

**Challenging
Cultural Barriers
and Creating a
More Supportive
Society:**

**Findings on
Breastfeeding
from
Focus Groups
with Moms
Across Illinois**

February 2020



*A report of the Illinois State Physical Activity and
Nutrition Program by the Illinois Public Health Institute*



Executive Summary



The Illinois Public Health Institute (IPHI) and Illinois State Physical Activity and Nutrition (ISPAN) program partners held focus groups with women in Champaign County, Chicago, Jackson County, and Peoria County, Illinois, in 2019 to help inform strategy development for the ISPAN breastfeeding initiative. The focus groups convened moms from low-income and rural communities, and communities of color to provide input on the barriers and facilitators to breastfeeding, and what more can be done to better support women to breastfeed their babies. The discussions revealed a need for more cultural and societal support for breastfeeding; more support to help with the mechanics of breastfeeding (such as latch, milk supply, etc.); the need for increased access to useful, relevant, and sufficient information about breastfeeding; more support for navigating the logistics of breastfeeding; and more support for going to work while breastfeeding; among other themes. The results of the focus groups will help to shape the breastfeeding support strategies implemented by the ISPAN program in 2020 through 2023.

Introduction

In 2018, the Illinois Public Health Institute (IPHI) was awarded a cooperative agreement from the Centers for Disease Control and Prevention to implement the Illinois State Physical Activity and Nutrition (ISPAN) program. ISPAN is a five-year, \$4.6-million initiative to implement physical activity and nutrition interventions designed to make it easier for Illinoisans to live the healthiest lives possible. ISPAN focuses on low-

income and rural communities, and communities of color that have been the hardest hit by chronic diseases like type 2 diabetes and heart disease. With three geographic regions of focus in Illinois (Chicago/Cook County, the Peoria-Tazewell-Woodford Tri-County region, and Jackson County), four key strategies are being implemented. They are:

- 1 Physical Activity: Connecting activity-friendly routes to everyday destinations by improving walking, biking, and transit systems to promote physical activity;
- 2 Food Service Guidelines: Implementing food service guidelines in worksites and community settings to increase the availability of healthy foods;
- 3 Early Care and Education: Implementing and integrating physical activity and nutrition standards into early childhood education systems;
- 4 Breastfeeding Support: Increasing the number of community and clinical settings supporting moms to breastfeed their babies for as long as they want to.

While the main goal of the breastfeeding strategy is to improve the continuity of care and community supports for breastfeeding, it was critical to hear from moms directly about their experiences breastfeeding or trying to breastfeed to inform ISPAN's approach to achieving this goal. To accomplish this, focus groups were conducted as part of an assessment of the current state of breastfeeding in low-income and rural communities, and communities of color. The results were combined with data from a statewide environmental scan of breastfeeding continuity of care assets and barriers and input from a strategic planning team of ISPAN partners and community advisors from the ISPAN priority population. These data were used to set a vision and will inform strategies for the ISPAN breastfeeding support work for years three through five of the initiative.

Methodology

In August and September 2019, IPHI and partners conducted focus groups with the ISPAN priority populations in the three ISPAN priority regions. Five focus groups were conducted by IPHI staff and partners at HealthConnect One, the University of Illinois at Chicago, the Chicago Region Breastfeeding Task Force (Chicago), the Peoria City/County Health Department, the Illinois Chapter, American Academy of Pediatrics, the Central Illinois Breastfeeding Task Force (Peoria/Tri-County region), and the Jackson County Health Department (Jackson County). Additionally, partners in Champaign, IL, who were participating in an ISPAN-sponsored statewide learning collaborative to improve community supports for breastfeeding, conducted two additional focus groups using the same facilitator's guide and format.

Participants were recruited through flyers posted in doctors' offices, WIC clinics and community sites, and through word of mouth. To participate, women had to confirm their eligibility based on the following criteria: they had ever breastfed, were currently breastfeeding, or had wanted to but couldn't breastfeed their babies; they had a child between the ages of eight weeks and two years; they were eligible for the Supplemental Nutrition Assistance Program (SNAP), the Women, Infants, and Children (WIC) program, or another means-tested benefits program; they were 18 years or older; and they lived in one of the priority geographies. Women who didn't meet the full set of criteria were included as space allowed. Focus groups lasted one and a half hours. The focus group in Chicago Lawn was conducted in Spanish. Women were awarded a gift card for their participation.

