SEPTEMBER 2020
EXECUTIVE SUMMARY
COMMUNITY ASSESSMENT
LISTENING SESSIONS

PREPARED BY

MATERNAL TELEHEALTH ACCESS PROJECT

THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL
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ABOUT

The overall goal of the Maternal Telehealth Access Project (MTAP): Collaboration and Innovation for Equity and Healthy Families is to increase equitable access to quality telehealth and distant care services for pregnancy, childbirth, and postpartum during the COVID-19 pandemic and beyond.

The project charges are: (i) to increase access to perinatal services and supports via telehealth, including clinical care, care coordination, and community support services throughout pregnancy until the first year postpartum; (ii) to increase the capacity of providers to offer trauma-informed perinatal care via telehealth; and (iii) to disseminate web-based information and public service announcements.

FUNDING STATEMENT

The Maternal Telehealth Access Project (MTAP): Collaboration and Innovation for Equity and Healthy Families (Grant # H7EMC37564) is a collaborative initiative with several partnering agencies aimed at ensuring that women at highest risk are receiving quality maternal care services via telehealth during the COVID-19 pandemic. The project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an Award totaling $4,000,000 for one year with 0% percentage financed with nongovernmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by HRSA, HHS or the U.S. Government.
INTRODUCTION

Quality and respectful care throughout pregnancy and the postpartum period are critical to ensuring the health and well-being of families, communities, and populations. COVID-19 social-distancing restrictions have disrupted access to essential care and wrap-around perinatal and postpartum care services across the U.S.

Maternal and infant mortality is higher within Black, Indigenous, and People of Color (BiPOC) communities, a problem that has been exacerbated by COVID-19. Structural, legal, geographic, and political economic barriers to quality perinatal and postpartum care services disproportionately affect BiPOC communities, rural communities, low-income communities, incarcerated people, people with disabilities, people with substance use disorders, and people with perinatal mental health care needs during the COVID-19 pandemic.

Telehealth and other forms of remote services delivery are a promising means to improve equitable delivery of care to communities in the greatest need.

This document is a summary of findings from listening sessions that were conducted in order to gather various stakeholder perspectives of telehealth and distant care services for critically underserved and marginalized populations during the COVID-19 pandemic.

The insights drawn from these listening sessions will help to ensure that all MTAP program implementation is aligned with stakeholders’ concerns, needs, and priorities. Specifically, these findings and recommendations will inform MTAP funding decisions related to technical assistance, supply purchases, training curricula, and media outreach.
ASSESSMENT GOALS

The goals of the MTAP Community Assessment are:

• to gather various stakeholder perspectives of telehealth and distant care services for pregnant and parenting people in critically underserved and marginalized populations

• to ensure that MTAP program implementation is aligned with stakeholders' concerns, needs and priorities

• to inform funding decisions related to the project charges, including technical assistance, supply purchases, training curricula, and media outreach
LISTENING SESSIONS

In August 2020, the National Birth Equity Collaborative (NBEC), Reaching our Sisters Everywhere (ROSE), and the UNC Department of Maternal and Child Health developed a shared approach to the listening sessions. A core facilitation guide was designed to gather stakeholder perspectives that aligned with aims of the broader MTAP assessment goals and program charges.

NBEC and ROSE tailored the facilitation guides and recruitment strategies for their respective communities of practice. Their approach to the listening sessions was culturally relevant.

From August 10 to September 5, 2020, NBEC and ROSE facilitated 13 listening sessions with 75 stakeholders from different backgrounds. Participants were invited to discuss their specific needs and concerns related to telehealth access, acceptability, feasibility, and funding priorities during COVID-19.

Stakeholders included:

- Childbirth educators
- Community health workers
- Doulas
- Lactation support persons
- Midwives
- Nurses
- Physicians
- Pregnant and parenting individuals
- Public health agency representatives

Viewpoints from both current and prospective users and providers of telehealth services for pregnancy and postpartum care were recorded during these listening sessions. Sessions lasted 60-90 minutes. Ethics review of the listening sessions protocol was completed by the University of North Carolina at Chapel Hill Institutional Review Board (IRB 20-1490).
ROSE partnered with Indigenous Breastfeeding Counselors (IBC), Health Connect One (HCO), and the Appalachian Breastfeeding Network (ABN) who held MTAP listening sessions within their communities of practice.

HCO conducted two listening sessions in Spanish for Spanish-speaking providers and clients. IBC facilitators led a listening session with Indigenous women who were pregnant or recently postpartum.

