/or various programs. They bring unique insight and experience, and are prepared to advocate on behalf of MCH. Family engagement refers to a range of activities that engage families in the planning, development, and evaluation of programs and policies at the community, organizational, and policy levels.

For instance, the Association of Maternal & Child Health Programs (AMCHP) consistently engages families in much of its work, especially along three main areas: organizational structure, leadership development, and program and policy activities. One example of family engagement related to Title V is the Collaborative Improvement and Innovation Network to Reduce Infant Mortality (Infant Mortality CoIIN). The Infant Mortality CoIIN is a multi-year national initiative to engage state and local leaders in efforts to combat infant mortality, decrease inequities associated with the social determinants of health (SDoH), and ultimately improve birth outcomes. Several states participated in the Infant Mortality CoIIN Learning Networks, which are targeted strategies that state teams chose to focus their infant mortality reduction efforts.

AMCHP had the opportunity to engage MCH professionals from New Jersey to learn more about their experience with alignment of Title V, Healthy Start, and family engagement. New Jersey is one of 51 states and U.S. territories that participated in the HRSA supported, National Institute for Children's Health Quality (NICHQ)-led Infant Mortality CoIIN. The New Jersey Infant Mortality CoIIN team tapped into partnerships and ongoing initiatives to increase new mother wellness in the state.

New Jersey participated in two of the six Infant Mortality CoIIN Learning Networks, so its participants were primed to share their journey. New Jersey chose the Pre-and Interconception Care (PICC) Learning Network and the Smoking Cessation Learning Network, which were facilitated by NICHQ. The New Jersey Infant Mortality CoIIN team made progress toward getting more women to attend their recommended postpartum visits (PPV) by employing several key strategies around family engagement as well as policy alignment and cross-sector partnerships.

The New Jersey Department of Health (DOH) Infant Mortality CoIIN team discovered that alignment of its work with state priorities, local initiatives and the federal MCH Block Grant Performance Measures provided opportunities to maximize resources, deepen impact, and extend reach. The team used the Infant Mortality CoIIN collective impact approach to engage a diverse set of partners and stakeholders, placing the essential voices and experiences of families and patients at the center of its work. As a result, a new process was developed for frontline health and community health workers to talk with new and expecting mothers about the PPV.

Background: Building on Partnerships

Title V and the Infant Mortality CoIIN: New Jersey serves about 500,700[i] vulnerable women and children annually through its Title V MCH Service Block Grant, which is funded by the HRSA Maternal and Children's Health Bureau and administered by the DOH. The block grant, under Title V of the Social Security Act, is the only federal program devoted to improving the health of all women, children, and families.

The DOH participated in the Infant Mortality CoIIN beginning in 2014 as part of its block grant activities to address infant mortality and improvement of birth outcomes. The New Jersey Infant Mortality CoIIN team emphasized collaboration with key stakeholders, including patients and families. Partners included the March of Dimes, Amerigroup (health benefits provider), the New Jersey Department of Children and Families, the New Jersey Division of Medical Assistance and Health Services, three statewide Maternal and Child Health Consortia, the Statewide Parent Advocacy Network (SPAN), and Camden Healthy Start.

The state Infant Mortality CoIIN team identified two priority areas: improvement of maternal postpartum visit (PPV) rates, and reduction of smoking among pregnant and post-partum women.[ii] These priority areas aligned well with one of the Title V National Performance Measures (NPM) selected by New Jersey: "The Well Woman Visit," or NPM 1, which recognizes that the PPV is an opportunity to establish a pattern of regular, annual wellness care after pregnancy.

Infant Mortality CoIIN Learning Networks: The PICC Learning Network aimed to improve life course care for women related to pre- and interconception care. Increasing PPV was one of several strategies identified within the learning network. (The Infant Mortality CoIIN Prevention Toolkit is an interactive guide that includes strategies and case studies for all of the Infant Mortality CoIIN Learning Networks.)

Other State Entities and Initiatives:

- Improving Pregnancy Outcomes (IPO) for Women and Infants, a DOH program that provides grants to local entities to improve outcomes through the use of community health workers (CHWs) and a central intake system.
- Statewide Parent Advocacy Network (SPAN), which used an IPO grant to fund CHWs who connect underserved women of childbearing age to health care and other services.
- State Health Improvement Plan (SHIP), which includes several performance measures focused on reducing infant mortality, low birth weight and premature birth.

For more information on these, see section below, Aligning with State Efforts.