A profile of the participants is found in the table below. The demographic information was self-identified.

Focus Group	Number of Participants	% Qualifying for a Means-Tested Program	Race/Ethnicity
Peoria County	7	100%	3 Black/African American 4 White
Jackson County	6 (7 surveyed)	86%	5 Black/African American 2 White
West Garfield Park, Chicago	7	86%	6 Black/African American 1 Biracial
Englewood, Chicago	9	100%	9 Black/African American
Chicago Lawn, Chicago	4	100%	4 Hispanic/Latinx
Champaign County	16 (across 2 groups)	47%	4 Black/African American 4 Hispanic/Latinx 7 White 1 Unknown

Methodology continued

A facilitator's guide was developed by IPHI staff in collaboration with ISPAN breastfeeding strategic planning partners. It asked the following key questions:

- 1 What did you learn about breastfeeding while you were pregnant? Where did you get that information?
- 2 What are some of the things in your life that have supported your ability to breastfeed?
- 3 What are some things that make it hard for women to breastfeed?
- 4 What are some of the reasons you stopped breastfeeding when you did?
- 5 What do you think would need to change before you, or moms in your community, would breastfeed for longer than they do?
- 6 What is the number one thing that would help more moms breastfeed for as long as they want to in your community?

Each focus group included an assigned notetaker who used a common note-taking template to capture the discussions. While the focus groups were recorded, verbatim transcripts were not created. However, the women's ideas were captured thoroughly in the notes. To analyze the data, IPHI staff developed a codebook based on an initial reading of a sample of the data, and on the common barriers and facilitators discussed in the statewide environmental scan and among ISPAN partners. Three IPHI staff members developed inter-rater reliability using the codebook against the data. Then, two staff members coded the data using the software program Dedoose. The quotes in the analysis below are quotes from the summarized notes and may not reflect the exact words of the participants.



Findings

A mom in Jackson County noted that in “other cultures, breastfeeding is open, breasts are out, but here people expect you to cover up. I refused to feed my child on a toilet, shouldn't have to consider doing that.”

The most frequently coded themes in the focus groups were the **need for more cultural and societal support** for breastfeeding, and **trouble with the mechanics of breastfeeding**, citing issues with latch, milk supply, etc. Including those, the top themes that emerged across the focus groups included:

- 1 Need for more cultural/societal support
- 2 Trouble with the mechanics of breastfeeding
- 3 Unhelpful and/or insufficient information
- 4 Challenges with breastfeeding logistics
- 5 Work as a barrier
- 6 Need for accessible, culturally appropriate information and support
- 7 Breastfeeding support supplies (as a facilitator)

CULTURAL AND SOCIETAL SUPPORT FOR BREASTFEEDING

References to cultural and societal support for breastfeeding included ideas around the need to normalize breastfeeding, support breastfeeding through the media, provide breastfeeding education to the public, provide community places that support breastfeeding, and stop shaming mothers who breastfeed.

For example, a woman in Chicago Lawn said, “I stopped breastfeeding when my baby was 1.5 because people would tell me that what he was drinking wasn't even milk anymore. People said I didn't need to be doing 'that.'” A woman in Peoria said it would be nice to have “breastfeeding posters at [the] doctor's office and out in the public like on billboards, grocery stores, public health offices, where people are going.” A mom in Jackson County noted that in “other cultures, breastfeeding is open, breasts are out, but here people expect you to cover up. I refused to feed my child on a toilet, shouldn't have to consider doing that.”

TROUBLE WITH THE MECHANICS OF BREASTFEEDING

Related to the mechanics of breastfeeding, a woman from Englewood said she “switched to formula due to milk production,” and a woman in Champaign said it was “hard for baby to latch, so baby couldn't pee, so the hospital gave a bottle.” As several ISPAN partners pointed out upon hearing the top themes, problems with latch and milk supply can often be averted with access to lactation support services.