The ABN led one listening session with community-based perinatal care providers. ROSE facilitated three sessions, including one for Black pregnant and postpartum participants and two for community-based perinatal and postpartum care providers serving BIPOC communities.
NBEC held three listening sessions with Black birthing individuals and three listening sessions with Black birth workers, using a facilitator guide informed by Black Feminism, Reproductive Justice, and Intersectionality.

Participants in the Black birthing individuals sessions were between 3 months pregnant and 3 months postpartum.

Black birth workers also participated in the listening sessions representing a wide range of providers serving Black communities.
Listening Session Stats

57% Community Perinatal Care Providers
43% Pregnant or Postpartum Clients/Patients

75 Participants
28 States
13 Sessions
RAPID QUALITATIVE ANALYSIS

Listening session participants provided verbal informed consent to participate and have the sessions audio recorded. Sessions were transcribed verbatim. Transcriptions were reviewed for accuracy and de-identified prior to the analyses.

Themes from the listening sessions were developed using rapid qualitative analysis techniques, debriefs with listening session facilitators, and group discussions to reach consensus.

This report summarizes key insights from a synthesis of the listening sessions. It highlights overarching themes that pertain to:

- the impact of COVID-19 on access to care during pregnancy through the first year postpartum
- stakeholder perceptions of telehealth acceptability and feasibility
- stakeholder recommendations for telehealth-related funding priorities
THEMES
HOW HAS COVID-19 IMPACTED CARE?

"The care being provided is inadequate."

COVID-19 has worsened existing poor quality of care experienced by BIPOC people. Black, Indigenous, and Latinx participants, in particular, described previous experiences with racism, poor quality of care, disrespectful care, and difficulty accessing care before COVID-19. Pre-pandemic barriers persist and have made finding quality care even more difficult.

Before the pandemic, participants described barriers related to finding childcare, transportation to appointments, and financial barriers to accessing services. Black birth workers talked about clients who were facing challenges with quality of care in medical facilities, including: having to advocate for doula services in hospitals or a lack of acceptance of doulas; a lack of compassion among non-Black entities and providers; and a lack of cultural humility. Black and Indigenous women in particular noted that they have always been concerned about neglect, and COVID-19 has only increased these worries.

COVID-19 has reduced the availability of health care and wrap around services for BIPOC patients and clients. Many hospitals and clinics have discontinued services, WIC offices in some states have had to close, physicians have limited their hours, and some providers are not taking new patients or clients. Reduced contact with care providers, fewer appointments during pregnancy and postpartum, delays in pediatric visits and receiving childhood vaccinations were all concerns raised in the listening sessions.

Pregnant and parenting participants described increased isolation from family and community support during pregnancy, childbirth, and postpartum. They discussed feelings of fear, uncertainty, and anxiety as a result of trying to navigate disrupted health care systems. Community-support providers raised concerns about perinatal mental health, intimate partner violence, and child maltreatment.
"...falling through the cracks"

Broken referral systems between hospital obstetric care providers and community-based support was widely discussed. Participants explained that poor coordination and weak continuity of care perpetuated increased disconnections in care that clients and patients urgently needed.

Participants noted that telehealth can be one strategy to ensure that these connections are preserved. They explained that telehealth is not as effective as it could be, because physicians and other obstetric care providers were failing to make referrals to community support providers.

Pregnant and parenting participants described an increased burden to identify resources in the community on their own, without the assistance of their clinical obstetric health care providers.

Both community-based care providers and clients raised concerns about patients being neglected during pregnancy and after giving birth. Pregnant and parenting participants reported that they are not a priority to their obstetric care providers. They used words like "abandoned," "rushed," "dismissed," "neglected," and "ignored." Clinical encounters and hospital experiences were linked to worries that something important about their health or their baby’s health would be missed.

Disruptions in staffing was another key concern. Black, Latina, and Indigenous providers and clients alike discussed the importance of relationships of trust in seeking care and providing care. Adaptations to COVID-19 reflected provider-centered care, not the complex needs of patients.

"I've had two moms pass away during COVID, and it just really hurts me, because they're going into the hospital, complaining about their issues. And I understand that COVID is first and foremost to some of these hospitals, but these moms are getting sent away and passing away at home or coming in to have a baby and passing away at the hospital because they weren't given the proper help that they needed."

