EVERTHRIVE ILLINOIS
CHAMPIONS FOR HEALTH EQUITY

Birth Equity Listening Sessions

The purpose of the Listening Sessions was to bring together medical professionals, social service providers, and community members with lived experiences to discuss maternal and child services throughout Illinois. The six in-person and virtual sessions were hosted in McLean, Champaign, Madison, and Williamson counties, and the City of Chicago. Approximately 35 individual community members and 63 community-based organizations participated in the Listening Sessions between November of 2023 and June of 2024. The aim was to better understand the different social drivers of health and systemic issues that directly impacted parents' ability to have and raise children in their communities while feeling safe and supported.

A summary of the participants' feedback, categorized by key barriers to equitable healthcare, and their proposed recommendations to improve healthcare access are included here. Community members' experiences were also described to further exemplify each barrier.

Key Barriers:

Standard of Care & Experiences with Hospital System

Theme	Patients report negative experiences with their hospital systems. These lead patients to be fearful/distrustful of clinical providers, preventing them from seeking further medical care. Patients describe the clinical setting is not a "true safe space" for them. These issues are oftentimes explained by limited capacity of clinical staff, lack of clinical staff training, and communication issues.
Community Experiences	• Patients are talked to disrespectfully, feel judged based on appearances or marital status, or are ignored by hospital staff • Poor follow-up by medical or social service providers • Patients who have had a traumatic birthing experience don't feel comfortable continuing their postpartum care with the same hospital system • Doulas are not allowed in a birthing space or are being treated poorly • Medical providers do not explain medical issues in a way that is compassionate and easy to understand, so patients feel forced into medical procedures against their wishes, their birth plans ignored, and rushed through appointments

Service Provider Collaboration

Theme	Representatives from community-based organizations experience a lack of connection and awareness of other organizations doing similar or related work.
Community Experiences	• There is a "competitiveness" for funding, resulting in nonexistent collaboration • There is difficulty collaborating across states • There is no comprehensive central database/directory of resources, so organizations are unable to effectively identify community supports/services for their clients

Patient Education

Theme	Patients are often unaware of the services that are available to them. There is also a lack of proper education about the importance of prenatal/pre-conception/postpartum care. Organizations need more support with community outreach and building awareness of programs so that more families connect to resources.
Community Experiences	• Public health departments often have a lot of resources available, but community is often not aware of those resources • Patients/clients are not attending visits due to not knowing why or when they need to receive care • Providers do not always explain what happens at visits; the use of medicalized language leaves patients unaware of what is “normal” and the proper timing of care • Repeat parents don’t think they need additional support • Pressure from families to not seek out additional care (i.e. “My grandmother told me about pregnancy, so I don’t need a parenting class”)

Housing

Theme	There is a lack of affordable and accessible housing options for families. Existing resources do not meet the demand.
Community Experiences	• Impossible processes to access services, including long approval times • Changing/unclear eligibility requirements

Childcare

Theme	Limited childcare options and non-existent emergency childcare results in families missing their appointments or bringing other children with them to doctor’s appointments.
Community Experiences	• Patients check themselves out of the hospital using an Against Medical Advice (AMA) form due to lack of childcare • Doctors are judgmental when children are brought to appointments

Transportation

Theme	The distance to hospitals and clinics in rural areas, especially to those providing high-risk services, hinders timely perinatal care. This was exacerbated by the lack of transportation options available to families and the unaffordability of car seats.
Community Experiences	• Unreliable non-emergency transportation services for Medicaid Managed Care Organization (MCO) were late, absent, or not allowing children in the vehicle; certain car seats cannot be accommodated • Illinois MCO policies do not allow for Illinois residents to request transportation services to their medical appointments in Missouri

Mental Health

Theme	Individuals do not seek mental health services due to stigma (both cultural and systemic), fear of punitive measures stemming from a distrust in the state, long wait times, and overall lack of availability of mental health providers that accept Medicaid. Providers express that there is poor care coordination which leads to an inability to connect their patients with mental health services.
Community Experiences	• Patients feel they must "watch what they say" around medical providers and are fearful of Department of Children and Family Services (DCFS) involvement, so they are not honest about their substance use, postpartum depression, or other mental health struggles • Providers do not explain what a mental health referral is for, so patients don't have the information they need to support themselves • Cultural factors put pressure on birthing person to "be strong" and not seek help • Male partners not encouraged to receive mental health services which can affect family well-being • Mental health organizations do not connect with other community-based organizations to help coordinate services, resulting in no warm handoffs and lost patients

"We lack coordination between service providers and clients. The system has not established trust with clients. There are multiple entities telling clients multiple things. This has caused confusion and a lack of trust. Clients must prove they are entitled to the services they are receiving."

Springfield, IL

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Proposed Solutions from Listening Session Participants

Throughout the Listening Sessions, community members, medical providers, and social service providers provided guidance on what *they* needed to effectively address the issues they are experiencing. These proposed solutions were categorized depending on which area of the healthcare system the solution is intended to target. Elevating and taking seriously the recommendations of those most impacted by these barriers is an essential step in the effort to achieve health equity.

System Improvements

- Increase funding for evidence-based solutions for social drivers of health, including home visiting programs, childcare services, public transportation, treatment for mental health and substance use disorders, housing, and infant supplies
- Incentivize collaboration between state and local health departments and across social service organizations
- Address the competitive nature of grants/funding by removing limiting criteria (such as # of clients required, etc.)

"The system is not built to support us, so what is the alternative?"

Healthcare & Hospital Systems

- Integrate doulas into healthcare system at all stages of the perinatal spectrum and ensure doulas are supported within healthcare system
- Increase telehealth access options
- Build harm reduction approach into hospital policies and systems

Healthcare Providers

- Provide training opportunities that incorporate the living experiences of pregnant and postpartum people
- Utilize nurses/case managers/doulas to support patient education and other supportive services to alleviate clinician workload
- Provide intentional and non-judgmental open-door approach to care by creating a safe space for patients to share their needs and ask questions without risk of punitive measures, feeling ignored, or rushed through their appointment
- Developing individual birth plans collaboratively with patients and commit to respecting birth plan of the patient regardless of personal bias/opinion
- Create a family-centered approach for appointment experience (e.g. allow for all children to attend appointments)

Health Insurance Plans

- Improvements to current non-emergency medical transportation services across MCO's and transportation vendors
- Coordinate with neighboring states to ensure Illinois Medicaid recipients can receive care at nearest health and social service providers.

Community-Based Organizations

- Develop comprehensive care coordination systems, especially in rural areas, to provide community members with the support needed to navigate across all needs of the family, decrease system silos, and reduce the competitive nature of services
- Build a comprehensive and accessible community/ statewide directory to serve as a one-stop-shop for connecting social service organizations and streamline close-loop referral process
- Provide individuals with the capacity to create their own systems of care within their communities, such as "health hubs", for the purpose of centering their specific community health needs, sharing of resources, and dismantling systemic power dynamics