

CARE COORDINATION OF SERVICES FOR PREGNANT AND POSTPARTUM PEOPLE

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INTRODUCTION

Illinois is a national leader in implementing policies to improve outcomes for birthing people and families. In 2021, Illinois became the first state to extend full Medicaid benefits from 60 days to 12 months postpartum. Illinois has expanded Medicaid to cover certified doula and lactation consultant services and is working to implement Medicaid coverage of home visiting, including universal newborn support visits.

Stakeholders have also collaborated with public officials to plan for the future of maternal and child health. For four years, Illinois has been exploring a universal newborn support system through its Early Childhood Comprehensive Systems grant. The State recently released, “Coordination and Collective Action: Illinois’ Blueprint for Birth Equity,” which identifies strategies, strengths, assets, and gaps across the maternal health ecosystem. Given these advancements in maternal and child health, now is the time to maximize recent investments and ensure all birthing families can access care and support during the perinatal period, through the development of a single point-of-entry system for maternal and child health services and programs.

This report explores prenatal through postnatal care coordination systems to inform the development of such a statewide system in Illinois to improve birthing people’s access to services through one year postpartum. It focuses on states and communities that have developed central or coordinated intake systems and includes a literature review; themes from interviews with Illinois stakeholders; highlights from interviews with leaders in other states and communities about their care coordination models, along with an examination of these model components; and finally, recommendations for developing a statewide system in Illinois, along with additional issues for consideration.

WHERE WE ARE IN ILLINOIS: HIGHLIGHTS OF THE MATERNAL CHILD HEALTH AND EARLY CHILDHOOD LANDSCAPE

Illinois is well-positioned to explore and develop a robust statewide system of care coordination. There have been considerable policy achievements in the last five years which expanded access to and funding for services and supports for pregnant and postpartum individuals. Several planning and coordinating bodies have provided vision and direction for programming in the state, including the State of Illinois’ Early Childhood Comprehensive Systems (ECCS) planning grant work and the work of I PROMOTE-IL. Further, recent and impending reports and strategic plans provide a roadmap for the future, including the Maternal Health Strategic Plan and the recently released State birth equity blueprint: Coordination and Collective Action: Illinois’ Blueprint for Birth Equity.

As noted by two Illinois stakeholders:

“Right now, there is great momentum, and I think it is a perfect time for people to come together, have these conversations, and really think through how to offer the best possible service and make Illinois unique in doing something like this.”

“There is currently good synergy in Illinois around care coordination with I PROMOTE-IL and the Maternal Health Innovation grant. We have the Maternal Mortality Review and Infant Mortality Review Committee and their recommendations.”

In addition to the ECCS and Illinois Maternal Strategic Plan work, the Early Learning Council’s Integration & Alignment Committee presented recommendations for aligning regional intermediary functions in February 2024.¹ These offer additional infrastructures to support birthing families and their young children.

[1] [IAC PowerPoint Presentation Extended for ELC Exec. Mtg-02.05.2024.pdf](#)

As a few Illinois stakeholders noted:

“I see all the work that MIECHV coordinated intake/home visiting is doing, UNSS, all need to work together in a coordinated system. We don’t necessarily need another layer—not more— but we need connections to happen so that we are effective, efficient, and maximizing what we currently have and identifying the gaps.”

“In getting UNSS to complement and integrate with an overarching coordinated intake system, we would have to be really creative. We would have to think about nesting and aligning. I know that the Family Connects model is for postpartum, but I am all about being creative.”

UNIVERSAL NEWBORN SUPPORT SYSTEM (UNSS) EXPLORATORY WORK THROUGH THE EARLY CHILDHOOD COMPREHENSIVE SYSTEMS PLANNING GRANT

The State of Illinois received a five-year planning grant from the Health Resources and Services Administration (HRSA) under the Early Comprehensive Childhood Systems (ECCS) program in 2021 to explore building a statewide UNSS framework and to use the development of this framework as a pathway for systemically aligning the many maternal child health and early childhood programs in the state. ECCS workgroups have built an understanding of the logistics required to scale UNSS across Illinois, considering implementation cost, workforce needs, and an understanding of the UNSS models that best align with the goals of the State’s advisory team. The ECCS Advisory Workgroup is finalizing the ECCS report with recommendations, which will be completed in Fall 2025.

MATERNAL HEALTH INNOVATION PROGRAM

Illinois was one of nine states to receive State Maternal Health Innovation (MHI) program funding in 2019 from HRSA. Illinois’ MHI program, Innovations to Improve Maternal Outcomes in Illinois (I PROMOTE-IL), led by the University of Illinois Chicago convened the Illinois Maternal Health Task Force in March 2020 to develop the Illinois Maternal Health Strategic Plan.

The Maternal Health Task Force has four committees focusing on the plan’s strategic priorities:

- Care Coordination and Case Management²
- Community Access, Systems Equity, and Education
- Root and Structural Causes of Health Inequity
- Maternal Health Data to Action

COORDINATION AND COLLECTIVE ACTION: ILLINOIS’ BLUEPRINT FOR BIRTH EQUITY

Illinois’ maternal health and birth equity report, Coordination and Collective Action: Illinois’ Blueprint for Birth Equity, is a state agency-led landscape that compiles current strategies, strengths, assets, and gaps across the maternal health ecosystem in Illinois. This document includes high-level strategic goals for a universal system for birth equity in Illinois that addresses maternal mortality and morbidity. It maps all the work state agencies are doing, including other strategic planning processes underway, existing state assets, and lists key maternal health policies in Illinois.

[2] Priority Area #1 of the Maternal Health Strategic Plan is “Care Coordination and Case Management” and its first strategy under this priority is to create a shared understanding of the framework for the universal newborn support system (UNSS) as undertaken through the ECCS planning grant.

MEDICAID AND COMMERCIAL COVERAGE OF DOULAS, LACTATION CONSULTANTS, AND HOME VISITING

By the close of 2024, the State of Illinois had operationalized Medicaid reimbursement for certified doulas and lactation consultants. In addition, state regulated private health plans are also required to cover these services. The State is currently operationalizing Medicaid reimbursement for UNSS visits. On December 3, 2024, the Centers for Medicare and Medicaid Services (CMS) approved Illinois' State Plan Amendment to add coverage of home visiting services, including those home visits provided through a universal newborn support system, to Illinois' Medicaid program.

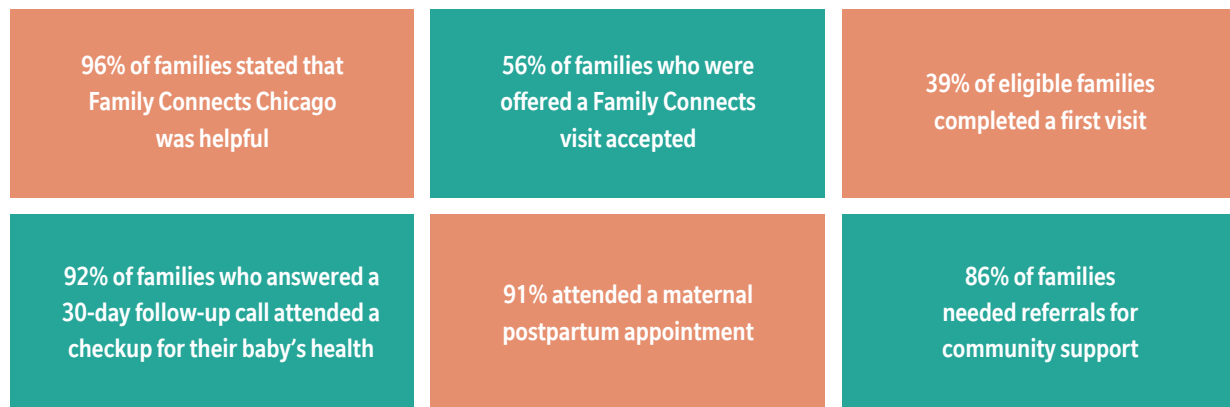
CREATION OF THE ILLINOIS DEPARTMENT OF EARLY CHILDHOOD

In June 2024, Governor Pritzker signed legislation to create the Illinois Department of Early Childhood. The Department of Early Childhood expects to be operational by July 2026 and will house the early childhood programs currently administered in the Department of Children and Family Services, the Department of Human Services, and the Illinois State Board of Education. Housing early childhood programs under one roof should streamline the administration of programs to cut inefficiencies, make it easier to braid and blend funds, and facilitate easier engagement for parents and families.

FAMILY CONNECTS

Chicago, Peoria, Stephenson County, and Winnebago County all have implemented the Family Connects universal newborn support system in their communities. Family Connects universally offers between one and three nurse home visits to every family with a newborn in the community at approximately three weeks of age. Nurses check on both newborn and maternal health, assess a family's needs, and connect families to appropriate needed resources in the community. An integral component of the Family Connects model is the community alignment board and position, which helps navigate the connection of families to resources, assess gaps in resources and services, and provide outreach to community-based resources and providers.

Family Connects Chicago 2024 Annual Report noted that:



ILLINOIS MATERNAL CHILD HEALTH & EARLY CHILDHOOD PROGRAMS/INITIATIVES AND RESOURCES FOUNDATIONAL TO THE DEVELOPMENT OF A STATEWIDE CARE COORDINATION SYSTEM

The following table highlights the exceptional maternal and child care coordination programs which could serve key roles in a statewide care coordination system.³ A second table of existing systems infrastructure upon which a care coordination system could be built is in the recommendations section of this report.

PROGRAM/INITIATIVE	PURPOSE	ADMINISTRATIVE HOME
Better Birth Outcomes — Comprehensive	Statewide program providing 1:1 nursing assessment for pregnant and parenting clients, connecting them to medical homes and needed services; includes initial prenatal and postpartum visits with follow-up as indicated.	Illinois Department of Human Services (IDHS), Division of Family & Community Services, Bureau of Maternal and Child Health
Better Birth Outcomes — Navigation	Chicago program helping pregnant and parenting clients establish a medical home and connect to medical, social, and other supports; in-person navigation to identify and reduce access barriers.	IDHS, Division of Family & Community Services, Bureau of Maternal and Child Health
Early Intervention	Developmental supports and services for families/caregivers of children with delays or disabilities.	IDHS - Division of Early Childhood (DEC)
High Risk Family Case Management Pilot (HRFCM)	Two pilot cohorts in communities with high mortality rates; Better Birth Outcomes — Comprehensive is not offered where HRFCM is funded.	IDHS, Division of Family & Community Services, Bureau of Maternal and Child Health
Illinois Healthcare Transformation Collaboratives (e.g., South Side Healthy Community Organization)	Collaboratives improving healthcare access and outcomes with community-specific focuses (e.g., maternal health).	Illinois Department of Healthcare and Family Services (HFS) in partnership with each nonprofit collaborative
Illinois Transforming Maternal Health Model (TMaH)	10-year Centers for Medicare & Medicaid Services (CMS) initiative improving maternal health—especially for Medicaid/Children’s Health Insurance Program (CHIP) enrollees—through holistic prenatal, childbirth, and postpartum care addressing physical, mental, and social needs.	HFS; pilot communities (Rockford, Aurora)
MIECHV Home Visiting (iGrow) and local home visiting	Voluntary home visiting that provides family support and coaching through scheduled visits by trained professionals; Maternal, Infant, and Early Childhood Home Visiting (MIECHV) uses coordinated intake and a coordinated-intake toolkit.	IDHS-DEC HV

Table continued on next page.

[3] This table is not exhaustive.

PROGRAM/INITIATIVE	PURPOSE	ADMINISTRATIVE HOME
UNSS programs (Family Connects, Baby Talk, local UNSS)	Universal Newborn Support System (UNSS): universal newborn home visits in the first weeks of life by a nurse or other practitioner, connecting families to local services as needed.	Local lead agencies (e.g., Chicago Department of Public Health) with support from IDHS Division of Family & Community Services and the Illinois Department of Public Health
Special Supplemental Nutrition Program for Women, Infants, and Children (WIC)	Provides nutritious foods, breastfeeding support, nutrition education, and referrals for birthing families.	IDHS, Division of Family & Community Services, Bureau of Family Nutrition
Healthy Choices, Healthy Future Toolkit	Evidence-based tools and resources to support women during the reproductive years; for families and social service providers.	EverThrive Illinois
Maternal Health Digital Resource Bundle	Compiled resources for providers (including Federally Qualified Health Centers) and their patients to promote health during pregnancy and postpartum.	I-PROMOTE IL– University of Illinois Chicago
Nurturing You for a Healthy Tomorrow (campaign)	Educates birthing people on Medicaid-covered services from pregnancy through 12 months postpartum.	Chicago Department of Public Health; Illinois Department of Public Health; HFS; I-PROMOTE IL– University of Illinois Chicago
Summary of Tools to Identify Resources to Address SDOH	Table of common Social Determinants of Health (SDOH) needs and screening tools recommended by the Illinois Perinatal Quality Collaborative.	Illinois Perinatal Quality Collaborative

LITERATURE REVIEW

This section highlights academic literature on the barriers to accessing prenatal and postnatal care and on the systems that facilitate improved access, providing an evidence-based foundation and context for considering statewide perinatal care coordination in Illinois. We prioritized sources on maternal and child health centralized and coordinated intake systems, barriers to care, and care-coordination program implementation.⁴

These themes emerged from the literature review in relation to care coordination during the perinatal period.