UNHELPFUL AND/OR INSUFFICIENT INFORMATION

This theme was coded when moms referenced that breastfeeding classes or information provided by medical or lactation support providers was not useful, insufficient, or not the “real” information they needed. It cited references that more real and/or accurate information should be available. Many moms felt the information did not prepare them for the realities of breastfeeding.

Statements included, “There's not enough information around different situations and how to deal with it,” and “not told the raw truth about breastfeeding—fatigue, demand from children, etc.”

Some moms noted that the information was not enough, saying things like they “took hospital classes which helped to get going, but not enough for day to day,” and “the night nurses were not so great. They said this is how you do it and they left.” Another mom noted, “the lactation consultant gave me a flyer with class information but that was it. No REAL information, no patience. Didn't ask me questions to understand me or my concerns and questions,” and another said, “the person that helped me at the hospital demonstrated technique for me, but she was occasionally rough and insistent.”

CHALLENGES WITH BREASTFEEDING LOGISTICS

This theme was noted when participants referenced challenges with the logistics of breastfeeding, like the need to plan (schedule feedings/pumping, for travel, etc.), to pump frequently, to have to clean pump parts and store breastmilk, etc. It was also coded when women said the logistics were a lot of work, overwhelming, or difficult to keep up. Mentions of expensive supplies were also included in this theme. Statements included, “[I was] just ready to be done. I wanted independence, more rest/relaxation,” and “didn't know how to use a hand pump — had to buy an electric pump and didn't realize they were that expensive.” One mom noted “the huge amount of planning involved for storage, warming milk, when will feeding happen, with travel, etc., can be overwhelming.” Logistics for baby can also be a challenge. For example, “covers make baby too hot.”

BREASTFEEDING SUPPORT SUPPLIES

Another commonly discussed topic was that breastfeeding support supplies, like pumps, nipple shields, creams, etc., were facilitators of breastfeeding. Receiving free pumps through programs or insurance was useful, and many women reported receiving nipple shields and cream from WIC or a lactation support provider.

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“When I returned to work no one even knew the rules regarding breastfeeding. They had to call HR to learn what the rules were. I had to tell my manager I wanted to pump, and she didn't know where or what I could do.”

There's a “sentiment that black women are 'lazy' when it comes to infant feeding, [they] just want to use a bottle because it's easier.”

WORK AS A BARRIER

This theme refers to moms that cited the workplace was unsupportive of breastfeeding or was not familiar with workplace breastfeeding laws/rights. For example, one mom in Peoria said, “My manager first let me go to her office for 15-minute breaks before, during, and after shift. But she took back the privileges. Now it's hard for me to pump. My job is giving me heck about breastfeeding and trying to rush me. And if I'm at my job for 5 to 8 hours, I can't breastfeed and now it hurts. My manager makes me clock out during break time. I started having anxiety. I need to pump, but I don't want to bother them.” Another mom in Chicago Lawn mentioned, “When I returned to work no one even knew the rules regarding breastfeeding. They had to call HR to learn what the rules were. I had to tell my manager I wanted to pump, and she didn't know where or what I could do.”

Several moms mentioned that the 15 minutes allotted was not enough time to pump. For example, “My worksite [is] not supportive. They know it's the law but won't give more than a 15-minute break,” and “15 minutes is not enough time.” Other women noted, “Workplace [is] not fully supportive. They are obligated to allow time for pumping, but it feels like workplace is begrudging and just wants me to get it over with,” and “I didn't have a private space to pump. I had to pump in a public space/common area.”

NEED FOR ACCESSIBLE, CULTURALLY APPROPRIATE INFORMATION AND SUPPORT

This theme emerged most prominently in the West Garfield Park and Chicago Lawn focus groups and included women mentioning that they wanted culturally competent information and support from people who looked like them, without judgment based on race, ethnicity, age, or other demographics. One woman in West Garfield Park said, “Don't push breastfeeding and then discriminate based on age, income, etc.” Another woman from West Garfield Park said she “wants information from people who look like her,” and another said there's a “sentiment that black women are 'lazy' when it comes to infant feeding, [they] just want to use a bottle because it's easier.”