[ABC provider session]
# IMPACT OF COVID-19

## SUMMARY OF THEMES: CLIENTS & PATIENTS

<table>
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<tr>
<th>THEME</th>
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<tr>
<td><strong>ISOLATION</strong></td>
<td>&quot;I feel like it's isolated me, not only from the community, but like my family. Usually during pregnancy, my family is really involved in, for as far as taking care of me. ... the paternal mother-in-law or their mother-in-law, supposed to take care of you and the baby, and that couldn't happen during COVID because no one was really allowed to go anywhere.&quot; [IBC Session]</td>
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<td><strong>ASSEMBLY LINE</strong></td>
<td>&quot;It was just like no concern for my individual situation, no real investment in what the outcome would be, a very rushed experience. And I'm wondering to myself, how can I receive medical care from someone who is disconnected from my pregnancy?&quot; [NBEC Session #1]</td>
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<td>&quot;...you really don't have any interaction with anyone really.&quot; [IBC Session]</td>
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<td><strong>AVOIDANCE</strong></td>
<td>&quot;I'm in my eighth month of pregnancy and my youngest is four. When all of this started and then they first said that they want us to wait in the car and stuff like that, and then when they finally did open it, and they said that we couldn't have visitors or extra people in there, I kinda stopped going and waited into like my fifth or six month to start going back.&quot; [ROSE Session]</td>
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<td><strong>RELATIONSHIPS</strong></td>
<td>&quot;It was like they didn't spend too much time or concern.... they just did not care.... it got to the point where I was like, I don't even want to be here, because every time I come here, it's nothing but stress on me. I'm here by myself and I already have bad anxiety. And so it's like, you're just making it so much harder on me and my pregnancy by doing that.&quot; [ROSE Session]</td>
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<td><strong>NAVIGATING CARE</strong></td>
<td>&quot;So to a point it's like, once they've provided your service they're kind of like, 'well, we did our job, you're on your own.'&quot; [ROSE session]</td>
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<td>&quot;Suddenly was less, you know, and I understand for safety, but also like being Black. I was not going to tolerate that. So, I got all my appointments.&quot; [NBEC Session #3]</td>
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"We're bringing life into the world and we can't even have any support."

ROSE client session
# IMPACT OF COVID-19

## SUMMARY OF THEMES: CARE PROVIDERS

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<td><strong>Birthing in Fear</strong></td>
<td>&quot;And the hardest thing has been... people who were choosing home birth... They chose it because they are afraid to go to the hospital and that isn't great. We had a lot of transports because of that....&quot; [ROSE session]</td>
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<td><strong>Human Rights</strong></td>
<td>&quot;It's really stripping away different rights reproductive human rights from these families.&quot; [ROSE, provider]</td>
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<td>&quot;I get to sit at the table with the CEO and all the other executives, I hear how they talk, I hear how they think. The compassion is not there...Because passion is not there, [it] is strictly about them filling their pockets.&quot; [NBEC Session #2]</td>
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<td><strong>Neglect</strong></td>
<td>&quot;There's been quite a few births that I've attended where the placentas were really scary and falling apart and not aligned with the age of the baby.&quot; [ROSE session]</td>
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<td>&quot;...knowing the literacy issues that we have here in [urban city] the prenatal at home kits are just, I feel like they are an absolute failure of the medical staff.&quot; [ABN session]</td>
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<td><strong>Mental Health</strong></td>
<td>&quot;PPD [postpartum depression] is very, I've seen it increase exponentially with moms...It's heartbreaking.&quot; [ABN session]</td>
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<td>&quot;...another thing in our area that we've been talking a lot about, is we're fearful. There is a lot of child abuse and neglect cases going on right now, a lot of domestic violence going on right now.&quot; [ROSE session]</td>
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<td><strong>Burnout</strong></td>
<td>&quot;I think most people who do this work get to a point of burnout, especially if it's in high demand or you're in an area where you're seeing a lot of people.&quot; [ROSE session]</td>
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<td>&quot;...the funders don't see us as an investment or care. Because if we're [community birth workers] not well, how are we going to be able to give services to our community.&quot; [HCO session]</td>
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"Black women don't want to be in your hospital because they're afraid they're not going to come out."

NBEC Session #2
WHAT DO YOU THINK ABOUT TELEHEALTH?

"Sometimes just that conversation can save a life."

Discussions about the added value of telehealth to improve maternity care services during the COVID-19 pandemic emphasized situations where telehealth could support referrals, following-up and checking in on clients, providing basic education or counseling services, and disseminating information.

In this public health crisis, clients and providers agreed having access to telehealth and distant care services was "better than nothing." Telehealth was described as a lifeline during shelter-in-place situations or when in-person visits were highly restricted. Some noted that telehealth-based screening could be used to identify at least some emergent cases that required urgent referrals to in-person support.