IMPORTANCE OF TIMELY PRENATAL AND PERINATAL CARE THROUGH ONE-YEAR POSTPARTUM AND OPPORTUNITIES FOR IMPROVEMENT

Timely and appropriate prenatal and postpartum care significantly improves maternal and child health outcomes. Early prenatal care presents a “critical window for changes to systemic factors that may compromise the health of women and infants” (Krukowski, 2021, p. 329). Barriers such as transportation challenges and maternity care deserts limit access and contribute to worse outcomes (Reyes et al., 2021; Atwani, 2025). Between 2018 and 2021, the U.S. maternal mortality rate rose 89% to 32.9 deaths per 100,000 live births (Hoyert, 2021). Mortality rates are higher in maternity care deserts versus full-access counties (32.25 vs. 23.62) (Atwani, 2025).

The American College of Obstetricians and Gynecologists recommends that all women have initial contact with their obstetric provider within three weeks postpartum, followed by ongoing care and a comprehensive postpartum visit within 12 weeks after birth (ACOG, 2018; reaffirmed 2025). This recommendation recognizes the critical nature of the postpartum period for women and infants, and the sometimes-fragmented nature of care straddled between maternal and pediatric health care providers. Nearly one-third of pregnancy-related deaths in the United States occur six weeks to one year postpartum, underscoring the need for comprehensive follow-up (Chen, 2025).

Pregnancy Risk Assessment Monitoring System (PRAMS) data reveal a gap between pregnancy recognition (average 6 weeks gestation) and the first prenatal visit (average 9.3 weeks), with disparities by race, age, and education (Krukowski, 2021). Structural and financial barriers were common reasons for delayed care, suggesting an opportunity to improve early access and reduce adverse outcomes.

BARRIERS TO CARE

To ensure that each pregnant woman receives the prenatal care and support she needs for a healthy pregnancy, it is necessary to understand existing barriers to care. A 2022 systematic review of 34 studies identified three main categories of barriers among low-income women: structural barriers (the most common), personal barriers, and experiences of care (Bellerose, 2022)

[4] Sources were identified searching on a variety of search engines, including the Home Visiting Applied Research Collective (HARC) Resource Library, Springer Nature Link, Google Scholar, and PubMed, supported by The National Library of Medicine. The main search terms were “home visiting,” “perinatal care,” “centralized intake,” “maternal health,” “prenatal health,” “newborn,” “infant,” and “postpartum”, along with a search of specific program names such as “Connecting New Jersey” and “B’more for Healthy Babies.”

BARRIERS BY CATEGORY FROM BELLEROSE STUDY

STRUCTURAL BARRIERS	PERSONAL BARRIERS	BARRIERS DUE TO PAST EXPERIENCES OF CARE
• Medicaid enrollment challenges and delays and the cost of care without insurance • Challenges finding a provider accepting new patients on Medicaid/appointment times • Challenges with provider continuity and poor inter-provider communication • Transportation challenges • Childcare challenges • Poor linkages to services, such as postpartum depression and substance use treatment • Fear of legal consequences because of care or insurance seeking	• Lack of awareness of pregnancy • Considering abortion • Shame and stigma surrounding pregnancy • Limited support from friends or family • Lack of knowledge or belief that prenatal or postpartum care visits are important– especially when feeling fine • Conflicting life priorities and challenges	• Not feeling heard • Not enough time with providers, especially in comparison to wait times • Language barriers • Lack of respect for cultural differences and preferences • Racism or discrimination from providers

From November 2023 through June 2024, EverThrive Illinois hosted Birth Equity Listening Sessions to bring together medical professionals, social service providers, and community members to discuss maternal and child health services in Illinois and to better understand the barriers to services and care. The six in-person and virtual sessions were hosted in McLean, Champaign, Madison, and Williamson counties, and the city of Chicago. Key barriers identified from these sessions align with the barriers identified in the Bellerose study and include standards of care and experiences with the hospital system, service provider collaboration, patient education, housing, childcare, transportation, and mental health, specifically stigma and fear of punitive measures.⁵

A recent qualitative study explored pregnancy and the postpartum experiences of Black birthing people in Chicago neighborhoods with high rates of maternal morbidity and mortality (Perry et al., 2024).⁶ Five themes emerged from the study's participant focus groups (Perry et al, 2024, pgs. 327-328):

- Need for interpersonal and mental health support during and after pregnancy
- Preferences for multiple sources of health information
- Need for strengthened connection with medical providers
- Lack of clarity regarding maternal morbidity and mortality and the postpartum period
- Differences in language and associated gaps in understanding

[5] [EverThrive Birth Equity Listening Sessions Summary](#)

[6] The Perry study is unique in that it utilizes a community-based participatory research approach that involved community members in the research process and incorporates their perspectives. As stated in the study's introduction, "Given that we are discussing structural inequalities at the community level, it is important to shift the power dynamics from the researchers to the community itself, as this aligns with the principles of health equity and helps to preserve the authenticity of the community's voice." (Perry et al, 2024 at 323).

The study noted that participants emphasized that a lack of social support and isolation can lead to stress, which is associated with adverse pregnancy outcomes. As discussed in the study:

“For pregnant people, social support is inversely associated with depressive symptoms and perceived stress. People who do not have social support feel more isolated. Maternal stress is associated with adverse pregnancy outcomes such as preeclampsia, preterm birth and smaller newborns. Social support can act as a buffer, protecting people who are pregnant from adverse social situations. Moreover, when health care providers are a source of support. They can encourage engagement with medical care, which may help to improve outcomes” (Perry et al., 2024, pg. 331).

OPTIMIZING PERINATAL CARE

In the maternal and child health and early childhood home visiting context, service coordination is defined as the “organization of activities between two or more organizations to facilitate, in partnership with the family, the delivery of the right services in the right setting at the right time” (West, et al. 2021, pg. E10). Such care coordination requires developing partnerships across maternal and child health, social determinants of health, and early childhood community-based organizations and providers. Many factors impact the effectiveness of perinatal care coordination systems and support, including referrals to home visiting, substance use treatment, and behavioral health treatment among others. Below are the themes that emerged from the literature reviewed for this report.

OPTIMIZING CONNECTIONS TO BEHAVIORAL HEALTH AND SUBSTANCE USE TREATMENT

A 2017 study argues that weaving behavioral health screening into the first point-of-entry for maternal and child health home visiting programs allows interventions to be “tailored to the unique needs of women from the time of enrollment, simultaneously enhancing retention and successful home visiting outcome” (Price, et al., 2017, pg. 237).

A 2021 study examined why referrals and coordination from home visiting programs with community-based services for pregnant women experiencing poor mental health, partner violence, and substance misuse show limited effects (West, et al., 2021). The study asserts that referrals alone are often not enough to ensure a parent receives needed services, rather successful service coordination requires four key aspects: screening, referral, linkage, and follow-up, described as closing the loop between family and provider to ensure that services were received (West, et. al., pg. 634). Limited-service ability and poor access to transportation also limit the effectiveness of referrals (West, et al., 2021).

A 2024 dissertation examined New Jersey’s home visiting reach, engagement of pregnant women who screen positive for substance use risk, and data from New Jersey’s single point-of-entry platform to examine levels of engagement (Correll, 2024). This study found that engagement of participants was positively influenced by participants’ experience with the referral and referral source; the provision of tangible supports, such as food, transportation, and diapers; closed loop and continual follow-up after referral; and tailoring services to each participant’s unique circumstances. Conversely, home visiting association with child welfare can negatively impact engagement. The dissertation also affirms that the relationship between participants and their home visitors was central to their engagement in services.

BARRIERS TO PROVIDERS MAKING REFERRALS

A study examining solutions for increasing referrals from health care providers to early childhood home visiting providers demonstrates the role a care coordination hub can play in successful referrals (Cruz, 2022). Health care providers indicated that insufficient knowledge about providers and program eligibility, lack of knowledge and trust among participants, the absence of an internal referral process, time limitations, lack of feedback following a referral, and stigma around programs created barriers for successful home visiting referrals. Providers did express that a care coordination or centralized intake system could alleviate these barriers and facilitate the process for increasing referrals.

“Some providers stated that having a centralized intake point and standardized form would allow them to refer without worrying about specific programs and eligibility criteria” (Cruz, 2022, pg. 74).

CO-LOCATING SERVICES

Co-location of services is a common recommendation when considering care coordination and maternal and child health clinical-community linkages. A study looking at the structural and relational factors for successful collaboration in home visiting noted that interpersonal relationships, shared data systems, written agreements and co-location all enabled care coordination activities, and that community advisory boards can provide a venue for developing partnerships and resource sharing (Williams, et al., 2024).

Co-locating home visiting services in a clinical setting to facilitate communication about programming and initiation of contact at the time of referral may increase home visiting engagement after a referral. The University of Illinois Health System has successfully implemented two-generation care clinics on the south and west sides of Chicago. This model combines care with behavioral health support and material aid for postpartum families. A recent study examining whether a two-general model of interdisciplinary, postpartum primary care increased postpartum visit attendance found that mothers who visited the two-generation clinic had higher rates of postpartum care utilization – and significantly higher rates of later postpartum primary care (Wainwright, et al., 2025). I-PROMOTE-IL has developed a Two-Generation Postpartum Care Toolkit to explain the care model and suggest ideas for other health organizations to improve postpartum care using this model.

STATE STRUCTURES AND PROCESSES TO SUPPORT SERVICE COORDINATION

State leadership, MIECHV leadership, shared goals, data and finance are all state level infrastructure that can support the care coordination of home visiting programs (West, et al., 2018b). A survey of state MIECHV administrators found that data sharing and data systems posed the biggest challenges to care coordination– particularly for sharing data in early childhood systems to or from social services and health systems (pg. E14).

The California Home Visiting Coordination Project has developed the following policy recommendations for structuring a coordinated early childhood system (Sturmfels, et al., 2022).

- 1. Governance** - interagency steering committee, shared goals, and infrastructure for parent leadership
- 2. Funding** - create a state-level home visiting fiscal map and identify opportunities to leverage funding
- 3. Data** - aligned data collection, report requirements, and create state-level infrastructure to support data integration
- 4. Accountability** - state-level communications strategy and annual state-level home visiting scan to inform future funding and policy recommendations

ILLINOIS STAKEHOLDER PERSPECTIVES⁷

Fourteen Illinois stakeholders were interviewed between April and June 2025 to gather the expertise and perspectives of Illinois leaders working in maternal and child health and early childhood.⁸ A standard set of interview questions was developed for these interviews, which were then tailored to best gather the expertise of the individual interviewees. These are the themes from the synthesized perspectives that emerged.

“Illinois is long overdue in thinking about a system to connect pregnant people prenatally to care.”

IDENTIFYING THE PROBLEM WE WANT TO SOLVE—WHAT IS THE BIG GOAL?

Illinois stakeholders recognize the need for improving the coordination of perinatal services, so all birthing people have access to services with streamlined delivery and without duplication and reaching pregnant people as early as possible in their pregnancy, or even in the preconception period, to maximize healthy pregnancy outcomes. Several stakeholders noted the importance of considering the “big problem we want to solve” and building consensus around this goal as a critical first step in exploring and developing a comprehensive care coordination system in Illinois.

“What are you trying to solve for and what do you need. Are you trying to address chronic disease in pregnancy? Substance use? Mental/behavioral health? Social determinants of health?”

“What are we assessing for? This will influence the data that will go in. Is it assessing for medical? Social determinants of health? What is the goal and then you can build out. What data do we need, who assesses, and then where do folks go?”

IMPORTANCE OF UPSTREAM AND APPROPRIATE CARE

Stakeholders noted the importance of upstream care to improve both maternal and infant health outcomes. Substance use disorder was the leading cause of pregnancy-related deaths in Illinois between 2018-2020 at 32% of pregnancy-related deaths.⁹ The infant mortality rate was highest among infants born to women who did not receive any prenatal care. The infant mortality rate decreased as adequacy of prenatal care increased.¹⁰ While the infant mortality rate in the state has been declining over the past several years, the mortality rate among infants born to Black women was nearly three times that of infants born to white, Hispanic, and Asian women. This disparity is primarily influenced by trends in death due to prematurity and sleep-related deaths.¹¹

“We know if we really want to move the needle on infant and maternal mortality and morbidity that getting people into early and risk appropriate prenatal care is key.”

“I would argue that getting women into pregnancy healthier is what is most needed. When you look at maternal morbidity and mortality data, a lot of times it is chronic disease impacting outcomes, or substance use and mental health that is not addressed.”

[7] Please see Appendix A for a synthesis by theme of Illinois stakeholder interview notes.

[8] While the capacity of this project limited the number of conversations possible, there are many other stakeholders and voices from which it will be critical to get feedback as a statewide care coordination system is considered, and the development of a framework moves forward.

[9] Illinois Maternal Morbidity and Mortality Report (October 2023)

[10] Fetal and Infant Mortality Data Report (September 2024).

[11] Fetal and Infant Mortality Data Report (September 2024).

BARRIERS TO CARE

As discussed in the literature review, the Bellerose study from 2022 identified three categories of barriers to timely, high-quality care: structural barriers to accessing care (the most common), personal barriers to accessing care, and a pregnant person or parent’s experiences of care. Interviews with Illinois stakeholders also highlighted barriers that can be organized into the three categories found in the table below.¹²

STRUCTURAL BARRIERS	PERSONAL BARRIERS	BARRIERS DUE TO PAST EXPERIENCES OF CARE
<i>“Child care is also a huge issue for pregnant people accessing prenatal care.”</i> <i>“Transportation issues are a huge barrier to getting to prenatal appointments. And many women don’t know that insurance (Medicaid and private) will pay for their transportation. It is partly an education/ communications gap where women don’t know what is covered and available to them.”</i> <i>“People sometimes don’t have geographic access.”</i>	<i>“Lack of proper information is also a barrier. How do we get the proper information out to people. How do we get the correct information out, where there is so much misinformation on social media.”</i>	<i>“A provider’s bedside manner and really being able to listen to people makes a huge difference. Sometimes it is difficult in practices where you see many different providers within a practice, as it becomes harder to establish a relationship with that many providers.”</i> <i>“There can be issues of quality, where do people like to get care? They like to go where people respect them and not judge them.”</i> <i>“People feel stigmatized, people don’t feel welcome in the health system– it is discombobulated and not coordinated.”</i>

One solution that arose in the interviews to help address these barriers is co-locating services:

“I think co-locating maternal and infant visits during the first year to the greatest extent possible is one opportunity to break down barriers to postpartum care. Mothers often bring infants for their well-child visit, but she might not go for her own care.”