A woman in Jackson County suggested that there should be “culturally competent organizations, especially administrators since they set the tone and training for organizations around breastfeeding.” Women also noted that information tailored to a woman's age and life circumstances might be useful. For example, one mom in Peoria County noted, “Maybe should teach it in health class for young mothers. A lot of the young mothers stopped breastfeeding after one month because of school and stuff.” A mom in Chicago Lawn pointed out, “There are young moms and older moms who are first-time moms and we all need to learn more.”

DISCUSSION OF OTHER THEMES

While not cited as frequently, **women also discussed medical providers who were unsupportive or uninformative, hospital or clinic practices that were not supportive, friends and family who were not supportive, and that support from moms and peer support groups was useful.**

Related to **medical providers**, a mom in Chicago Lawn said she “didn't learn about breastfeeding from her medical provider. Her first experience was very new and she was uncertain about breastfeeding and she didn't even really know anything about breastfeeding.” Another mom in Champaign County said her “OB wants me to stop breastfeeding due to my pregnancy,” with another woman agreeing that “doctors are not supportive of breastfeeding while pregnant.”

Others thought medical providers could or should do more to support breastfeeding. “Doctors need to teach that we need to keep going, positive encouragement, and that breastfeeding is hard. I didn't realize it was going to be this hard.” The group in Peoria County all agreed that it would be nice to hear from the obstetrician and that doctors should try to talk more about breastfeeding.

Related to **hospital practices**, some women felt that formula was pushed on them when they did not want it, others did not have full access to a lactation support provider while in the hospital, and still others felt that the hospital separated the mom and baby for longer than necessary or without explanation. A mom in Jackson County said her “baby went to [the] nursery.” She was asking for her baby, but nurses didn't bring her for seven hours. “I didn't know why baby wasn't brought to me, couldn't breastfeed while baby was away.”

A mom in Englewood said the “hospital gave milk even though she told them [she] wanted to breastfeed.” A few women in West Garfield Park also noted that hospitals gave formula without permission or despite wishes to breastfeed: “Hospital didn't believe [I] could breastfeed, gave [me] prepared milk, information on bottle feeding,” and “hospitals gave baby bottle without asking mothers.” A woman in Champaign County mentioned that there was pressure to provide formula and that they “gave formula while [I] was asleep.” Of note, some women did report positive experiences at the hospital, especially hospitals designated as “baby-friendly,” but it came up less often than discussion of unsupportive hospital practices.

Friends and family can play a critical role in supporting moms, or in some cases, are unsupportive of mom's decision to breastfeed. This theme was most frequently discussed in the Peoria County and Chicago Lawn focus groups, and not mentioned in Jackson County. In Peoria County, a mom said, “My boyfriend used to say, 'You just want your boobs out.' Also, [have] a grandma who is still trying to talk me out of breastfeeding--'How long are you going to breastfeed for.'” A woman in Englewood said her “mom told [me] breastfeeding hurts. Told [me] that breastmilk was too thin, told [me] to add cereal or formula to thicken the breastmilk.”

Finally, there was a resounding sense from moms that **support from other moms and peer support groups** were important facilitators to their ability to breastfeed and maintain their breastfeeding relationships despite the challenges. One mom said, “I found a community of moms who breastfed that was helpful. I was able to reach out to problem-solve with and talk to them.”

A woman in Peoria County said, “doctors gave the least information about breastfeeding. I had to look and reach out to WIC and [a local organization] to get information. If I just talked to my doctor, I would have been screwed.”

A woman in Englewood noted that she was separated from her baby because of health issues, but “learned upon discharge that they gave baby formula despite written and verbally communicated plan to not give any formula.”

In Chicago Lawn, one mom said, “People shame me for breastfeeding and my family says I should cover up. I have tried to be strong for my baby, but I still feel embarrassed, people think I'm revealing my body on purpose.”

Regional Findings

CHAMPAIGN COUNTY



The top theme discussed in the Champaign County focus groups was that **information was not helpful or insufficient**. Some women noted that the information provided, including through classes, was hard to use and did not prepare them for reality. Others mentioned that people who had not breastfed often provided unsolicited advice that was shaming or negative.