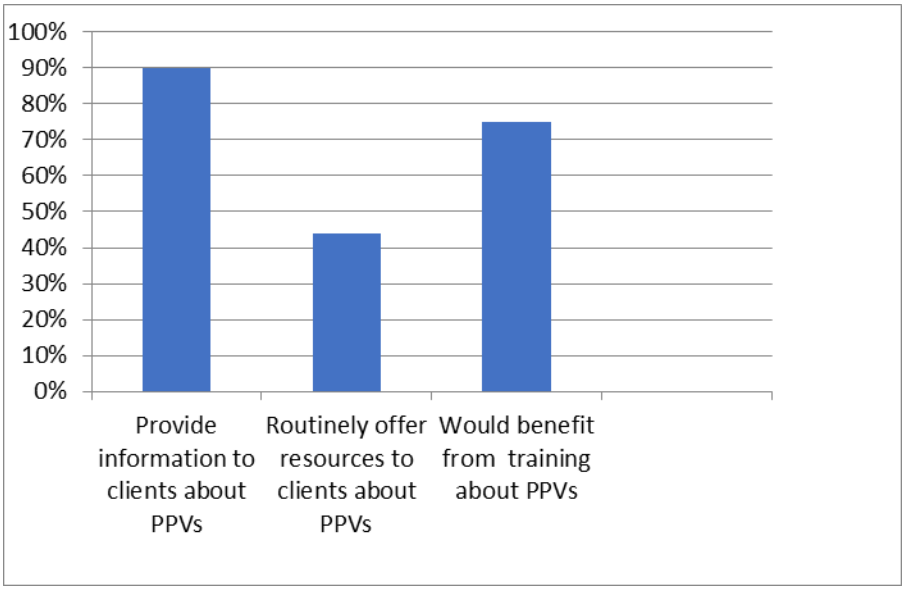
Low PPV Rates Spur Worker Survey

The New Jersey Infant Mortality CoIIN Team had reason to target PPV for improvement. Reducing infant mortality is a priority for New Jersey's Title V program, even though it has one of the lowest infant mortality rates in the nation, at 4.7 infant deaths per 1,000 live births, compared with a national ratio of 5.9 infant deaths per 1,000 live births.[iii] Racial disparities persist, as black infants remain significantly more at risk than white infants.

PPV has been shown to be effective in reducing infant mortality and improving maternal health.[iv] According to the Pregnancy Risk Assessment Monitoring System (PRAMS), 87.6 percent of New Jersey women ages 18-44 with a recent live birth received postpartum check-ups in 2009, compared with a low of 84.2 percent in Texas and a high of 94.4 percent in Massachusetts.[v] "What concerned the DOH," said Loletha Johnson, MSN, RN, a nursing consultant in the Family Health Services Division of the DOH, "was the especially low rates among low-income women." Among new mothers on Medicaid in New Jersey, just 57.6 percent attended the PPV in 2015, even lower than the national average of 61.8 percent.[vi]

Hoping to increase that rate, the state's Infant Mortality CoIIN team surveyed nine community health workers in the IPO program that year to learn more about barriers to and facilitators of postpartum follow-up care. The CHW survey assessed knowledge about the importance of the PPV, the timeframe in which a woman should attend the visit, and possible barriers impeding attendance. The survey results demonstrated a need for more training among CHWs about the PPV, as well as opportunities to better engage CHWs in promotion of the visit with clients and families.

Community Health Workers Said They …[vii]



Connecting with Families

While the CHW feedback was valuable, the team also wanted to learn firsthand what prevents new moms from attending PPVs and to develop strategies to overcome the barriers. "We wanted to understand what was holding women back," said Johnson, the DOH coordinator of the Infant Mortality CoIIN team.

Recognizing the need for family and patient engagement and identifying roles for moms in improving PPV rates are just two ways that the team's approach reflects the key steps for engaging families and patients in Infant Mortality CoIIN projects. (See Box 1.) Another step was identifying ways to reach out to moms and creating a mechanism for learning from their perspectives. With funding from the March of Dimes, a longtime

partner of the DOH, the team coordinated focus groups (one in English and one in Spanish) in each of three regions (northern, central, and southern). In all, 61 women attended the groups, which were conducted by SPAN and the MCH Consortia. Several factors contributed to the high attendance rate, including:

1. Staff from the MCH Consortia and SPAN recruited mothers for the focus groups, providing both logistics support and anticipatory guidance so that the women had all the information they needed to make an informed decision about participation.

2. Of incredible value was that the recruiters knew or were members of the same communities as those they were recruiting. This helped to facilitate trust and effective communication. In neighborhoods with large Hispanic/Latina populations, this was a particular advantage. “We have a deeper connection with the community because we’re from the community and we look like the community,” said Gloria Nieves, one of the CHWs from SPAN who was involved in the project. “You can relate more to that person or to the families when you understand where they’re coming from.”