Co-locating services can also happen within other perinatal partnership contexts, such as a home visiting program co-locating in a health care setting.

[12] Please also see EverThrive’s Birth Listening session summary and the Perry et.al study highlighted in the literature review that include the birth family’s firsthand experience with barriers to accessing care.

REACHING PREGNANT PEOPLE

The birthing hospital or center is an easy spot to make sure every new mom and their baby receives care and provides a touchpoint for continued postpartum services. It is more difficult to reach people when they are pregnant to make sure they are receiving adequate care. Outreach within communities and meeting pregnant people where they already are is critical to ensuring pregnant people are connected to care. As Illinois stakeholders explained:

“It is easy enough to connect with families once the baby is born, but more challenging looking at connecting women to prenatal care.”

“If you go to the hospital, you get most folks when the baby is born, but there is not the same pathway—point-of-entry—for pregnant people.”

SUPPORT FOR STATEWIDE CARE COORDINATION FOR ALL

“We have all these initiatives, task forces, locally funded and state funded initiatives. We have so much great work taking place in Illinois, but how does someone know what services exist? If someone moves, how do they know what services are available?”

Stakeholders emphasized the impact of Illinois’ commitment to programs and policies that support pregnant and birthing families. Most interviewees did see room for improvement in the coordination and connection of women to these resources.

“I would love a statewide system— a simplified statewide system. A lot of us have talked about this for years. However, there are nuances with funding, and we have real deserts in Illinois. There are obstetric shortages and medical shortages. And in the absence of a statewide system, people have developed systems that work for their areas.”

“We have many, many programs in Illinois but there is not really a good way to ensure that people get the programs that they need. Some women get no programs, and some women get exposed to multiple programs.”

Improving education and communication about the important work that is already happening is also necessary.

“I think there are already a lot of good things happening, but they are not connected, or their scope is so small—these efforts could help with what needs to happen going forward.”

“In the IPLQC work, we are making intentional efforts to get the birthing hospital teams to know what is happening in the communities. People in the community assume, of course, that everyone in the community knows we are doing this work. But the hospitals really don’t know of all the resources in their areas— we need to let them know of the work happening at the health departments, FQHCs, other community-based organizations.”

Stakeholders also noted the importance of such a system being universal, which aligns with the philosophy behind a statewide UNSS framework.

BUILDING ON AND ALIGNING EXISTING MATERNAL CHILD HEALTH AND EARLY CHILDHOOD SYSTEM STRUCTURES

Stakeholders emphasized that Illinois should be building on existing maternal child health and early childhood system structures and programs. The state has existing systems and infrastructure that can be leveraged and bolstered.

“All the work that MIECHV coordinated intake/home visiting is doing, UNSS, it all needs to work together in a coordinated system. We don’t necessarily need another layer, but we need connections to happen so that we are effective, efficient, and maximizing what we currently have and identifying what the holes are for services for families.”

“We have a lot of regional systems. Can we align these regions? We’ve got Birth to 5 regions, which are aligned with the Regional Offices of Education, we have the Child Care Resource and Referral agencies, we have the Early Intervention regions. If we aligned these regional systems, it would streamline things. Then, in some of the regions, we could see coordinated intake happen regionally, if that is what the community wanted.”

“We do have mechanisms to help people get connected to care and services, but we tend to think really siloed within the public health system. We need to think about how we interface with other programs/mechanisms in the state.”

The challenge of broad systems coordination to move the needle on maternal and infant health was a common refrain in interviews with other states as well. System building and coordination takes time and requires a shared vision.

DATA INFRASTRUCTURE AND PRIVACY ISSUES

Data infrastructure, sharing, and privacy issues are all complicated and necessary to tackle in building a perinatal care coordination system.

“The data sharing is an enormous piece of all of this. And then, where are you capturing the data once you have connected to people— where is it housed? How are you tracking it to know the outcomes of individuals getting connected to care but then more aggregated impact outcomes as well?”

“A huge barrier for any of this is the data sharing issues. What are the hardware, software, legal barriers, and people barriers. These are all fundamental to this.”

The Children’s Behavioral Health Transformation Initiative confronted similar data challenges when developing its BEACON centralized access system. This system development could provide guidance on trouble-shooting some of the thornier data sharing and privacy issues.

OUTREACH, COMMUNICATIONS, AND APPROPRIATE FRAMING

Outreach to community partners and a high-quality, multi-layered communications campaign to the broader community, including families, health care providers, faith-based organizations, and other entities serving families, is an integral component of any care coordination system. Illinois stakeholders noted the staffing and messaging challenges around outreach and reaching community members where they are:

“You cannot expect one coordinated intake worker to cover your entire community or region. Coordinated intake is a shared community partnership.”

“How do you convey the message of the importance of initiating early prenatal care and help people find their way to risk-appropriate care and health care settings that are as comprehensive as possible.”

“For any central intake/care coordination model, it is important to understand what the community outreach looks like. Are they building real awareness at a community level and in particular, in communities that are harder to reach?”

LESSONS LEARNED FROM OTHER STATES

New Jersey, Baltimore, Maryland, Florida, and Ohio all have single point-of-entry and referral components to their care coordination models and these systems were highlighted in conversations with Illinois stakeholders. For this review, background information and system studies were analyzed and tailored discussion guides were developed for informational interviews with program leaders, staff members, and policymakers involved with each model.

CONNECTING NEW JERSEY¹³

Connecting New Jersey (CNJ) is a statewide centralized point-of-entry and referral system that connects pregnant people, fathers, and families with young children to care and services from the prenatal period through age five– and in some counties even through age eight. Each of New Jersey’s 21 counties has its own Connecting New Jersey “hub” and these hubs are administered through seven community organizations that serve as lead agencies, funded by the Department of Children and Families and the Department of Health.

Each Connecting New Jersey hub has four staff members:

Connecting New Jersey Specialist– The CNJ Specialist is the initial CNJ staff person with whom a family connects when referred. When New Jersey’s statewide central intake system was first developed, the CNJ Specialist was the sole referral staff person dedicated to each county hub. The CNJ Specialist is responsible for appropriate triaging within the CNJ hub.

Early Childhood Specialist– Early Childhood Specialists work with parents that have completed the Ages and Stages Questionnaire (ASQ) to help families interpret the results and connect with appropriate services. The Early Childhood Specialists handle 0-5 referrals and attend the Plans of Safe Care meetings with the Department of Children and Families.

Community Alignment Specialist– Community Alignment Specialists are a required position of the Family Connects UNSS model, and they provide outreach to community partners and providers.

Case Manager– Case Managers work with families that need more intensive support than a referral and can work with a family for up to three to six months.

What are the big goals?

In 2019, First Lady Tammy Murphy launched Nurture New Jersey to reduce maternal and infant mortality and morbidity, as well as ensure equity for New Jersey’s Black and Brown women. The goal of this multi-pronged, interagency initiative is to make New Jersey the safest place for women to give birth and raise a child and to eliminate maternal and infant health disparities. This plan recommended expanding the use and improving the utility of the Perinatal Risk Assessment¹⁴ and continuing to improve and transform Central Intake. Around the same time, Advocates for Children of New Jersey (ACNJ) convened leaders to develop an action plan to ensure that an additional 25% of low-income infants and toddlers in New Jersey– 27,000 young children– have access to high quality services by 2023.

History

New Jersey’s centralized single point-of-entry system, now called “Connecting New Jersey,” was launched 16 years ago as Central Intake by the Department of Children and Families to link families to home visiting programs. The state funded grantees and phased implementation across three to four counties at a time.

[13] Thank you to the ECCS Finance Workgroup for sharing their Universal Screening System State Profile notes that served as a key source for both this paper’s New Jersey and Florida profiles. These full state profiles can be found in the report, *Illinois Early Childhood Comprehensive System (ECCS): Health Integration 0-3 Program Grant Advisory Committee Recommendations* (2025).

[14] In 2019, New Jersey passed legislation to require providers to complete the Perinatal Risk Assessment for all Medicaid and uninsured patients.

By 2015, New Jersey had implemented central intake in all of its 21 counties. New Jersey leveraged funding from several federal grants, including their Maternal, Infant, and Early Childhood Home Visiting (MIECHV) funds, Early Childhood Comprehensive Systems (ECCS), Linking Actions for Unmet Needs in Children's Health (Launch), and Race to the Top– Early Learning Challenge (ELC) to support expansion of the hubs. Until around 2019, there was only one staff person in each county, and the county hub was a web-based system, with electronic perinatal risk assessments routed to each county hub based on zip code and town. In 2019, with receipt of the ECCS impact grant and PDG funds, each county added an Early Childhood Specialist and built out a parent-driven ASQ screen.

New Jersey became the second state in the country to establish a statewide universal newborn home visiting program, Family Connects, with legislation passed in 2021.¹⁵ As part of the Family Connects model, a Community Alignment Specialist has been added to each county hub to develop new partnerships and identify additional community resources for pregnant people and families. The Community Alignment Specialist position has bolstered CNJ's outreach and has played an essential role in developing relationships with community partners. As a CNJ leader explained,

"The community alignment specialists are connecting to other community agencies, they are connecting to the hospitals, they are connecting to OB/gyns, more than we were doing before, and they are also bringing those resources and connections back to our hubs, so that it is connected to the CNJ specialists and the other hub staff."

In 2022, New Jersey First Lady Tammy Murphy, introduced the state's central intake system as the rebranded "Connecting New Jersey." The rebrand emerged from a recommendation from New Jersey's *Nurture NJ Maternal and Infant Health Strategic Plan* to improve its single point-of-entry-referral system to address the state's maternal and infant health crisis.

Governor Murphy's FY 2023 budget included \$2.1 million to add case management capacity. Each county hub now has its own case manager who can work with pregnant people and families that need longer-term support -- up to three to six months. New Jersey's Family Connects program will continue to roll-out to all of New Jersey's counties by 2027.

Governance and State-led Coordination Between Hubs

Connecting New Jersey is jointly supported by the Department of Children and Families and the Department of Health-- both providing funding and support for hub staffing. The Department of Children and Families and the Department of Health also lead and work as a team on the CNJ database, which was created by an organization called Family Health Initiatives. Most lead agencies manage multiple county hubs-- up to five counties for one of the lead agencies. The State facilitates regular meetings and opportunities for the hubs to share best practices.

Scope and tailoring to best serve families

While the state outlines many of the core components of each hub, each CNJ hub is uniquely tailored to the communities it serves. All hubs provide a single point-of-entry for families to access referrals and information on services and providers that support pregnant people, infants, and young families, including obstetrical and prenatal providers, doulas, early care and education, behavioral health support, nutrition and housing supports, insurance, transportation, and substance use and addiction treatment. As noted by a CNJ leader:

"Even though CNJ is a system, all of our hubs are going to do things a bit differently, and you have to give them that leeway because every community is different. The way they are reaching out to families -- you really need to give them that leeway to do the work."

[15] Oregon was the first establishing its statewide UNSS program in 2019.

Screening and Referrals

New Jersey requires that all pregnant people enrolled in Medicaid receive a Perinatal Screening and Risk Assessment (PRA). The PRA is a standardized form administered by prenatal care providers to screen pregnant women for risks in three key areas: sociodemographic factors, medical risks, and economic and psychosocial factors.

New Jersey also utilizes a Community Health Screen (CHS), an abridged version of the PRA usually administered by community health workers and social service providers. The CHS can be administered to pregnant or parenting people. When a referral is warranted, the PRA and CHS are both sent to the state's single point of entry system called CNJ Link, which sends results to the appropriate CNJ hub.

"When we receive a referral in, we make three attempts at contact. The first is a text message explaining who we are and why we are calling. The second and third are phone calls—when we speak to a client, we determine what their needs are, and we explain what programs are available and figure out what will fit the client's needs best. It could be a home visiting program, community health workers, or case management."

The CNJ Link data system allows community partner programs to accept referrals and track information about a families' participation. Data from the CNJ Link system can be used to explore the timeliness of referrals and if a program's capacity is sufficient to meet demand.

The Department of Children and Families hosts quarterly Connecting New Jersey CQI meetings where information is shared, and a CNJ dashboard has been established where measures can be tracked. Johns Hopkins University is Connecting New Jersey's evaluator, and they help run the CNJ CQI meetings.

"We have CQI quarterly meetings, and we have our Partnerships for Families' meetings, which are really for all our frontline workers, our case managers, our community alignment specialists, our community health workers and our doulas. They all come to the quarterly meetings. We have made it a culture of its all learn, all teach."

Relationship with Family Connects

The Community Alignment function of New Jersey Family Connects is embedded within each of the CNJ hubs. Family Connects is expected to be fully implemented statewide by 2027. New Jersey stakeholders emphasized the symbiotic nature of Family Connects and Connecting New Jersey. The community alignment piece of Family Connects has been particularly impactful through the community alignment specialist's outreach work to develop relationships with community partners and educate providers.