Cited equally as often, the next two top themes in Champaign County were that women had **problems with the mechanics of breastfeeding** and that there was a need for **more cultural and societal support for breastfeeding**. For example, one mom noted she had the “assumption that milk is just there after delivery” and another said she “dried up.” For societal support, participants said people need to be more comfortable with women's bodies and women need to be more comfortable with their own bodies. They also have heard negative opinions about breastfeeding, such as “cow jokes.”

Finally, **challenges with breastfeeding logistics** were commonly discussed. Women said it was hard to find time to breastfeed with older children around, night feedings, getting enough rest when returning to work, and that balancing pumping at work in a field job is challenging.

Top themes from Champaign County focus groups:

- 1 Unhelpful and/or insufficient information
- 2 Problems with breastfeeding mechanics
- 3 Need for cultural/societal support
- 4 Challenges with breastfeeding logistics

Regional Findings

CHICAGO (Chicago Lawn, Englewood, and West Garfield Park)

Top themes from Chicago area focus groups:

- 1 Problems with breastfeeding mechanics
- 2 Need for cultural/societal support
- 3 Need for assistance from more organizations
- 4 Hospital and clinic practices not supportive
- 5 Need for accessible, culturally appropriate information and support

The top themes that emerged in the Chicago focus groups included problems with breastfeeding mechanics, the need for more cultural and societal support, the need for assistance from more organizations, hospital and clinic practices that were not supportive, and the need for more accessible, culturally appropriate information and support.

For challenges with **breastfeeding mechanics**, women in West Garfield Park noted that mastitis, engorgement, chafed nipples, and feelings of insufficient milk supply were all problems they faced, and that healthcare professionals did not always discuss those challenges before breastfeeding started to help moms know how to deal with them. Women in Englewood cited problems with milk production, feeling upset when they had no milk after three days and having to cluster feed, and “not being calm, things going on, disrupted milk supply.” In Chicago Lawn, moms mentioned inverted nipples, difficulties with latch, and worries about milk supply. For example, one mom said, “I didn't see a lot of milk, so I thought I was losing it.”

In wanting **more cultural and societal support for breastfeeding**, a woman in West Garfield Park said she “didn't know anyone who had breastfed, no model, and so I had no way of knowing whether I was doing it correctly.” Women in Englewood also mentioned that their friends did not breastfeed, but that breastfeeding could become the norm if more women did it and they made it a norm from a young age with celebrities promoting it. In Chicago Lawn, moms discussed frustration with family culture around the need to cover up and to give formula since “the baby was hungry [after breastmilk].”

The need for assistance from more organizations, hospital and clinic practices that were not supportive, and the need for more accessible, culturally

appropriate information and support were all equally mentioned throughout the Chicago focus groups. Regarding the need for **more organizations to support breastfeeding**, women in West Garfield Park mentioned needing more lactation clinics, like WIC but centered on breastfeeding, 24-hour services, and lactation consultants always available. There was a feeling that different neighborhoods in Chicago have different levels of support, and classes and discussions should not include any discrimination/judgment. Women in Englewood mentioned not having enough resources and that “there are programs and support, but people don't know how to access them.” There was a desire for more programs in community settings, like libraries, churches, and grocery stores. In Chicago Lawn, the idea that there should be more information to support breastfeeding was confirmed.

Unsupportive hospital practices ranged from providing babies formula without asking or against a mother's wishes, not having lactation support providers available to moms, not respecting women's bodily autonomy, not allowing skin-to-skin contact right after birth, and being separated from baby without knowing the reason.

For the **need for more accessible, culturally appropriate information**, moms in West Garfield Park mentioned that there are assumptions about Black/African American women and breastfeeding and that racial discrimination/judgments based on race are made by healthcare professionals. They mentioned wanting peer support groups (on social media) of women of color and wanting professionals to address concerns for moms of color. Moms in Englewood and Chicago Lawn felt younger moms do not receive the support they need, and they wished more relevant information was offered by healthcare providers.