Community-based providers mentioned that they were most excited about the flexibility telehealth afforded them to be able to see clients during the pandemic, "meeting parents where they're at." They noted that with telehealth, they were able to reach clients over a broader geographic area.

Black birth workers discussed challenges in navigating care during the COVID-19 pandemic. Advocating for doula services in hospitals, navigating lack of compassion, emotional intelligence, and cultural humility among non-Black providers, shifting outreach strategies to expand coverage, and limitations in scopes of practice were noted challenges.

Telehealth provided birth workers and lactation support providers with greater flexibility in balancing their own professional and personal responsibilities during the pandemic.

Providers were interested in learning about effective strategies to increase awareness of available services in their communities and beyond, to build rapport with new clients through telehealth, and to implement evidence-based practices for ensuring the quality of care via telehealth. Pregnant and parenting participants expressed an interest in learning how to make the most of their visits with obstetric care providers.
"...the digital divide"

All participants emphasized the lingering influence of pre-pandemic structural barriers in access to telehealth and related technology. Several participants described this as "the digital divide." The listening sessions amplified a heightened concern for how already marginalized and oppressed communities of color would be able to access telehealth and other distant care services in the context of COVID-19.

Related to this were numerous challenges linked to inequities in digital literacy. Even if access to technology and services was improved, many people would not be able to use telehealth because they lack basic skills to operate devices, connect to the internet, or understand how to use various online platforms.

Both providers and clients were very concerned about the gap in services available to non-English speakers. The digital divide exacerbates challenges caused by language barriers. One participant added that without translators in hospitals, non-English speaking populations are still at risk of poor health outcomes because they do not have the information to make informed decisions about their health care.

Throughout the various listening sessions, participants lifted up the following communities that may be least able to access telehealth services for pregnancy and postpartum care: immigrant populations, Black and Brown undocumented populations, non-English speaking populations, homeless populations, pediatric populations, populations in low-income areas, rural populations, incarcerated people, and sex-trafficked individuals.

"...we had a mother postpartum who was sort of postponing the care for whatever reason, she’s, she has a lot of kids at home and we were doing a lot of virtual stuff. And by the time I went over there, her baby was very jaundice...even if we have had funding for excellent telehealth technology, that doesn't mean that they have excellent technology or cameras for us to see how yellow is this baby, or how you know, if a mother's bleeding that can usually be seen... or even looking at a mother and how pale are her eyelids or her lips, you know, is she blanching out from some other condition that's going on. So that's my concern with it. I want to make sure we're not missing really important details"

[ROSE provider session]
# Telehealth

## Summary of Themes: Client & Patient Perspectives

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<th>Theme</th>
<th>Illustrative Quote</th>
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<td><strong>Convenience</strong></td>
<td>&quot;I have a five-year-old and a ten-year-old, so not having to coordinate with my husband if one of them were to be home from school or something else, like, okay, who’s going to watch the kid so I can go into the appointment and not have to bring them with me. So, there’s a convenience factor in that, um, childcare in not having to coordinate that.&quot; [NBEC Session #1]</td>
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<td><strong>Trust</strong></td>
<td>&quot;Like having providers see into your home... that can create a lot of anxiety and fear around them having access to your life and your privacy.&quot; [IBC session]</td>
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<td>&quot;I think it’s also very important when there is person-to-person contact. You can see their gestures, their face. And that’s very important, because it creates trust. And I think that when they’re behind a screen it doesn’t give me that confidence.&quot; [HCO session]</td>
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<td><strong>Home Monitoring</strong></td>
<td>&quot;...and then they asked me questions like your blood pressure, your weight. And it’s like, I don’t have these tools at home to like, if you want me to give you that information, provide me with the tools. That’s how I feel. And then also I haven’t heard my baby’s heartbeat yet. I haven’t seen my baby yet. So that’s also kind of like, okay, but I’m trying to like, just take it easy and just go with the flow for now.&quot; [NBEC Session #1]</td>
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<td><strong>Disconnected</strong></td>
<td>&quot;I think we just all assume that everybody has access to the internet and has a cell phone and something that they can use, but there are still plenty of people that don’t have access to that.&quot; [ROSE session]</td>
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<td>&quot;Sometimes I pay more for my home internet than for the electricity. So, I don’t know. I can imagine someone who has no income because they don’t have a job...&quot; [HCO session]</td>
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<td><strong>Quality</strong></td>
<td>&quot;So it’s really been a battle... with trying to find a good doctor that actually cares and shows they care. I think that’s one of my issues with the telehealth, because you can’t, can’t get an ultrasound. They can’t see. And some people need that human interaction that they’re not getting, because they’ve been so cooped into the house, and it’s a lot of people literally going crazy over it. It’s really taken a toll on a lot of people’s mental health.&quot; [ROSE session]</td>
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"I can't even imagine, like ... before we were able to reach as many people and obviously like zoom and stuff during a pandemic like this, I just feel like so many more pregnant and postpartum women would just suffer because there wouldn't be any other way to see them, you know? So at least now it's like, yeah, this isn't ideal, but at least it's better than nothing."