"Our Community Alignment Specialists work directly with Family Connects New Jersey. And in that role, they connect to other community agencies, they connect to the hospitals, they connect to providers, and they are also bringing those resources and connections back to our hubs, so that it is connecting to the CNJ specialists and other hub staff."

Challenges and Lessons Learned from Stakeholder Interviews

New Jersey CNJ stakeholders noted that the system is constantly adapting to best engage families, community partners, and providers.¹⁶ Some challenges and lessons learned shared during stakeholder interviews include:

Anticipate the volume of referrals: As the volume of referrals has increased in the CNJ hubs, managing this additional volume has been challenging and having several CNJ hubs under one lead agency can assist with this increased volume as CNJ staff from one hub can assist with another hub.

Managing the duplication and timeliness of referrals: Duplicative referrals from multiple hospital systems can sometimes be a challenge. CNJ is also working on getting referrals in as early as possible in a birthing person's pregnancy.

Robustly train hub staff to be ready to receive intake information: The appropriate training of all hub staff positions is critical to successfully helping families and connecting them to needed services and supports. The State brings in trainings and other resources to make sure that CNJ hubs have what they need to support families in their communities.

Outreach and communications are key and can reduce stigma: The community alignment role, which was added to each CNJ hub as part of Family Connects, has enhanced outreach capacity to hospitals and providers and communicating the universality of the program can help reduce stigma.

Balance the prescriptive processes for each hub with flexibility to best serve each community: While each hub is staffed with the same four positions and the State developed guidelines for each hub to ensure consistency in operations, CNJ hubs engage local program staff and families to determine the best way to refer families to services and to ensure each hub's work best meets the needs of their community. The hub staff know each other and are available to share best practices and troubleshoot.

Systems building work takes time: The CNJ hubs have been developed over decades, with the system being enhanced as new funding sources became available and best practices discovered. A Zero to Three report on Connecting New Jersey notes that:

"Systems work takes time. It is important when working on a project of this scale to keep that in mind and expect to face hurdles along the way. New Jersey stakeholders said focusing on their ultimate goal helped them stick with the work when things got hard" (Zero to Three, 2019, pg. 5).

[16] Please see Appendix B for a table of challenges and lessons learned from synthesized interview notes from conversations with one Department of Children and Families staff member and three staff at two Connecting New Jersey lead agencies.

BALTIMORE'S B'MORE FOR HEALTHY BABIES

B'more for Healthy Babies (BHB) is an initiative that has lowered the infant mortality rate and cut by nearly half the Black-white racial disparity in infant mortality in Baltimore, Maryland. In 2009, Baltimore had one of the worst infant mortality rates in the country at 13.5 deaths per 1,000 live births, and Black babies were five times more likely to die than white babies. By 2019, Baltimore's infant mortality rate had decreased to 8.8 per 1,000 live births, with this drop primarily driven by a 7.1 decrease in the Black infant mortality rate. (Johnson & Thiesse, pgs. 4-6). While BHB's big goal is lowering the infant mortality rate and decreasing the racial disparity in infant mortality, the strategy recognizes all the factors that impact a baby's health and development and encompasses initiatives to address those areas that have the greatest impact.

BHB is a multi-disciplined health strategy led by the Baltimore City Health Department, in partnership with the Family League of Baltimore City and HealthCare Access Maryland (HCAM), which administers the model's central intake and referral component, which is called B'more Beginnings.¹⁷

Components of the B'more for Healthy Babies Strategy include:¹⁸

- B'more Beginnings– the centralized intake, outreach, and access to care system for pregnant people and infants
- Citywide Sleep Safe campaign to eliminate sleep-related deaths
- A unified evidence-based home visiting system
- U Choose initiative which educates young people on reproductive health
- Neighborhood outreach and education in the Upton/Druid Heights and Patterson Park North & East communities
- B'more Fit for Healthy Babies– a nutrition education and fitness initiative
- Aligned action by BHB partners on priority health areas
- Systemic improvements to city health care services
- Baby Basics Moms Clubs
- A provider portal

What is the big goal?

B'more for Healthy Babies' (BHB) big goal is lowering the infant mortality rate and eliminating the racial disparity in infant mortality in Baltimore City, Maryland. As BHB has developed and expanded, it encompasses trauma-informed and explicitly anti-racist initiatives to support health and well-being at all stages of a person's life course recognizing the interconnectedness of a community's health and the health of its infants. As explained by a BHB leader, "The infant mortality rate is a litmus test for a community's well-being."

History

In 2009, Baltimore's health commissioner wanted to take bold action to address the infant mortality crisis. The Baltimore City Health Department (BCHD) in partnership with the nonprofit Family League of Baltimore City and HealthCare Access Maryland, launched B'more for Healthy Babies. Both Maryland's governor and Baltimore's mayor similarly wanted to tackle this issue, and the convergence of these leaders' political alignment facilitated the launch of the initiative.

Commissioner Rebecca Dineen joined the BCHD to lead BHB and had deep experience working internationally with maternal and child health initiatives in extremely under-resourced communities. The Annie E. Casey Foundation also embedded Gena O'Keefe, a program officer with a public health background, to co-lead the initiative for several years.

[17] The Family League is a Baltimore City nonprofit and designated local management board that provided both staffing leadership and funding resources to BHB/ HCAM is a nonprofit organization that helps residents enroll in publicly funded health insurance, along with managing BHB's central intake, community outreach and serving as the single point-of-entry for Baltimore's home visiting system.

[18] This list is not exhaustive but highlights some of the primary components of this citywide strategy. See more at <https://www.healthybabiesbaltimore.com>

CareFirst BlueCross BlueShield, a nonprofit health care organization and leading insurer in the Baltimore region, made an initial commitment of \$3 million in funding to lead the initial BHB strategic planning efforts. This effort required examining and aligning federal, state, city, and foundation funds for maternal and child health initiatives. These private dollars were leveraged to secure an additional \$1 million in state funding—effectively a match to the CareFirst grant. This exploratory work required looking at the landscape of maternal and child health programs and initiatives and considering how they could be organized and funded under a shared vision. The 2009 Strategy to Improve Birth Outcomes in Baltimore City resulted from this planning work and served as the blueprint for BHB’s launch.

As Rebecca Dineen explained on a recent episode of the Johns Hopkins Bloomberg School of Public Health “Public Health on Call” podcast:

“What I found when I came to Baltimore and was asked to look at the issue of infant mortality, is that the work that was happening in Baltimore City was very programmatic. It wasn’t a big picture look. We had home visiting programs, we had WIC programs, we had adolescent reproductive health programs, lots of different funding streams to different community organizations, and it was coming from the state, and it was coming from the city, and it was pretty disorganized. And really good work was happening in each of those areas but not necessarily combined with a vision.”¹⁸

Consensus needed to be reached on a shared vision to shift the focus from isolated programs to a collaborating network of programs and services. This effort required building on programming that already existed and filling in gaps. A “basket of funds” approach was needed— the braiding and blending of public and private funding for a greater population level impact. As Rebecca Dineen explained:

“You look at how to put together all of the resources you have into one basket. They call it a ‘basket of funds’ approach and think about how to address the supply side of services. How do you organize the services that are available to everybody related to maternal and child health? And then you look at the demand side— how do you communicate about accessing services? How do you talk to residents— being scrappy and going door to door and talking to them about the work.”

One key initiative in BHB’s early years was transitioning all of Baltimore’s home visiting programs to evidence-based models and creating a unified home visiting system. In 2008, nine home visiting programs were operating in Baltimore but only one was implementing an evidence-based model. Baltimore transitioned to utilize two home visiting models— Nurse Family Partnership and Healthy Families America.

Prior to BHB, there was duplication in recruitment and programs did not always share data or maintain a centralized intake, evaluation, and referral system. BHB revised and standardized the process for connecting families with the home visiting model that best meets their needs and ensures that families who most need home visiting services are matched with them. Families with less acute risk factors are connected with appropriate services through the B’more Beginnings platform and outreach.

As the 2015 Pew Charitable Trust report, “Bringing Up Baltimore” emphasized:

“A central triage, or intake, and referral process is essential to ensuring that the most vulnerable families are served with the most intensive interventions and that more stable families receive an appropriate level of care. This process can help eliminate duplication of services and deliver the most targeted use of limited funds” (pg. 8).

[18] From Johns Hopkins Public Health on Call podcast: “B’more for Health Babies: A Look Back at 15 years of Infant mortality reduction in Baltimore (May 7, 2025).

Since its 2009 launch, BHB now includes over 150 partners that support BHB's shared vision and have adopted BHB's life course approach. As BHB's 5-Year Strategy Update for B'more for Healthy Babies explains:

"It requires a life course approach, one that understands infant survival is influenced not only by a mother's health in pregnancy, but also by the health of parents well before pregnancy, the community in which they lived, and the social and economic factors— particularly racism— that shapes their lives" (pg. 4).

HealthCare Access Maryland and BHB's Centralized Access System to Care: B'more Beginnings

HealthCare Access Maryland (HCAM) is the central triage and coordinating entity for BHB— the B'more Beginnings system. Since 1997, HCAM has served as Baltimore City's Medicaid administrative care coordinating unit, funded by the state to ensure Medicaid recipients have community support, access to resources, and reduced barriers to care.¹⁹ HCAM collaborates with managed care organizations and providers by, for example, helping to locate members who miss prenatal visits.

Because HCAM was already working in this space, the organization was well-poised to support BHB. The HCAM centralized intake function was bolstered and built upon HCAM's existing care coordination work. Pregnant people and families are referred to HCAM's B'more Beginnings system through four avenues:

- Maryland's Prenatal Risk Assessment (PRA) which is required to be offered by providers to all Medicaid clients at their first prenatal care visit. The PRA is currently transitioning to a digital form and is being linked to a client's electronic medical record.²⁰
- Maryland's Postpartum Infant & Maternal Referral (PIMR) which is offered to all infants, regardless of insurance status, by the birthing facility.
- Community-based partners
- Self-referrals

Over 60% of referrals come from providers and birthing hospitals. When HCAM's B'more Beginnings receives a referral, the team assesses the person's profile against a tiered hierarchy of risk factors - in addition to the PRA or PIMR- to match women with appropriate services. HCAM's B'more Beginnings 27-member outreach team includes community health workers, licensed social workers, and registered nurses who provide tailored support and connect families to care. Administrative staff process and receive the referrals while the outreach team engages directly with clients in the community— at emergency rooms, at Judy Centers— meeting pregnant people and new families where they are.²¹

In conversation with an HCAM leader, she stressed the importance of having outreach workers who reflect the community and speak the language of the families served, "we want to be a reflection of what our community looks like." The team works directly in communities to reach pregnant people and families, develop a relationship, and ensure families are connected to needed services, "it is through the experience and the relationships that we get to the next level with some of the benefits and services."

[19] Maryland has a statewide system of administrative care coordination units to help Medicaid enrollees understand their benefits and assist in accessing services.

[20] Maryland was awarded a HRSA Integrated Maternal Health Services grant to consolidate and coordinate the disparate components of the existing perinatal care coordination systems into an integrated model that can be used across Maryland. This project is digitizing both Maryland's PRA and PIMR statewide and creating a digital system that allows real time access to patient data to facilitate perinatal care coordination. A perinatal risk assessment working group, which includes public health, ACCU, MCO stakeholders and patients are looking at the best way to develop referral pathways that work for everyone and will increase birthing people's connections to services.

[21] Judy Centers are community-based organizations that connect families to education services and act as resource hubs. HCAM has team members at 5 Judy Centers across the city to follow up with pregnant people who have been difficult to reach through the centralized intake process.

Services that expectant mothers and families might be connected to include:

- Home visiting
- BHB group programs (including prenatal education, grief support and nutrition and fitness classes available through B'more Fit for Healthy Babies)
- Support services (WIC, mental health and substance abuse services, adolescent reproductive health services)
- Services to address social determinants of health (job training, housing, GED/literacy classes and others)
- Health care services

B'more Beginnings have shared testimonials from parents who have worked with the B'more Beginning guides:

*"She was incredibly understanding, patiently guiding me through everything, even with my kids running around in the background. No matter how many times I needed something repeated, she never showed irritation. Plus, she reassured me that whatever I shared was confidential and I could skip any question I wasn't comfortable with. I always felt like there was someone I could talk to, whether on the phone or at my door, creating a very comfortable space."*²²

Communications Campaign

Early in the planning phase, BHB awarded the Johns Hopkins Center for Communication Programs a contract for communications and marketing. Johns Hopkins global public health communications experience was integral to BHB's launch and success. As explained by BHB leadership:

"Having Johns Hopkins' public health communications and campaign expertise made it easier to bring people together -- it sent the message that this was a strategic, well-executed, encompassing initiative that all stakeholders should be a part of."

In one early campaign, Safe Sleep, Johns Hopkins partnered with coordinators at HCAM to educate expectant mothers, families and caregivers on the ABCDs of safe sleep (alone, back, crib, don't smoke). HCAM also delivered and assembled cribs while communicating their role in infant safety. Today, 100% of Baltimore birthing hospitals provide safe sleep education at discharge from labor and delivery, and in 2016, 565 cribs were provided to families (Johnson & Thiesse, pgs. 16-17).

Governance

The BHB collaborative leadership structure includes the Core Implementation Team (CIT), the Community Advisory Board (CAB), and a citywide Steering Committee. The CIT is made up of staff from each of the lead agencies– the Baltimore City Health Department, the Family League and HCAM. Community members who use or provide maternal and child health services serve on the CAB, and the Steering Committee, chaired by the Baltimore City Health Commissioner, includes funders and medical and public health leaders. The Steering Committee mobilizes resources so that the CIT and CAB have what they need to implement the BHB strategic plan.