Regional Findings

PEORIA COUNTY

Top themes from Peoria County focus group:

- 1 Need for cultural/societal support
- 2 Information from supportive organizations
- 3 Unsupportive or uninformative medical provider
- 4 Partner support
- 5 Challenges with breastfeeding logistics



The need for cultural/societal support for breastfeeding also topped the list of themes in Peoria County. Subsequent themes were getting or wanting information from support organizations and receiving unsupportive or unhelpful information from medical providers. Having support from mom's partner/child's father as a facilitator and challenges with breastfeeding logistics were also discussed.

For **cultural and societal support**, one woman mentioned, "Society, that's been my biggest problem--the availability of private rooms--seems like people right now are shunning us or bad-eyeing. We should normalize the fact that a human mother feed[s] their baby. It should be normal and it's not." Another mom noted "going somewhere makes me anxious. I don't want to be judged by society." Women in this group also noted the current movement to normalize breastfeeding, with celebrities and women posting photos of breastfeeding to try to normalize it.

A unique attribute in Peoria County was the amount of **support women mentioned getting from organizations**. They agreed that the local health department provided breastfeeding information, and that a local hospital had a breastfeeding resource center. Many noted a good breastfeeding class hosted by a social service organization in Peoria County.

However, many women in Peoria County felt they **did not receive enough information or support from their medical provider**. They said the doctors (OBs) gave the least amount of information about breastfeeding and that it would have been nice to hear more from them about breastfeeding.

Overall, women in Peoria County **felt supported by their partners**, noting that the babies' fathers attended prenatal and breastfeeding classes with them and were supporters of breastfeeding.

Regional Findings

JACKSON COUNTY

Top themes from Jackson County focus group:

- ① Need for cultural/societal support
- ② Unhelpful and/or insufficient information
- ③ Insufficient private spaces to breastfeed
- ④ Shame or stigma for breastfeeding in public
- ⑤ More information needed for men



In Jackson County, the top themes were similar to the statewide findings of the need for more cultural/societal support for breastfeeding and having unhelpful/insufficient information. But additional top themes included having a lack of private spaces to breastfeed, the existence of shame or stigma for breastfeeding in public, and more information needed for men.

For **private spaces to breastfeed**, women mentioned not wanting to feed their children in bathrooms and cars, and that even doctors' offices do not have comfortable places to breastfeed. One woman said, "The OB office suggested breastfeeding in a restroom. If it can't be accepted there, and if there's not a space there, then where can it be?"

Most women in Jackson County felt **pressure to cover up while breastfeeding**, saying "here, people expect you to cover up," and "the stigma and pressure from the public that breastfeeding in public is wrong make you want to cover up or breastfeed in the restroom."

Related to **men**, the women in the focus group said men need more education and information about what women go through, and that men should go to the breastfeeding classes, too. One mom mentioned that men do not always know what is appropriate to say about breastfeeding.

Challenges

A couple of challenges were faced in implementing these focus groups. While IPHI had local ISPAN partners to help recruit women, it was challenging filling the spots for the Spanish-language group in Chicago Lawn. It is unclear if the day and timing, location or other logistics were a barrier, or if the overall cloud of federal policy and practice threats to the immigrant community may have impacted participation. Additionally, in Peoria and Jackson Counties, some of the focus group participants knew the group facilitator, and it is unknown if this familiarity impacted the responses from those participants.

Conclusion

Overall, women in the focus groups discussed more challenges to breastfeeding than facilitators, and there was a clear need for more useful, culturally relevant information and support from society at-large, lactation support providers (to help with the mechanics of breastfeeding), medical providers, and friends and family. Women wished breastfeeding was normalized and that more professionals, hospitals, clinics, and organizations could help them with the mechanics and support for breastfeeding. Many women felt supported by other women who have breastfed, but discrimination, shame, and stigma for breastfeeding were issues women faced. Despite these challenges, many persevered in meeting their breastfeeding goals.

Next Steps

The IPHI staff integrated the findings from the focus groups into information provided at an in-person ISPAN breastfeeding strategic planning meeting in November 2019. The vision, goal, and objectives discussed and decided upon by the ISPAN breastfeeding strategic planning group at that meeting and in subsequent phone meetings help to address the top challenges identified in the focus groups and support expansion of the facilitators of breastfeeding. IPHI will continue to use the focus group results to guide the strategy development and implementation of ISPAN breastfeeding activities for the remainder of the grant period (through September 2023).





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