3. The provision of funding and in-kind support for participation was a successful incentive. The March of Dimes funding covered not only meeting logistics, such as the provision of a trained facilitator (an epidemiologist), but also food for the gatherings. The MCH Consortia provided tokens of appreciation, including gift cards to stores such as Walmart. SPAN provided bus tickets and a stipend to offset other transportation costs. Child care was available on site. “We had a lot of babies in attendance,” Johnson said. These methods of supporting attendance not only removed potential financial barriers for the moms, but also served to acknowledge that the team valued their feedback and the time they gave to be a part of the focus groups.

Among the questions posed to the mothers:

- How is the PPV important for the mom?
- How is the PPV important for the baby?
- What are some reasons women might not attend their PPV?
- What might make it easier for women to attend the PPV?

Results

The results produced rich and sometimes surprising answers. For example, 88.9 percent of CHWs taking the survey saw transportation as the greatest impediment to women attending the PPV. The parents did not cite transportation as a significant impediment. The most common reason shared by women in the focus groups was that they did not fully understand the importance of the PPV for their health. They associated the visit with depression, and saw no reason to attend if they were not depressed. Others noted unsatisfactory experiences during such visits in the past: one said it was “all paperwork”; another said her visit lasted two minutes.

The focus group responses convinced the Infant Mortality CoIIN team that addressing barriers such as transportation and child care would not boost PPVs if they did not increase understanding among women and families about the visits’ benefits. This highlights the importance of inviting families to the table so that their voices and experiences can inform the interventions that will affect them.

“If we don’t set out to teach them how to shape services and processes," Nieves said, “then we’re always making decisions for them.”

The focus group facilitator solicited recommendations from mothers about how to better communicate the benefits of the PPV. The team was particularly interested in feedback on a brochure being created to educate parents about the visits. One common suggestion was to re-name the PPV to sound more positive and focus on the wellness of the woman.

Communication Changes

The feedback from the workers and mothers compelled the Infant Mortality CoIIN team to fundamentally change how state and community partners communicate about the PPV. The team replaced an old, text-heavy brochure with a brightly colored, two-sided sheet that is essentially an infographic, dominated by images and short blocks of text. The revised brochure is entitled “Taking Care of Mom After Child Birth,” and features more drawings of smiling moms and babies (five) than full paragraphs (three). Answers to questions such as “Why do I need postpartum care?” are given in blocks that range from one word to two sentences, while a rundown of what happens during the visit takes just seven icons and 11 underlying words.

Nowhere does the phrase “postpartum visit” appear; the appointment is called the “wellness visit,” placing the visit in the context of well-woman care and making the purpose of the visit clearer.

The Infant Mortality CoIIN team provided all-day training in 2016 to CHWs and central intake staff on the importance of the PPV and other related topics. “The training was important to set the stage for rolling out the brochure” to parents, Johnson said.

The team established an attendance goal of 50 percent of the targeted staff. This goal was exceeded, as 85 percent of targeted staff attended (54 in total). Pre- and post-test training results showed gains in all areas of knowledge on such questions as:

- Which of the following is not a risk factor for preterm labor: women younger than 17 or older than 35; stress; early prenatal care; working long hours with long periods of standing.
- In what timeframe should women attend the PPV: 1 week after delivery; 6 weeks after delivery; 8 weeks after delivery.

As the team revised the brochure, SPAN and the New Jersey Supplemental Nutrition Program for Women Infants and Children tested versions with their clients. While the feedback was positive, the Infant Mortality CoIIN team wanted to test if the brochure could affect the likelihood of women attending the wellness visit. Again, it identified an organized approach for reaching the key populations: CHWs and women in the community.

The team partnered with Camden Healthy Start to conduct a three-month pilot spanning 2016-17, with the brochure serving as a tool for staff to start conversations about the PPV with clients sooner and for women to reflect on their visits and ask questions. Three Healthy Start family support specialists met with 11 women to discuss the brochure after they gave birth at hospitals. The specialists wrote information about the client's wellness visit appointment (time and location) on the front of each brochure. The specialists followed-up with each new mother six to eight weeks later to determine whether she attended the visit, and the women completed a brief survey.

As with most pilots, the sample-size was small (11 women) but the results were validating. All the women reported attending their wellness visits. Eight remembered discussing the brochure in the hospital. Six said they looked at the brochure after the specialist left it with them.