[22] From the B'more Beginnings webpage at <https://www.healthybabiesbaltimore.com/bmorebeginnings>

Challenges and Lessons Learned

The impact of BHB has been well documented. For this report, four BHB leaders and team members were interviewed, and their reflections have been incorporated alongside published findings about BHB to highlight challenges and lessons learned below.

Map out and involve existing maternal child health programs and partners: It is critical that all maternal and child health stakeholders are included in the conversation. Community based organizations are often trusted partners in the community and the journey with partners is key— leaders do not want to burn trust. It is key to educate about the resources that exist already at the community level.

Robustly engage providers and recognize their key system role: The trust of and referrals from providers contribute to BHB's success. Providers understand the work of BHB and trust that if they refer a birthing person or family to BHB they will be well-served. As an HCAM leader emphasized, "providers really do have the lifeline to how BHB thrives."

Braid and blend funds and recognize that a private/public partnership of funders allows for more flexibility and increased funding stability: Braiding Medicaid and Title V dollars can allow for greater flexibility in funding the full scope of services needed for both care coordination and education. This requires strong accounting and the ability to carefully track dollars. Private dollars are necessary to support the work that is more challenging to publicly fund. As discussed in an Annie E. Casey Foundation report examining BHB's collaborative funding model:

"Totalling roughly 5% of the BHB budget, this private support has funded a range of things, including general infrastructure and management; robust outreach efforts to a wide range of health and social services providers, including doctors and home nurses who have helped share literature and other information; the communications campaigns about safe sleep; and various community engagement efforts that likely would not have been possible otherwise but have proven vital to the initiative's success" (Annie E. Casey Foundation, 2018, pg. 5).

Dedicate a skilled team to data: Access to data and good data practices are critical and will require a skilled and dedicated team. The data tells a story, and it sometimes takes the convergence of several data sources and points to understand that story. HCAM has a quarterly data share with BCHD and shares this robust data with funders. As the Abell Foundation's report explains:

"BHB leaders combine quantitative data with the lived experiences of mothers to make injustice visible and to drive decision-making."

"Teen pregnancy rates, prenatal care access, and hypertension are additional data points that BHB uses to create strategies that target the root cause of infant and maternal fatalities" (Johnson & Thiesse, pg. 27).

Funding is a challenge: The one-year grant cycle of state funding can prove challenging. It is difficult to strategically plan with this type of annual funding. As the report from the Annie E. Casey Foundation program explains:

"Long-term funding is often a critical challenge, and it's important to develop robust public-private partnerships to fill gaps and maximize impact, as well as a strong policy and advocacy strategy to ensure these funding streams are sustainable" (pg. 10-11).

FLORIDA HEALTHY START UNIVERSAL SCREENING AND THE CONNECT PROGRAM²³

In 1991, Florida became the first state in the country to require providers to offer a universal risk screening to every pregnant woman during her prenatal visit and to her newborn infant in the hospital, regardless of insurance status, as part of the Healthy Start Initiative. The enacting legislation also created local Healthy Start Coalitions, which serve as triaging “hubs” for these screens. Screens are routed to each client’s local coalition, which operates “Connect,” a centralized intake and referral system that connects pregnant people, infants, and families to home visiting and other services.

Healthy Start coalitions serve pregnant women, babies, and women with children under age three, regardless of immigrant or insurance status, if they live in the coalition’s jurisdiction. Thirty-two coalitions cover all 67 of Florida’s counties. Connect receives referrals from prenatal/infant screens, Medicaid, the Department of Children and Families, health plans, community referrals, and self-referrals. It assesses family needs and connects them to resources such as home visiting programs, WIC, food banks, housing assistance, and behavioral health services.

Coalitions are also home to additional home visiting models and other programs serving families (e.g. a program for fathers, behavioral health programming). As explained by Connect program staff:

“In Connect, we will refer women to different organizations, not just home visiting programs, we will refer to food banks, we will refer them to WIC, to the homeless trust, if they need help with eviction services. We will guide them and make that primary connection, and it is then the home visitor that will sit with a client and provide more of the intensive case management.”

What is the big goal?

The Healthy Start Initiative’s overarching goal is to improve maternal and infant health outcomes and support healthy child development. In 1990, Florida had an infant mortality rate of 9.7 infant deaths per 1,000 live births. The Florida Association of Healthy Start Coalition’s stated purpose is “To develop and support local systems of care to optimize the health of Florida mothers, pregnant women, babies, and families.”

History

In 1991, Florida became the first state to require that every pregnant woman and newborn be offered a universal risk screening regardless of insurance status as part of its Healthy Start initiative. The Florida Department of Health established this screening program and created community-based Healthy Start Coalitions to coordinate local systems of care and community-based resources. Changes to Florida’s Medicaid program shifted much of Healthy Start’s funding from State general revenue to Medicaid and required new contracting mechanisms. This led to the creation of the Healthy Start MomCare Network, which handles Healthy Start billing.

Since 1990, infant mortality rates have declined from 9.7 deaths per 1,000 live births to 6.0 deaths per 1,000 live births between 2017-2019. The Florida Prenatal Screen is predictive of preterm birth and low-birth weight. 48% of the women who had an adverse birth had a positive screen. Women with positive scores are 70% more likely to experience preterm birth or have a low-birth-weight infant.²⁴

[23] Thank you to the ECCS Finance Workgroup for sharing their Universal Screening System State Profile notes that served as a key source for both this paper’s New Jersey and Florida profiles. These full state profiles can be found in the report, “Illinois Early Childhood Comprehensive System (ECCS): Health Integration 0-3 Program Grant Advisory Committee Recommendations (2025).”

[24] Florida Prenatal and Infant Screen. Florida Healthy Start referencing data from the Florida Department of Public Health

Governance and State-led Coordination Between Hubs

Multiple entities are involved in administering the Healthy Start initiative. At the state level, Florida's Healthy Start initiative is owned and funded by the Department of Public Health, in coordination with the Agency for Health Care Administration (AHCA), Florida's Medicaid agency. The Florida Association of Healthy Start Coalitions (FAHSC) manages contracts with AHCA, coordinates with 32 local Healthy Start Coalitions, and oversees braided funding and contracts.

Scope

In addition to the Connect coordinated intake & referral system, the local Healthy Start Coalitions also manage and administer:

- The Fetal and Infant Mortality Review regions
- T.E.A.M. DAD: a program for new fathers that offers education, training and support to help men become responsible, engaged and empowered fathers
- Healthy Start home visiting (distinct from the federal Healthy Start program)
- 16 local MIECHV-funded programs
- The G.R.O.W. Doula model
- Florida's ECCS Healthy Integration Prenatal to Three Program

Screening and Referrals

Florida statute requires that all pregnant women be offered the Florida Prenatal Screen and that all parents or guardians of infants are offered the Florida Infant Screen. Florida's universal screens are Florida Department of Public Health forms and include both a prenatal and postnatal risk screen, as described below.

- Prenatal risk screen: Offered to all pregnant women at their first or consequent prenatal visit and collected by the Department of Public Health, which is transitioning from paper to electronic format,
- Postnatal risk screen: Offered to parents or guardians before leaving the delivery facility and completed electronically, along with the birth certificate.

The screens are voluntary and research-based, using a brief questionnaire to identify pregnant women and infants at risk for poor birth outcomes by assigning points to various risk factors. If a screen meets the threshold of "high-risk," the information is sent to the local Healthy Start Coalition Connect team, who contacts the mother, asks permission to conduct an intake assessment, and assigns additional points for risk factors identified during this assessment. Pregnant people and infants can also get connected to services from Medicaid, health plans, and community partners like WIC or Catholic Charities.

The steps for the Connect coordinated intake & referral process include:

- Reviewing the mother's (or infant's) risk factors
- Connecting prenatal medical care and WIC
- Addressing barriers to accessing care
- Assessing social determinants of health and other needs and connect with community resources
- Encouraging enrollment in a home visiting program
- Informing of resources available through the health plan if the mother does not want home visiting²⁵

In the latest data available (2023-2024), the prenatal screening rate hovered at around 68% (down from over 90% a decade ago), and the infant screen rate is at approximately 95%. The Association of Healthy Start Coalitions hopes that the prenatal screen transition from paper to electronic will increase referrals from prenatal providers.

[25] From the Florida Association of Healthy Start Coalitions slide deck entitled *Coordinated Intake and Referral*

Challenges and Lessons Learned

The Healthy Start Coalition of Miami-Dade noted that one of their most significant challenges is building trust, as some clients are fearful of sharing information and receiving assistance. Making sure the Coalition is visible, trusted and known in the community is critical.

An additional challenge is that the prenatal screen is still paper-based, even though it is currently being upgraded to an electronic format. Because of administrative challenges, the prenatal screening rates have hovered between 67% and 75%, while the infant screening rate is at approximately 95%. Other challenges noted by the ECCS Finance Workgroup from their interview with the Florida Association of Healthy Start Coalitions include:

Data System Limitations: The current data system has reporting limitations and struggles to meet the program's growing needs.

Coordination Challenges: Home visiting programs don't always document in the Well Family System, leading to potential gaps in tracking referrals and enrollments.

Prenatal Screening Rates: Since COVID-19, prenatal screening rates have declined from 75% to about 67%.

Service Deserts: Rural areas in particular face gaps in available services.

Cross-System Coordination: Achieving seamless coordination between CI&R/CONNECT and various home visiting programs requires ongoing attention.

Electronic Transition: The transition from paper-based prenatal screening to electronic screening presents implementation challenges.

Closed-Loop Referrals: The lack of a standardized closed-loop referral system for community resources creates inefficiencies.

OHIO HELP ME GROW CENTRAL INTAKE AND REFERRAL SYSTEM

Ohio's Help Me Grow program is a statewide system that provides a single point-of-entry for birthing people and families to connect to community resources, home visiting, early intervention, developmental screenings, and universal newborn supports and services. Help Me Grow provides a single point-of-entry and referral system for home visiting and all community program partners, which gathers information from clients, refers clients to partners, and directly connects them to needed services. Certain types of referrals are automatic, such as when clients have certain health risk factors.

What are the big goals?

Ohio enacted its Help Me Grow program and launched it in 2018 with these four goals:

1. Improve maternal and child health
2. Prevent child abuse and neglect
3. Encourage positive parenting
4. Promote child development and school readiness

History and Governance

The Help Me Grow system began in 2018 as a county system, with each county having their own Help Me Grow “hub.” Bright Beginnings is the statewide management contractor for the system. Ohio has called its statewide county-based system “Help Me Grow” since its inception, but just this year, it joined the national Help Me Grow model organization and has transitioned to a regional model framework.²⁶ As explained in an interview with Help Me Grow leaders:

“Our regional approach emphasizes the importance of developing relationships with community providers. Regional subcontracts build trust within communities that have different needs (rural, urban, etc.).”

The State of Ohio administrative home for Help Me Grow is Ohio’s new Department of Children & Youth (DCY), which was created in 2023 and became fully operational in 2025. Prior to the creation of DCY, Help Me Grow was jointly administered by Ohio’s Department of Health, which was the state’s administrative home for Ohio’s home visiting programs, and the Department of Disabilities, which houses Early Intervention.

Screening and Referrals

Referrals into the Help Me Grow Central Intake and Referral system (CIR) come from prenatal providers, other medical providers, public children’s services agencies, the electronic pregnancy risk assessment form, WIC, early care and education providers, Early Intervention providers, home visiting providers, community health workers, neighborhood navigators, and managed care providers. Individuals can also self-refer to the Help Me Grow CIR. Certain referrals to Help Me Grow are automatic.²⁷ The website referral form is Help Me Grow’s largest referral source. From these referrals, CIR staff connect clients to the following types of programs and resources:

- Newborn home visiting: Family Connects is currently available in eleven counties in Ohio.
- Early Intervention: CIR specialists work directly with families to connect them to Early Intervention services.
- Ongoing home visiting: Nurse-Family Partnership, Healthy Families American, and Parents as Teachers are Ohio’s evidence-based home visiting models to which CIR connects families.
- Developmental Screenings: The Help Me Grow platform connects families to the Ages and Stages Questionnaire (ASQ).
- Community resources: Help Me Grow includes a community resources directory which has local lists of community resources, including maternal and child health and early education resources, services to address the social determinants of health, career development, and behavioral and substance use treatment resources.

Help Me Grow CIR also partners with Pathways HUBS across the state for families who choose not to participate or are not eligible for home visiting programs. Pathways is a paid for success model where Pathways are assigned to clients for different health challenges, and positive outcomes are incentivized with pay. As a Pathways HUB client, a mother is assigned a community health worker who provides wrap-around services and supports.

Relationship with Family Connects

Help Me Grow works with each Family Connects region on outreach. Ohio has Family and Children First Councils in each county that serve as the Family Connects Community Advisory Board (CABs) to identify gaps in local services and resources, which Help Me Grow then works to address in all counties. Since Bright Beginnings manages the Community Resource Directory, they manage the follow-up on identifying resources, including case conferences. Families can sign-up for Family Connects through the Help Me Grow website. Family Connects has currently been rolled-out in eleven counties in Ohio.

[26] Connecting New Jersey is also an affiliate of the Help Me Grow model national organization.

[27] For example, children with high levels of lead in their blood are automatically referred

Biggest Challenges

One challenge for the Help Me Grow system is managing competition as programs are gradually added into the statewide single point-of-entry system. To address this challenge, Ohio's Help Me Grow system emphasizes the importance of building relationships across agencies to ensure all of a community's needs are being met through the collective efforts of a community's providers. Coordinating data systems from different agencies and data sharing has also proven challenging.

