

Community Organizing and Family Issues (COFI)

Aligning Early Childhood and Medicaid Listening Sessions (Feb to May 2023)

Overview:

- COFI conducted 4 listening sessions with 24 participants
- Listening sessions were conducted in 4 areas: Aurora, Chicago, East St. Louis, and Elgin
- Participants were a combination of White, Latinas, and African-Americans with many monolingual Spanish speakers.

Key Themes:

1. Lack of maternal health care information and accessible services overall for immigrant moms (very little Spanish speaking services – in Kane County) and also noted a lot in East St. Louis where 6 participants were African-American and 1 was White
2. Perception that Latina (Spanish speaking) moms are treated differently in medical care – with a lack of empathy
3. Once mothers learned of Medicaid, they generally found it easy to enroll except they had some confusion around the various insurance options under Medicaid
4. Once enrolled, though, information about services covered was not provided. Several mothers talk about being confused about whether Medicaid was going to cover certain things and ending up paying out of pocket. Some received reimbursements and others didn't.
5. Once enrolled, they often felt discriminated against for having Medicaid - and many services were not available or not covered (including and especially dental)
6. Strong belief that peer support and peer information sharing is helpful and needed
7. Also - Belief that more information, communications and translators are needed – in Spanish media, on social media (Facebook), at schools and at clinics
8. Participants recommended that Medicaid coverage last longer for new mothers
9. *General Observations:*
 - a. A very high percentage of C-sections mentioned, along with high-risk pregnancies and early deliveries.
 - b. A lot of gestational diabetes and post-partum depression.

Themes by Topic:

Insurance Themes:

- Participants identified they had the following insurers: Blue Cross Blue Shield; Meridian; Molina; CountyCare; Aetna, No insurance.
- Easy to apply for Medicaid but hard to get an appointment to apply and may have to visit the office numerous times before getting an appointment.
- Various options of medical providers but not a ton of options that were Spanish-speaking.
- Participants expressed the sense that there were a lack of options for Spanish-speaking doctors that took the insurance (not sure if this was because there really was a lack of options, or if there was fear around asking).
- English speakers had an easier time finding appointments and advocate for their needs.
- It seemed that hospitals over tested to get more money from the insurance company

- Received bills for things they didn't know about.
- It would be helpful to have more information on what insurance covers.
 - Wasn't sure if insurance covers mother classes or birthing classes
 - Heard of others getting transportation services but didn't know that those were covered services
- It wasn't always clear why mothers were being asked certain questions. Mothers mentioned not answering certain questions truthfully because either they didn't trust the professional or they weren't sure how the information was going to be used.

Access to Services During Pregnancy:

- Mothers generally agreed that some services were easier than others to get access to and varied depending on the time and place.
- Felt like they didn't receive the same treatment as people who were privately insured.
- Felt like there was little empathy or humanity given by health care providers given the cultural differences and language barrier.
- Need to increase access to dental care, lots of dental procedures are not covered.
- Services that were more optional but extremely useful were harder to access since people needed to advocate for themselves more.
- Most women weren't aware of services that were available such as doula's, home visitors, etc. If they had known the services were covered, they would have used them
- Mentioned they couldn't get a new breast pump as you can only get one once every 5 years
- There are very long waitlists, up to a year, for the well-respected and well-trusted doctors.
- Experienced medical complications due to childbirth and access to treatment was often delayed due to insurance status.
- Had to travel to find specialists since there was no one in the area who offered certain treatments and accepted Medicaid.
- Access to services after childbirth was inconsistent and felt non-existent. Felt like care just stopped after childbirth.
- Appreciated caseworkers who would talk to the pregnant moms and ask how they were doing and if they needed anything.
- Access to competent translators was lacking and, in some instances, dangerous.
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Access to Services Outside of Medicaid:

- Belleville, pregnancy care center
 - Recommended by WIC office
- Caridad Catolicas provided pacifiers and connected people to Parents as Teachers
- All Kids Above provided blankets, diaper, Christmas gifts, and assistance around postpartum depression.
 - Recommended by a gynecologist
- Family Focus provided child evaluation and provided speech therapy for children and connected mother to a group of mothers
 - Recommended by their church

- Elgin's Partnership for Early Learning provided diapers and have programs that help prepare children for kindergarten.
- VNA provided a lot of services.
- Parents as Teachers called the mother every 15 days to see if she needed anything
 - Recommended by Head Start

Recommendations for Improvements:

- Access to a packet of information that can be easily found in public spaces such as a clinic or hospital.
- Access to dedicated individuals that have knowledge about the type of services that are available would be helpful especially if they are accessible in common places such as schools or clinics.
- Access to therapy or other mental health supports would have been helpful due to the hormonal changes.
- Mothers also recommended access to a parent to parent support group.
- Offering open houses or forums where pregnant women can connect with other women to share information would be helpful
- Accessing a social worker at the clinic rather than having to see them at a different location.
- Longer postpartum coverage
- More dental coverage

Stories from Participants:

- *"We're treated as an incubator for 9 months and then you aren't helped with checkup postpartum so see how our bodies are holding up. Of my 2 last pregnancies I had the same doctor through my Aetna insurance. If I wanted to come back I couldn't because my insurance ran out. If I wanted a check up I needed to do it within a month or it would come out of my pocket."*
- *"They (parent support group) treat you like a blood family. I can call them whenever and be able to talk to them like family. I can go to them for anything, they make you feel comfortable. I would've lost my baby or been at a mental institution if it wasn't for them."*
- *"There is a resource that says who accepts it and who doesn't. For example, they have seven options, but only two of these seven speak Spanish and all the Latina mothers that speak Spanish only go with these two options and the service is saturated. I looked at COFI and learned to ask and look for options - The white doctor in this area does a lousy job with pregnant Latina women and has a bad reputation with the community, but we don't have any other options."*
- *"If we want to get an appointment at a well-rated and trusted clinic that does take our insurance, we're put on a waitlist that can go up to a year before we're seen. I need to see a doctor for my 10-week checkup- I can't wait that long."*
- (Ways for families to learn about services): *"Through the same avenues and with the same urgency that I'm reminded to do my taxes. Finding these organizations could be during an open house somewhere like our children's school or at the public library. I would also like a forum where we can connect with other women to see if the information we are given is correct as well."*

- One mom shared that she ended up scheduling the removal of 4 molars on one day because she knew she only had a short time left on Medicaid after the birth of her child.

Listening Session Questions:

1. Did you have a positive or negative pregnancy experience? Please Elaborate.
2. Did you have insurance during your pregnancy?
3. What did you think about the insurance you had?
4. Was it easy or hard for you to get help and care when you were pregnant?
5. If it was hard, what made it hard?
6. What would have made it easier?
7. If it was easy, what made it easy?
8. What kinds of supports did you use during your pregnancy?
9. Was it easy or hard to find and use these services?
10. Did someone help you during your pregnancy?
11. Did an organization work with you during your pregnancy?
12. How did you find out about them?
13. What other kinds of services would have helped you while you were pregnant?
14. Would you have found a parent to parent support helpful?
15. What would you change about the services you received while you were pregnant?
16. What is the best way for families to learn about the kinds of services that can help during pregnancy?