Healthy Start staff completed a survey about the pilot study and the brochure. The staff found the new process effective, said clients responded well to the brochure and the conversations, and recommended that it be included in Camden Healthy Start's routine work with pregnant women. They reported that the brochure increased the likelihood that they would discuss the PPV with clients after birth and that they would follow up to ensure that clients attended their visits.

Summary

The change process, driven by listening to women and those who work with them, led to the development of a product and to conversations that were more effective from the perspective of the CHWs and mothers. Johnson of the DOH notes that partnering with a diverse range of stakeholders – organizational leaders, staff, and clients – was essential. "People want to be included," she said. "You can have more of an eclectic point of view when people are engaged."

Box 1: Key Steps for Engaging Families and Patients in Infant Mortality CoIIN Work

- Assess Team Readiness and Attitudes Towards Patient and Family Engagement
- Build Infrastructure and Develop a Plan to Support Patient and Family Engagement
- Determine Roles Patients and Family Members Might Have in Your Work
- Determine the Demographics and Characteristics of Your Population
- Identify Ways to Reach Out to Populations of Interest
- Provide the Information and Support Necessary for Decisions re: Participation
- Select Patients and Family Members who will be Effective Partners
- Provide Support for Participation
- Work to Build Trust
- Foster Equality

Tara Bristol Rouse, director of Patient and Family Partnerships, Perinatal Quality Collaborative of North Carolina, and a member of the Patient Family Faculty at NICHQ.

Aligning with State Efforts

These were among the key state initiatives and entities with which the New Jersey Infant Mortality CoIIN team aligned:

Improving Pregnancy Outcomes (IPO) for Women and Infants: The DOH's IPO program aims to improve maternal, infant, and early childhood outcomes through the use of evidence-based best practice strategies during the preconception, prenatal/postpartum, and inter-conception stages. The program provides grants to community health centers, MCH consortia, local health departments, and social services agencies to implement collaborative approaches that rely on:

> **Community health workers (CHWs)** – trusted members of the community who perform outreach and client recruitment to identify and enroll women and their families in appropriate care, which includes referring clients for services and supporting them through Central Intake.
>
> **Central Intake** – a county-based single point of entry for referrals to medical care (including prenatal and postpartum), evidence-based home visiting programs, and social support agencies.[viii]

SPAN: The Statewide Parent Advocacy Network empowers families as advocates and partners to improve education and health outcomes for infants, toddlers, children, and youth. SPAN serves as a first stop for many New Jersey families to access information and resources.[ix] For more than 25 years the state DOH has partnered with SPAN on programs affecting maternal and child health, most often with regard to children and youth with special heath care needs.

In 2014, SPAN was awarded one of DOH's competitively-bid IPO grants.[x] SPAN's IPO project employs four CHWs to connect underserved women of childbearing age in Essex County to such services as health care, health insurance, substance abuse services, and parent-to-parent support. The project also provides leadership development and support to parent leaders, who conduct family support activities and represent family voices in the project and at the state level.[xi] SPAN staff and family members served on the state's Infant Mortality CoIIN team.

State Health Improvement Plan (SHIP): The team leveraged the state's commitment to improving birth outcomes and maternal health outlined in the State Health Improvement Plan (SHIP). The plan includes several performance measures focused on reducing infant mortality, low birth weight and premature birth, in addition to a performance measure focused on increasing the percent of women who receive adequate prenatal care.[xii]

Acknowledgments

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More Information

For more information on the Infant Mortality CoIIN, please visit the HRSA MCHB website, https://mchb.hrsa.gov, or the NICHQ website, http://www.nichq.org/infantmortalitycoiin. The AMCHP staff who were engaged in this work can be be reached at (202) 775-0436 or info@amchp.org.

End Notes

[i] New Jersey Division of Family Health Services. *Maternal and Child Health Services Title V Block Grant, New Jersey, FY 2017 Application/FY 2015 Annual Report* at https://mchb.tvisdata.hrsa.gov/uploadedfiles/StateSubmittedFiles/2017/NJ/NJ_TitleV_PrintVersion.pdf

[ii] Ibid.

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[viii] New Jersey Department of Health. Improving Pregnancy Outcomes, at www.nj.gov/health/fhs/maternalchild/outcomes [ix] Statewide Parent Advocacy Network, Inc. About SPAN, at www.spanadvocacy.org/content/about-span

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[xi] Statewide Parent Advocacy Network, Inc. Major Project and Funding Sources, under Summary of SPAN Projects & Programs, at www.spanadvocacy.org/content/programs

[xii] New Jersey Department of Health. Improving Birth Outcomes, Healthy New Jersey 2020, at www.nj.gov/health/chs/hnj2020/maternal/improving

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