RECOMMENDATIONS: WHERE DO WE GO FROM HERE?

There is a clear benefit to making the system of maternal and child health programs easier for families to identify and navigate. Investing in care coordination and a single point-of-entry system can improve health outcomes for birthing people and infants but requires considerable investments of money, time, and expertise from a wide variety of partners. These synthesized lessons and perspectives gathered from the literature review, interviews with experts in Illinois, and review of other single point-of-entry, care coordination systems, including interviews with those leading these systems, have informed these recommendations.

1. BUILD CONSENSUS AROUND THE BIG GOAL AND DEFINE THE SCOPE

To develop an effective, accessible care coordination system for birthing people and families, Illinois leaders must first articulate the big goal of the single point-of-entry system as it relates to outcomes for communities and build consensus around that goal. The question, "What problem are we trying to solve?" should be answered. Convening leaders, providers and community members in the maternal child health and early childhood policy and community ecosystems to reach consensus on a shared vision, commitment and goal is a necessary first step in the development of a statewide system for care coordination.

After reaching consensus on a shared vision, stakeholders must clearly define the scope of the perinatal care coordination system, including the timeframe of engagement with families and the scope of programs and community-based organizations with whom the system will connect families.²⁸ Will the hubs connect families to resources through a child's first birthday or through age three or age five, depending on the timeframe upon which certain home visiting programs engage with families?

Illinois should also explicitly define the vocabulary used to describe its perinatal care coordination system. UNSS provides perinatal care coordination, and at the same time, in the states we examined, the UNSS model is embedded within the larger care coordination system. Language used in planning and implementing these systems should clearly delineate the overarching care coordination system and the UNSS model nested within the single point-of-entry care coordination system.

2. DEVELOP A UNIVERSAL SYSTEM AND TARGETED SUPPORTS

As Illinois works toward the expansion of a voluntary, universal newborn support system statewide, any effort to establish a single point-of-entry system should also be statewide, even if scaled to that reach over time. This program should provide more intensive interventions and supports to address persistent disparities in targeted communities and populations, informed by hyper local community alignment boards. This might look like a hybrid model that combines components of Connecting New Jersey and B'more for Healthy Babies— a universally accessible care coordination platform and a corresponding initiative to provide grassroots neighborhood outreach and work with communities experiencing the greatest maternal and child health disparities. In Baltimore City, two communities, Upton/Druid Heights and Patterson Park N & E had among the highest infant mortality rates in Baltimore City,

[28] While New Jersey's hubs generally target families for programs and services prenatally through age five, some hubs connect to resources through age eight— it differs slightly from hub to hub depending on each community's locally available programs. While Illinois could similarly differentiate between "hubs" based on local programming, it will still be critical to consider the target age range and scope.

and after 13 years of investment and collaborative efforts, infant mortality rates declined by 60% and 73% respectively (Johnson & Thiesse, 2023, pg. 21).

3. IDENTIFY AND EMPOWER CARE COORDINATION SYSTEM CHAMPIONS AND BUILD A COLLABORATIVE INTERAGENCY GOVERNANCE STRUCTURE

Building a statewide care coordination system will require interagency leadership and coordination, with champions leading the initiative from each of the following offices and agencies:

- Office of the Governor
- Department of Human Services, Division of Family and Community Services, Bureau of Maternal and Child Health
- Department of Human Services, Division of Early Childhood
- Department of Public Health
- Department of Healthcare and Family Services
- Department of Children and Family Services
- Department of Early Childhood

While the development and continued implementation of a care coordination system will require a robust interagency governance structure, possibly building on the Interagency Maternal Child Health Working Group, one agency should be responsible for leading the work and serving as the administrative home. The State agency administrative home should align with the selected UNSS administrative home, with a strong interagency governance framework.

The governing body of the care coordination single point-of-entry system should also include other stakeholders and funders with a demonstrated history of providing or advocating for evidence-based, community-informed maternal and child health programs, as well as all funders contributing to this partnership. These critical partners will help provide a statewide perspective and technical assistance.

Local hubs, through community alignment boards, should identify hyper local partners that are engaged regularly in providing supports and services to pregnant and parenting people and children. As UNSS expands statewide, opportunities to use community alignment boards for both purposes should be explored. Further, local public health departments should be engaged, at a minimum, in their hub and managed care organizations should be engaged in any hub where they have members.

4. BUILD UPON EXISTING SYSTEMS, INFRASTRUCTURE, AND COMMUNITY-BASED PARTNERS

Developing a statewide care coordination system requires entities to serve as the single point-of-entry triage hub for coordination and connection to services. Illinois should build on local strengths and existing infrastructure and partnerships and take the time upfront to assess current infrastructure which could be bolstered. In New Jersey, these hubs are the Connecting New Jersey county hubs, in Florida these are the local Healthy Start coalitions, B'more for Healthy Babies utilizes HealthCare Access Maryland as the triage, single point-of-entry entity, and Ohio's Help Me Grow program has organized with Bright Beginnings to create a central intake system set-up into regions with local subcontractors assisting with the central intake and connection to resources.

As part of the infrastructure investment to create a framework of care coordination, investments will also need to be made in local community-based organizations that are already doing on the ground work to assist in building their capacity for increased referral demands. Families will need to be engaged to co-guide this program development and implementation.

As Illinois considers a framework for a universal newborn support system, and the development of statewide care coordination, assessing, aligning and building upon Illinois' existing maternal and child health and early childhood systems will be key. Existing networks and programs, outlined below, provide infrastructure that could be leveraged for this system. Once a goal has been

established, the governing body should consider whether it is appropriate and feasible to leverage one or more of these programs and whether consolidation or reorganizing of State agency led programs would be useful.

SYSTEM/NETWORK	PURPOSE/MISSION	ADMINISTRATIVE HOME
MIECHV Coordinated Intake includes 8 traditional MIECHV funded locations, 1 Custom Partner-Connect Chicago Home Visiting facilitated by Lurie, and 1 State funded CI-Near North ²⁹	Coordinated Intake is a collaborative process that provides families with a single point-of-entry for home visiting programs within a community. Most MIECHV CI sites have both a Coordinated Intake Supervisor and a Coordinated Intake Worker	Illinois Department of Human Services, Division of Early Childhood, Bureau of Home Visiting (IDHS-DEC HV)
All Our Kids Networks (AOK) - 11 AOK Networks statewide– they also utilize IRIS	Community-based collaborations engaging a diverse group of people who care about the health and well-being of expecting parents and children birth to 5 and their parents/caregivers.	IDHS-DEC
IRIS (Integrated Referral and Intake System) pilot. 4 regions (DuPage County Health, Regional Office of Education 47, SIU Medicine Dept of Pediatrics, and Brightpoint in the Madison and St. Claire counties)	A Coordinated Intake for Home Visiting Collaboratives Project provided an opportunity for four community collaborations across the state to implement IRIS and develop workflows that meet the needs of home visiting programs in their communities.	Governor's Office of Early Childhood Development when launched in 2021
Birth to Five Regional Councils	The Birth to Five Illinois Regional Community System is built upon the ISBE Regional Offices of Education statewide structure but operates independently. Each Region has its own Family Council and Action Council to guide the State informing policy around birth-to-five programs.	Illinois State Board of Education in collaboration with IDHS-DEC
Family Connects Community Alignment Boards (CABs) Chicago, Peoria, Stephenson County, and Winnebago County all have implemented the Family Connects UNSS model.	A community alignment board is a required component of the Family Connects model. Purpose of the CAB: Align resources relevant to families. Find solutions to address community needs. Listen to feedback and updates from community stakeholders Disseminate information from Family Connects to community stakeholders.	Each Family Connects community has its own lead agency– e.g. the Chicago Department of Public Health administers Family Connects Chicago. Due to its size, Chicago has multiple regional CABs.
Regional Offices of Education (ROE)	ROEs serve as intermediaries between ISBE and local school districts.	Illinois State Board of Education (ISBE)

[29] Rush also has a coordinated intake program known as the BRIDGES system of care initiative. They support a coordinated intake referral system with a BRIDGES navigator. Rush participates in MIECHV coordinated intake workgroups.

SYSTEM/NETWORK	PURPOSE/MISSION	ADMINISTRATIVE HOME
Child Care Resource and Referral Agencies (CCR & R) – 16 community-based organizations statewide	CCR & R is comprised of community-based organizations funded to provide services and supports to families, providers, and communities across all 102 counties.	IDHS-DEC
Illinois Perinatal Quality Collaborative	A statewide network of perinatal clinicians, nurses, hospitals, patients, public health leaders and policymakers that aims to equitably improve outcomes and reduce disparities for mothers and babies.	Illinois Department of Public Health and University of Illinois Chicago
Illinois Regional Perinatal Care System	Illinois has 10 regional administrative perinatal centers that supervise all obstetric hospitals in the region.	Illinois Department of Public Health
Child and Family Connection Offices (CFC) and Local Interagency Councils (LIC) – 25 CFCs throughout Illinois	The CFCs are the regional intake agencies for the Early Intervention program which supports families with children ages zero to three who have developmental delays or disabilities	IDHS-DEC

Children’s Behavioral Health Beacon System

In February 2023, Illinois released its, “Blueprint for Transformation: A Vision for Improved Behavioral Healthcare for Illinois Children.” The Children’s Behavioral Health Transformation Initiative (CBHTI) is a collaborative initiative of six Illinois agencies, with support from Chapin Hall at the University of Chicago. An essential component of this initiative was the creation of BEACON (Behavioral Healthcare and Ongoing Navigation), which is a centralized intake and referral system that connects families to behavioral health resources for their children.

The Illinois Department of Healthcare and Family Services, the Department of Human Services, the Department of Public Health, and the Department of Children and Family Services are four of the six agencies involved in the initiative and the State can gather lessons learned that might translate to a statewide perinatal care coordination system.

5. COMPLEMENT AND INTEGRATE WITH UNSS

New Jersey has developed a universal newborn support system (UNSS) that nests Family Connects within an existing and overarching care coordination single point-of-entry system. When exploring, planning for, and building such a statewide system in Illinois, it will be critical to differentiate between this larger perinatal care coordination system and the UNSS model, such as Family Connects or Baby TALK, which is ideally embedded within the system and integrating its UNSS community alignment work with existing community partnership development and outreach.

6. DEVELOP ROBUST AND ONGOING COMMUNICATIONS AND MARKETING

An expertly driven and developed communications strategy and campaign is critical to a care coordination initiative's development and continued success. Effective communication builds trust, raises awareness, and contributes to stakeholder buy-in and to a shared vision. In addition, language matters. The term "central" or "centralized" intake can have negative connotations. When bolstering and launching their expanded care coordination system, New Jersey rebranded their central intake system "Connecting New Jersey" and Baltimore's BHB has renamed its central intake platform "B'more Beginnings." In creating this system, Illinois should contract communications and marketing professionals in the planning phase to develop branding and marketing tools, with ongoing support for priorities identified by local hubs or alignment boards.

7. ENGAGE HEALTH CARE PROVIDERS FROM THE START

Continual, robust outreach to providers to build trust in the system is a key piece of a centralized access care coordination system. It is important to get feedback from providers to understand how referring to care coordination fits within a providers' clinical space, so it is seamless, and providers feel like a patient does better working with the care coordination system than not. Outreach with providers will be bolstered through the community alignment board and role of the UNSS program. New Jersey noted that the addition of the community alignment specialist at each hub, as part of the Family Connects implementation, has significantly increased outreach and engagement with hospitals and other health care providers.

8. HONOR THE LIVED EXPERIENCE OF BIRTHING PEOPLE AND FAMILIES

The experiences of expectant mothers and families should be honored, and all aspects of the program design should embed a trauma-informed, anti-racist approach. As birthing people, families and communities build trust in the system, a care coordination system can reach families who have been previously disconnected from health care systems or are experiencing social isolation. Stress and social isolation can impact both maternal and infant health outcomes, and ensuring pregnant people and families feel socially connected, cared for and supported is an integral component of a perinatal care coordination system.

Relationship building and honoring the lived experience of expectant mothers is a key component of the BHB initiative:

"The trust that BHB builds with moms creates a foundation that ensure current participants will encourage their friends and family to connect with BHB early in their pregnancies. . . With a network of trusted BHB messengers consisting of paid staff and informal mom ambassadors, BHB has cultivated an environment where everyone can feel supported in their journey, while helping more moms connect to BHB services and support"
(Johnson & Thiesse, 2023, pg. 28).

This outreach and support should include non-parental caregivers, along with intentional engagement and support for fathers.

9. PLAN FOR THREATS AND ADDRESS BARRIERS

Medicaid and SNAP cuts

Illinois is projected to lose billions of dollars in federal funding due to cuts to both Medicaid and SNAP enacted in the so-called "One Big Beautiful Bill Act" signed into law in July of 2025.³⁰ In addition to the loss of federal dollars, at least 330,000 Illinoisans are projected to lose their Medicaid coverage or 11% of current Medicaid enrollees. The cuts to Medicaid will be compounded by changes

[30] Manatt projects that Illinois will face a loss of \$51 *billion* in Medicaid expenditures over the next decade and maintaining existing SNAP benefits could cost the state over \$800 million annually. IDHFS's internal projections show the state will face at least \$26 billion in federal funding over the next decade (Medicaid Advisory Committee, August 1, 2025).

to the ACA Marketplace that make coverage more expensive. Given the scale of these changes, aligning and coordinating programs across the maternal child health landscape will help ensure dollars are being utilized effectively and efficiently.