ROSE Client Session
## TELEHEALTH

### SUMMARY OF THEMES: PROVIDER PERSPECTIVES

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<td><strong>DIGITAL DIVIDE</strong></td>
<td>Community-based providers raised serious concerns about inequitable access to telehealth, especially in BIPOC communities.</td>
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<td>“They don’t have the hot spots. They don’t have the internet. It’s one phone, many of them, they don’t even really have running water.” [ROSE session]</td>
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<td>“I believe low income families are the most impacted by not having phone service or not having the money to pay your phone service and things of that nature.” [ABN, provider]</td>
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<td><strong>DIGITAL LITERACY</strong></td>
<td>Participants raised the urgent need to provide linguistically appropriate education and support to teach patients/clients to use basic telehealth services and devices.</td>
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<td>“I work with the Hispanic community and ... a lot of sources aren’t even in Spanish. Or just the fact that their education level is not high enough for them to comprehend what the material says. So, I would say right now for the community I work with telehealth is not recommended. They don’t have the resources to you know even use telehealth. So it’s, it’s really difficult.” [ROSE session]</td>
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<td><strong>SENSORY ASPECTS</strong></td>
<td>Participants were concerned about rapid transitions to telehealth, due to the importance of sensory-based techniques that birth workers and lactation supporters use.</td>
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<td>“You can look at a mother’s belly, and kind of based on the shape and everything, you can tell - are amniotic fluids low or high? And what position is the baby? But being able to feel and touch is so important, even for symmetry in her ligaments and knowing whether she’s got tightness somewhere or anything unusual. Feeling the kidneys, you know, if there’s any swelling... That’s what I think the telehealth is missing.” [ROSE session]</td>
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<td><strong>RELATIONSHIPS</strong></td>
<td>Relationships were emphasized by community-based care providers as a core part of their care, which is difficult to nurture via telehealth.</td>
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<td>“As indigenous people kind of the basis of many of our tribes is relationships, right, and building those relationships and connecting with people. And so how, how do we do that when we're not with them in person?” [IBC session]</td>
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<td>“We work from our hearts, so we give that support from our hearts.” [HCO session]</td>
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<td><strong>INSURANCE</strong></td>
<td>BIPOC led community organizations noted that access to telehealth was largely determined by income and type of health care insurance.</td>
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<td>“Talking about the undocumented immigrant communities again ... it takes a long time to get an appointment with a provider, with any provider, who’s getting aid. Now, with this, there’s an even greater impact on access by people who simply don’t have insurance, they don’t have Medicaid, they don’t have any insurance, and they have to pay out of pocket.” [HCO session]</td>
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"Is telehealth the way to care for the most vulnerable among us – our babies and our elders? Our elders and our babies, our most vulnerable populations in our communities and our most valued populations in our communities, a lot of the times it could be harder for them to get the care they need if telehealth is the only option, right?"

IBC Client Session
RECOMMENDATIONS
FUNDING PRIORITIES

- COVID-19 responsive home-visiting programs for prenatal and postpartum care in BIPOC and rural communities, including PPE, supplies, and resources needed
- Remote monitoring supplies, education, and support
- Patient care navigation systems that improve coordination between clinicians and community-based providers
- Systems, supplies, education and technical support to use telehealth services
- Translation services
- Equitable wages for community birth workers, lactation support persons, and mental health/psychosocial support providers
- Programs that provide access to health care regardless of ability to pay or citizenship status
TRAINING PRIORITIES

- Implementation of evidence-based practices that support patient autonomy and quality of care via telehealth

- Integrating telehealth into patient records and automatic prompts for referrals to social services

- Educating providers on recommended practices to support quality and respectful maternity care for Black, Indigenous, and People of Color patients and clients

- Best practices for earning a livable wage while providing community-based telehealth services

- Effectively promoting and disseminating information about available telehealth services within priority communities

- Best practices for developing trusted relationships with new clients through telehealth services

- Creating "know your rights" resources for patient advocacy and informed decision-making
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