Need to build trust in current political climate

Building trust and working with existing community partners who have trust within the community will be essential to pregnant people and families feeling comfortable engaging with a statewide perinatal care coordination system. The targeting of immigrant communities and threatening rhetoric has created a fear and distrust in sharing personal information with government agencies. A recent KFF Survey of Immigrants found that worries about detention and deportation have risen among all immigrants, including those who are naturalized citizens and those who are lawfully present (Schumacher et al., 2025).

As one Illinois stakeholder noted:

“Now is a very vulnerable time. Are you going to trust and disclose to someone if you are not sure that person is going to do something helpful with the information that you are about to disclose?”

Stigma and fear in behavioral health and substance use treatment

Substance use disorder is the leading cause of maternal mortality in Illinois, and yet, pregnant people with substance use disorders are less likely to seek treatment or report substance use due to fear of criminalization and judgment (I-PROMOTE-IL, 2023). Destigmatizing the need for substance use and behavioral health services is a significant barrier to pregnant people getting treatment and adversely impacts maternal and infant health outcomes.

Last year, Illinois passed the Family Recovery Plans Implementation Task Force Act, which creates a task force to develop model family recovery plans, or plans of safe care, for helping infants exposed to substances during pregnancy. The goal of family recovery plans is to reduce harms, support at-risk new and expecting mothers, and to keep families together. The Act also amended the Juvenile Court Act to remove positive toxicology at birth as a basis for a finding of unfitness for terminating parental rights and charged the task force with identifying state statutes which must change in order to support pregnant people and substance exposed infants.

ISSUES FOR FURTHER CONSIDERATION

In addition to these recommendations, the following are issues that merit further consideration in exploring the development of a statewide perinatal care coordination system:

Addressing provider/services shortages – maternity care deserts: Illinois’ communities are not equally resourced when it comes to maternal health care. A 2023 report by the March of Dimes found that in Illinois, 34.3 percent of counties are defined as maternity care deserts and 13.7 percent of birthing people receive no or inadequate prenatal care.

Leveraging Community Health Workers: HFS is working on a State Plan Amendment for the Medicaid reimbursement for covered services provided by certified Community Health Workers. Community Health Workers play screening and navigation roles in the Connecting New Jersey system and represent many of the team members for Baltimore’s B’more Beginnings outreach and connection to care.

Engagement with managed care organizations: While interviewing managed care organizations was not within the scope of this project, they will be an essential partner in the development of a perinatal care coordination system.

continued on next page.

Prenatal risk assessment: The prenatal/perinatal risk assessment is required for Medicaid and uninsured populations in New Jersey and Maryland and is required to be universally offered in Florida. The use of prenatal risk assessments and how they can be referred into a coordinated intake system needs to be further explored. Maryland is currently developing both their prenatal risk and infant screens into electronic forms as part of its Integrated Health Services Project and developing referral pathways for these screens.³¹ State leaders should consider needed legislative action to mandate a perinatal/prenatal risk assessment to increase the number of referrals reaching the single point-of-entry system.

Active ingredients of a model: In the literature examining the effectiveness of home visiting, researchers have found that identifying the precise “active ingredients” in a home visiting model is necessary to increasing a model’s effectiveness (Supplee, 2019). Similarly, Illinois can consider the different “ingredients” in a universal care coordination system to make sure the active ingredient components are included to have the greatest impact on the shared goal Illinois sets out to achieve. Throughout the interviews for this report, the importance of relationships and building trust came up repeatedly, as a critical piece of the care coordination puzzle.

Data sharing and technology issues: The scope of this report did not allow for an in-depth examination of data sharing and related technology infrastructure requirements, but it is a large and critical piece of any care coordination system.

CONCLUSION

“As we face this budget uncertainty, we all need to be talking to one another. We all have to be thoughtful about funding. How do we create an ecosystem that does not follow the same patterns that seem to plague Illinois where we have the desire to do good work but tend to do it in a fragmented way. How do we try to be more coordinated in our work.”

A thoughtfully and intentionally designed care coordination model can get more birthing people and families connected to the care they need and reduce maternal and infant health disparities. In light of unprecedented federal funding cuts, it is critical to ensure that public funding to support birthing people and families is part of a larger vision and system to assure programs are non-duplicative and that families can easily connect to the existing resources available to maximize impact.

Developing a statewide care coordination system will ideally build on, bolster and connect existing programs, systems and investments, while simultaneously addressing both barriers to care and gaps in care. While such a system could serve Illinoisans universally, Illinois will need to consider if communities grappling with the highest maternal and infant morbidity and mortality disparities might need more intensive, locally-driven supports.

Illinois has made incredible investments in both maternal and childhood and early childhood systems, and coming together under a shared vision and goal will be the key next step, as Illinois moves forward in considering a statewide perinatal care coordination system.

[31] See more in the B’more for Healthy Babies and Maryland section of this report.

APPENDIX A

Illinois Stakeholder notes organized by themes

Interviews from late April-June 2025 with 14 Illinois stakeholders

“While it is good to know and to have some idea about the things that you need, at the same time, if you wait until you have all those things in place before you start, you will never start anything!”

“Alignment. There must be alignment between people working on this in the community and philanthropy and the state. There has been a lot of desire to bring this forth, but it is not happening in a way that is coordinated.”

THEMES	ILLUSTRATIVE QUOTES
Identifying the problem that we want to solve	<i>“We really need to look at the question of what do we want and why?”</i> <i>“What is the why behind it?”</i> <i>“The birth is important, postpartum is important, but if prenatal care is the key piece, how are you getting women into prenatal care.”</i> <i>“A lot of times the impetus, and even in Illinois with all the programs that exist, the focus is really on baby.”</i> <i>“We need to ask the question of what we are trying to address—what is the big goal.”</i> <i>“What are you trying to solve for and what do you need. Are you trying to address chronic disease in pregnancy? Substance use? Mental/behavioral health? Social determinants of health?”</i> <i>“What are we assessing for? This will influence the data that will go in. Is it assessing for medical? Social determinants of health? What is the goal and then you can build out. What are we trying to assess, what data do we need, who assesses, and then where do folks go.”</i> <i>“I love the idea of having a front door that will get you health insurance, and a doula, and make sure you get into a medical home if you don’t have a medical home, and making sure you get into home visiting that may start in the prenatal period—everything else you need in your pregnancy through the first year postpartum.”</i> <i>“We all need to agree to agree on whatever piece of the pie we are going to chomp at. But we will really need a backbone organization and a shared agenda.”</i> <i>“If our shared agenda is coordinated care, what are some of the measurable shared outcomes we want to see come from this shared agenda? And how can we have this continuous communication where we can be sure that all hands are on deck and that we understand who is leading here and who is leading somewhere else.”</i>
Challenge of connecting to services prenatally versus postnatally	<i>“It is easy enough to connect with families once the baby is born, but more challenging looking at connecting women to prenatal care.”</i> <i>“The really sticky piece is how you get women into prenatal care.”</i> <i>“The outcomes you are really looking at are improving outcomes for baby, because it is really hard to get mom in at a time that makes sense, unless you get all the prenatal care providers involved.”</i> <i>“We have heard from community that you really need to find people prenatally, but there is not an easy way of doing that.”</i> <i>“If you go to the hospital, you get most folks when the baby is born, but there is not the same pathway—point-of-entry—for pregnant people.”</i> <i>“The hardest part is how do you find those people who are not getting any prenatal care?”</i>

Challenge of connecting to services prenatally versus postnatally (continued)

"We really want home visiting enrollment to happen prenatally—when we think about making the greatest impact by having families enrolled earlier. Then we can refer them to Family Connects and then back to higher intensity home visiting."

"Downstate, in rural places, the health departments serve as a place where people can get free pregnancy tests, so that connects us."

"In the city, we have FQHCs who also have some of these wrap-around services. The history of our provider network is really strong and have reasons why they connect with people prenatally."

"It is always such a challenge connecting people prenatally. If we could just get conversations in place where OB providers can refer, but we have a lot of people who are not getting prenatal care until they get engaged with navigation and so that doesn't solve that problem."

"Oftentimes, the WIC worker or the case manager might be the first person to say, hey, let's get you connected with an OB provider. To me, that is probably the gap that we have yet to solve. How do we solve the piece if they are not receiving prenatal care??"

"We have always had this challenge. We always have this subset of the population that doesn't get WIC, doesn't get Medicaid, doesn't get services until the third trimester or even during labor. There are many reasons—people who are fearful of the system, domestic violence issues, is someone preventing them from getting services? This is the group that we would probably see the most cost savings from at a very high level if we could figure out how to engage with them sooner."

"What worries me is the people that we don't see. For the last thirty years, we are spending a ton of time with the people that come into see us, we spend tons of time with them, but I am worried about the people that don't come."

"Trying to have a relationship with doctors in the community to help them connect with those families that need more support early on is what we really should be focused on."

"From a system-based perspective, we recognize that it is challenging to start in pregnancy, so that is where a lot of the work would have to take place."

"I think you have to go outside of the clinical building to get people engaged and that is where it is really hard to know how to find people, so we have to use community-based partners who are truly not connected to the health system."

"We need to meet people where they are, so where are pregnant people when they are first getting pregnant. That is where a lot of effort can get people in early. It is not just getting people in early, it is getting people in at all. I think emergency departments, pharmacies—partner with pharmacies where people are getting pregnancy tests."

"We tend to do better on the postpartum side because we can find the new mom, because 98% of births occur in a birth center or hospital, and it is a way of locating someone. On the prenatal side, it is a lot harder because there is not one universal place where everyone shows up."

"If there was a simple risk assessment that the provider and birthing person could fill out together, then you could go through it together and see the programs a person is eligible for. We could make this happen."

Role of community health workers/navigators connecting pregnant people to care

"One important way that community health workers can come in is they can connect pregnant women to prenatal care."

"Community health workers can try and find people who they suspect are pregnant—there are organizations where community health workers are knocking on doors, doing outreach, and trying to connect people to prenatal care."

"If navigators help families connect with some of their needs prenatally, the Family Connects visit itself might be less intensive because some of that might just be following up. We are going upstream during these months of pregnancy—that is really the goal."

Importance of upstream care and appropriate care

“How do we go upstream to someone who just found out they are pregnant and early enough for interventions?”

“I would argue that getting women into pregnancy healthier is actually what is most needed. When you look at maternal morbidity and mortality data, a lot of times it is chronic disease that’s impacting, or substance use and mental health that is not addressed.”

“We know if we really want to move the needle on infant and maternal mortality and morbidity that getting people into early and risk appropriate prenatal care is key.”

“It is not just about initiating prenatal care as early as possible, it is about accessing care in an appropriate setting to treat any underlying health conditions a person might have, because those are the individuals with the worst outcomes.”

“Maternal child health care and interventions will be most felt if we move upstream into pregnancy rather than starting when a baby is born.”

Amazing work happening but sometimes siloed—importance of collaboration, coordination and relationship building

“I think there are already a lot of good things happening, but they are not connected, or their scope is so small— these efforts could help with what needs to happen going forward.”

“There is this amazing and interesting work happening to connect individuals to care. There needs to be more sharing and learning happening.”

“In the ILPQC work, we are making intentional efforts to get the birthing hospital teams to know what is happening in the communities. People in the community assume, of course that everyone in the community knows we are doing this work. But the hospitals really don’t know of all the resources in their areas— we need to let them know of the work happening at the health departments, FQHCs, other community-based organizations.”

“We all need to be more intentional in forging relationships and helping connect.”

“We have all these initiatives, task forces, locally funded and state funded initiatives. We have so much great work taking place in Illinois, but how does someone know what services exist? If someone moves, how do they know what services are available?”

“We have had many, many programs in Illinois but there is not really a good way to ensure that people get the programs that they need. Some women get no programs, and some women get exposed to multiple programs.”

“We do have mechanisms to help people get connected to care/services, but we tend to think really siloed within the public health system. We need to think about how we interface with other programs/mechanisms in the state.”

“As we face this budget uncertainty, we all need to be talking to one another, we all have to be thoughtful about funding. How do we create an ecosystem that does not follow the same patterns that seem to plague Illinois, where we have the desire to do good work but tend to do it in a fragmented way?”

“There are a lot of opportunities for home visiting to be much more visible and really leveraged and for there to be more understanding around it.”

Sensitivity to state access to reproductive care differences and federal political climate

"You have to be careful when you talk about a central intake of pregnant people, especially when a lot of people need to get their prenatal care in other states."

"And we would not ever want to use the term 'registry.' Pritzker just signed an order on no 'autism registry,' and we would not want to have a pregnancy registry."

"Now is really a very vulnerable time. Are you going to trust and disclose to someone if you are not sure that person is going to do something helpful with the information that you are about to disclose?"

"We've gotten some good systems right now, but there is a tension. We want the system where we know people are being triaged into the right programs. On the other hand, people are worried, and we have a huge immigrant population in Illinois. People are frightened."

Geography and system differences between states

"Just because it works somewhere else doesn't mean it might also work in your location because of all the other systems that exist."

"If I was trying to take on Illinois, I would probably think regionally. If you think of healthcare networks and funding streams, it is usually regionally. And it is difficult to get providers in that southern seven region."

Importance of outreach and communications

"How do you convey the message of the importance of initiating early prenatal care and help people find their way to risk-appropriate care and health care settings that are comprehensive as possible."

"For any central intake/care coordination model, it is important to understand what the community outreach looks like. Are they building real awareness at a community level and in particular, in communities that are harder to reach?"

"Consistent communication is important. Kane County's coordinated intake is very collaborative, and they put together a communications toolkit. Everyone in the home visiting system is trained on consistent messaging and the language used has been tested by their community. They are in constant communications."

"You cannot expect one coordinated intake worker to cover your entire community or region. Over the years, that is where we have seen challenges—if other members of the community say, 'that is not my job'. Coordinated intake is a shared community partnership."

"From what I understand, a lot of MIECHV coordinated intake workers understand that OB/gyn offices are really important strategic partners, but a lot of times it was difficult to get the foot in the door. Not all OB/gyn offices are aware of what home visiting is and if they don't have that public health perspective, it is really challenging to establish that relationship."

MCO considerations

"We have spoken to so many MCOs about this, and they are doing some things. But with a risk assessment they are working very narrowly, and we need to make sure that meeting needs is fleshed out a bit more."

"We need to consider, what is the role of the MCO/private insurer? What is the role of community-based organizations? What is the role of the health care provider?"

"The MCOs have a lot of resources. They have care coordinators who can help navigate people."

Importance of who is staffing and processing the central intake information and referrals

"It will also be important to consider the medical resources needed. Who is reviewing? Who is assessing? Is this happening at the medical home level?"

"I looked at the New Jersey model and I asked, ok, so you complete the form, maybe you register, and then someone reaches out to you? Who does this? Who would that be for us?"

Data infrastructure and data privacy issues

"Baltimore had some way of sharing data between their health and hospital system. How do you replicate that on a statewide level?"

"We don't have good infrastructure for the sharing of health information in general, and a lot of limitations on sharing Medicaid data with anyone else."

"The data sharing is an enormous piece of all of this. And then, where are you capturing the data once you have connected to people— where is it housed? How are you tracking it to know the outcomes of individuals getting connected to care but then more aggregated impact outcomes as well?"

"Under the Transforming Maternal Health (TMaH) model of care, we are focused on the data infrastructure component from transitioning from fee for services to a value-based infrastructure where we are looking at reimbursement for quality of care instead of quantity. We are looking at what systems talk to one another, so we are looking at WIC -- WIC has done amazing things and connecting with other resources."

"There are so many different databases!"

"You will be going between clinical, and you are going between community— how do you build (we don't even have interoperability for clinical) an interoperable system, where it is easy for anybody who is touching a person to see what other services a person has had. That is truly was needed. DC and NY have health exchanges that are more robust for clinical data."

"But I don't know how anyone has done intersection between clinicians. As a clinician, knowing that someone is supporting your patient in the community makes a big difference."

"We have this really creaky infrastructure. It has not been updated; systems don't talk to one another. Data sharing is nil."

"A huge barrier for any of this is the data sharing issues. What are the hardware, software, legal barriers, and people barriers. These are all fundamental to this. None of this is going to make any difference if we can't do data sharing."

"There are so many data systems that need to talk to each other if you are going to do this type of thing. You need to do data sharing— it depends on it."

What makes coordinated intake successful

"You cannot expect one coordinated intake worker to cover your entire community or region. Over the years, that is where we have seen challenges—if other members of the community say, 'that is not my job'. Coordinated intake is a shared community partnership."

"Coordinated intake takes the guesswork out of determining the home visiting model and eligibility criteria."

"In the Chicago area, it would be nearly impossible for the nurses to know about every single home visiting program and deal with natural turnover. It can be overwhelming for both the families and the staff, so having coordinated intake complements that."

"We have 102 counties, and everyone has found a unique pathway that works best for their community."

"Closing the feedback loop is really important."

Support for and with a statewide care coordination system

"I would love a statewide system— honestly. A simplified statewide system. A lot of us have talked about this for years. However, there are nuances with funding, and we also have real deserts in Illinois. There are obstetric shortages and medical shortages. And in the absence of a statewide system, people have developed systems that work for their areas."

"One of the things that I am envisioning as we embark on this work (ECCS grant) is that we are going to find a lot of need. Referrals are only as good as the services that are available to refer to. But that could be a very powerful tool to develop additional funding— to develop additional services throughout the state."

Support for and with a statewide care coordination system (continued)

"In my dream, I see all the work that MIECHV coordinated intake/home visiting is doing, UNSS, all need to work together in some kind of coordinated system. We don't necessarily need another layer— not more— but we need connections to happen so that we are really effective and efficient and maximizing what we currently have and identifying what the holes are for services for families."

"There is so much conversation always about this— it is the hardest piece to achieve, and we are always working towards this goal. There are a lot of conversations in all pockets of the state about how we can do this better, how we can go upstream, how we can centralize—I am not sure if we have cracked the code yet."

"At the end of the day, it really comes down to good care and good word of mouth referrals. I think if we do this really well, people are going to tell their friends to take advantage of this program and that is going to be the path to success more than any outreach or other communications that we do."

"We want to make sure all Illinoisans have access to services around maternal and child health. We brainstormed with the hope we could eventually implement such a care coordination system. And we know funding is needed for that."

"There is currently good synergy in Illinois around this with iPromote and the Maternal Health Innovation grant. We have the Maternal Mortality Review and Infant Mortality Review Committee and their recommendations. They are looking at what happened, what could be prevented, and what services need to be put in place."

"Do we create some sort of electronic system, where we can all agree that we all tap into it and that is how we navigate people— however who manages those updates?"

"How do we wrap our mind around a care coordination system when all the systems don't talk to each other? It is a challenge for all of us, but I think if there is a level of commitment, that we are all going to roll our sleeves up, because Illinois receives a lot of maternal health funding."

"In getting UNSS to complement and integrate with an overarching centralized intake system, we would have to be really creative. We would have to think about nesting and aligning. I know that the Family Connects model is for postpartum, but I am all about being creative. What do we have to wait?"

"Right now, there is great momentum, and I think it is a perfect time for people to come together, have these conversations, and really think through how to offer the best possible service and make Illinois unique in doing something like this."

"Illinois is long overdue in thinking about a system to connect pregnant people prenatally to care."

"If we have a statewide system, it should be open to everyone. I would like there to be access for everyone— universally accessible and offered—not just the Medicaid population."

How are the coordinated intake "hubs" structured— county level? Regional level?

"I think we have this tension— where does coordinated intake work best? At the local level for sure. That being said, a big part of our state is rural, so you can imagine, in these rural communities, a regional system might work. The volume is not that high, and there are not that many providers."

"We have a lot of regional systems. Can we align these regions? We've got Birth to 5 regions, which are aligned with the Regional Offices of Education, we have the Child Care Resource and Referral agencies, we have the Early Intervention regions. If we aligned these regional systems, it would streamline things. Then, in some of the regions, we could see coordinated intake happen regionally, if that is what the community wanted."

"When I look at Illinois' counties, each county has their own health department. Would this be something each county health department could navigate? This would be one FTE but I don't know if people can budget that?"

How to address maternity care deserts?

"How do we deal with the maternity deserts? How do we work with the birthing centers to fill in the gap and how do we keep them from closing?"

"There are obstetric shortages and medical shortages."

"It is hard to get providers in the southern seven region."

"In rural Illinois, it can be an hour to access care. Do you have time to take off a half day of work to get prenatal care? And in some areas, people are heading to other states for care."

"We have maternity care deserts. We have a lot of places where we do not have good sites for care."

Barriers to people receiving prenatal care

"There can be issues of quality, where do people like to get care? They like to go where people respect them and [do] not judge them."

"Transportation and child care are both barriers to care."

"In rural Illinois, it can be an hour to access care. Do you have time to take off a half day of work to get prenatal care? And in some areas, people are heading to other states for care."

"There are so many different things. Sometimes services for mom and child are in different buildings— the difficult logistics in accessing services."

"People have other issues in their lives related to low income, domestic violence, focusing on food and housing insecurity issues and these impact anyone's ability to access care—really access to any care even primary healthcare."

"I think co-locating maternal and infant visits during the first year to the greatest extent possible is one opportunity to break down barriers to postpartum care. Mothers often bring infants for their well-child visit, but she might not go for her own care."

"A lot of this is not just on the person who is pregnant and the person who has the baby, we tend to put a lot of onus on them. But providers are inundated with new QI, and they are never really given the critical information that they need to share with people."

"Transportation issues are a huge barrier to getting to prenatal appointments. And one problem is that many women don't know that insurance (both Medicaid and private) will pay for their transportation. It is partly an education/communications gap where women don't know what is covered and available to them."

"It is not just the Medicaid population that experience barriers to accessing care. We need to remember that moms are dying that are on private insurance too."

"SDOH are a barrier. Some pregnant people are just worried on a day-to-day basis about meeting their basic needs—food, housing—they will make sure their babies and children have what they need but not get help for themselves."

"Child care in general is a huge issue. I remember one story of a mom who was threatened with DCFS because she brought her children with her when she went into labor, and the hospital got DCFS involved."

"Substance use is also a huge issue. Moms are not coming into get the help they need because they are afraid, they could be at risk of losing their children. We really need education around being able to access help without putting your children at risk."

"A provider's bedside manner and really being able to listen to people makes a huge difference. Sometimes it is difficult in practices where you see many different providers within a practice. The practices do that so that pregnant individuals can get to know all the providers before going into labor, but this can impact that relationship building."

APPENDIX B

This table outlines challenges and lessons learned and synthesized from interviews with one Department of Children and Families staff member and three staff members at two Connecting New Jersey lead agencies.

CHALLENGES	ILLUSTRATIVE QUOTES
Volume of Referrals	<i>"The volume has been challenging. It ebbs and flows. Our CNJ has taken the approach that there is a required connection with every client. All these clients we get come through Connecting NJ. All the programs touch and go through Connecting NJ. And each client has a note from the Connecting NJ resource specialist as to what the client is looking for. So, there has been a contact with everybody. That has been a success, but it has also been a challenge at times- it can be a strain on staff. It can be, at times, very difficult to maintain."</i> <i>"We try to make that first contact within the first 24 hours but sometimes that is challenging because of the flow of referrals we receive."</i> <i>"Because we have been marketing CNJ, and the First Lady's funding, and the community alignment work, our numbers have shot through the roof- our numbers have tripled."</i> <i>"The volume is a challenge. The amount of families coming into the hub needing services. And trying to find resources for families."</i> <i>"Most of our lead agencies handle more than one hub, so when things are very busy and a CNJ specialist is struggling with volume, other CNJ Specialists can assist."</i> <i>"There is one resource specialist for each county, and they handle a lot. There are others on the team who can also take some of the calls."</i>
Duplication and timeliness of referrals	<i>"One big challenge is that the referrals we are getting in from the hospital systems, we are often getting later in pregnancy— during the second or third trimester."</i> <i>"Duplicative incoming referrals have sometimes been a challenge. We have not found a way that works to check and disregard referrals that are coming in multiple times. There are patients that go to one hospital, and are not happy with services, and then go to another hospital, and so we get multiple PRAs."</i>
Appropriate training of staff	<i>"Making sure your CNJ specialists all have the appropriate training to receive intake information- that at times can be difficult and traumatic. There can be challenging situations."</i> <i>"We (the State) bring in trainings, we bring in other resources- we are making sure that our hubs have what they need, so they can help the families in our communities."</i> <i>"We are making sure all our staff are trained properly, so they can help families. We are doing parent cafes, we have train the trainers that we put funding towards. It is constantly looking at the system as a whole. Who else can we do these trainings for?"</i>

LESSONS LEARNED

ILLUSTRATIVE QUOTES

Funding for language and translation critical

“Funding for services to be provided in different languages is essential.”

“Some of our hubs use a language line with certain populations.”

“Language funding is important. We try to hire staff that are bilingual in Spanish.”

System built and improved over time

“There have been all the pieces of staffing that have been added over time. We have really been building the system.”

“We are able to see all this data about families, and we are adding to this constantly. Because of how the system keeps building, it is a continual, ‘oh this is needed.’”

“Each county cocreates these referral pathways at our quarterly meetings, and it is to work out the kinks in these referral pathways– for example, NFP has a small window for referrals, so we try to refer to NFP when we can– the state wants to make sure these referral pathways are consistent.”

“When we first developed Central Intake, really for the first 15 years, most of the supportive referrals were focused on the Medicaid and uninsured populations– referrals to home visiting and community health workers. But this has now expanded.”

“We originally just had this one person per community hub and now we have these community alignment specialists that are often at a master’s degree level. Referral placement has really expanded, and we have a much more universal approach. Referral and intake really need to be looked at as a universal piece.”

“I am constantly looking at connecting these dots and working through the siloes and thinking about what is working and what is not working.”

Importance of outreach

“The community alignment specialist role within Family Connects has been amazing. We never had this role before, and now they are connecting us to resources, providers and outreach.”

“If families are not getting the idea of Connecting NJ socialized, then when they are getting their Connecting NJ follow-up, it is a cold call.”

“Hospital relationships are really critical. There is sometimes a lot of turnover on hospital staffs, and you need to make sure you are developing that relationship with the hospital staff person who can get the hospital fully engaged.”

Giving hubs flexibility to tailor to their community while continually sharing best practices

“Even though CNJ is a system. All of our hubs are going to do things a little bit differently, and you have to give them that leeway because every community is different. The way they are reaching out to families -- you really need to give them that leeway to do the work.”

“Because we have our partnership for families’ meetings and other work together, the hubs all know each other. They will ask each other questions around best practices and troubleshooting– ‘How are you doing this in your hub?’”

“Several of our hubs have managers that have been working together for years and years –they know each other, they have worked together, they are constantly communicating with one another.”

Flexibility of the database system

“You really want a database that is user-friendly, adaptable and that can make changes. You don’t want a packaged, premade product– because those can’t change that much –you want something that is tailored and specific to your needs, because that is one of the biggest challenges.”

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