### The VOICES/VOCES Initiative: Moving Forward through Women's Voices to Address Pregnancy and Birth Inequities in South Carolina





Presentation by: Deborah Billings, PhD Affiliate Faculty, IFS

South Carolina Birth Outcomes Initiative 2021 Virtual Series Building Resilience in Maternal-Child Health Thursday, November 18, 12-2:45 pm

### **Presentation Objectives**

- Raise awareness of the multi-dimensional life experiences of women using Medicaid during pregnancy-birthing-postpartum in South Carolina
- Bring beneficiary recommendations regarding health care services and Medicaid directly to discussions about policy and practice
- Highlight major equity issues described by women and other stakeholders
- Demonstrate the importance of combining qualitative and quantitative data for deeper understanding
- Demonstrate the power of the arts for communicating messages and fostering discussions about issues central to BOI's mission



### The VOICES/VOCES Initiative



### Part I: Technical Report

### June 2021

Prepared under a contract with the South Carolina Department of Health and Human Services (SCDHHS) and partially funded by the SC March of Dimes.

### Research and Authorship Team/ IFS Staff

Deborah L Billings, PhD Alyssa Robillard, PhD Chloe Rodriguez Ramos, MPH Ana Lòpez-De Fede, PhD Kathy Mayfield-Smith, MBA, MA

Abby Askins, BA (technical assistance)

### Part II: Theatrical Performance

### October 2021

Voices/Voces: Pregnancy, Medicaid, & COVID-19

Funded by the Institute of Families in Society in response to the request to share the messages and experiences from the research.

Playwright and Director: Patti Walker

Stage Manager: Lilly Heidari

**Cinematographer**: Jeffrey Williams

**Cast:** AJ Badillo, Aaliyah Broadwater, Jasmine Davis, Kristen Javis, Charlene Jones, Miranda McDermott



## Part I: Technical Report June 2021





# Background

- South Carolina Medicaid data, analyzed by the Institute for Families in Society (IFS) over the last decade, indicate that racial/ethnic inequities in maternal health and birth outcomes persist.
- The IFS Voices/Voces project documents the experiences, perspectives, and proposals for action among people using Medicaid to cover the costs of pregnancy-, birthing- and postnatal care during the COVID-19 pandemic.
- The project goal: uplift participants' voices in Medicaid-related decision and policymaking.



### Get the June 2021 Technical Report (PDF)

### The VOICES/VOCES Initiative:

Moving Forward Through Women's Voices to Address Pregnancy and Birth Inequities in South Carolina





### https://www.schealthviz.sc.edu/birthoutcomes-initiative



In 2019, the South Carolina Department of Health Human Services (DHHS) Medicaid program (*Healthy Connections*) covered the cost of 61% of all deliveries, including:

73% for women residing in rural areas
75% for women identifying as Hispanic
84% for women identifying as Black
93% for women under age 20.

#### Source:

schealthviz.sc.edu/Data/Sites/1/media/downloads/SCBOI\_D eliveriesandBirths-CY2019.pdf

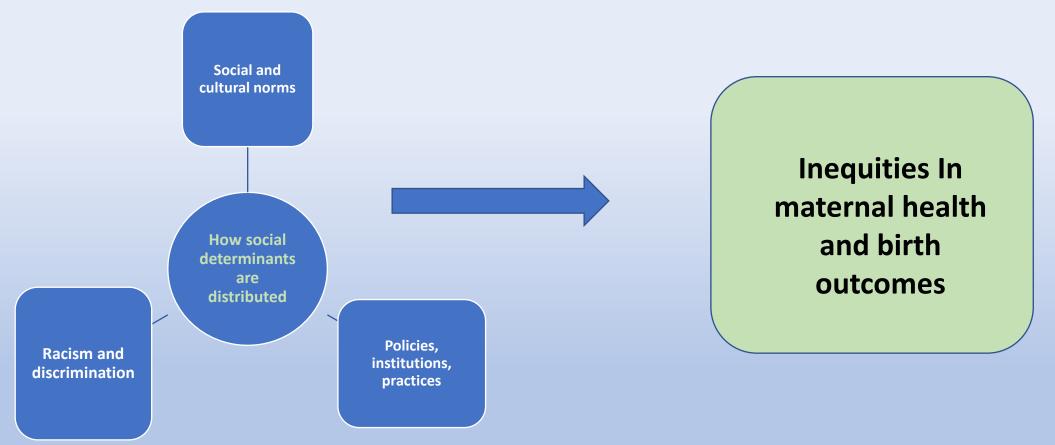


# Frameworks

- Equity
- Human Rights
  - Right to health: facilities, goods, and services are *available*, *accessible*, *acceptable*; *quality*
- Reproductive and Birth Justice
- Obstetric Violence
- Social Determinants of Health
- Structural Determinants of Health



# Structural Determinants of Health



See: Crear-Perry, J., Correa-de-Araujo, R., Lewis Johnson, T., McLemore, M. R., Neilson, E., & Wallace, M. (2021). Social and structural determinants of health inequities in maternal health. *Journal of Women's Health*, 30(2), 230-235.



Race/ ethnicity of VOICES/VOCES analytic team		Research roles	Training and experience
African American	1	Conduct interviews/analysis/report writing	Public health/ qualitative researcher (PhD)
White	3	Coordinate study/ Conduct interviews in English and Spanish/analysis/report writing (1)	Public health/Sociology/ qualitative researcher (PhD)
		Fidelity check interview transcriptions vs recording (1)	Biology and neuroscience (BS)
		Transform interviews into a script for a theater piece (1)	Theater, Actor (MFA)
Latina	1	Conduct interviews in English and Spanish/analysis/report writing	Public health (MPH)



# Methods (January 2020 – August 2021)

- Qualitative Methods and Approaches
  - Semi-structured interviews (English and Spanish), Verbatim transcription
- Recruitment: Women/Medicaid Consumers
  - Partnerships with local organizations
  - Participants (N=30) completed interviews by phone with a trained member of study personnel
  - Compensation (\$50 gift card) was mailed to participants post-interview
- Narrative Analysis used to understand the multiple dimensions of participants' experiences.



### ORGANIZATIONS PARTNERING FOR PARTICIPANT RECRUITMENT

Organization	Location
Family Solutions	Orangeburg
BirthMatters	Spartanburg
PASOs	Columbia
Power in Changing	Columbia
MUSC Women's Reproductive Behavioral Health Division	Charleston





#### Are you currently pregnant? OR Did you have your baby in the last 12 months?

We'd love to talk with you! The Voices Project would value hearing about your experiences. We are working throughout South Carolina to provide better support to pregnant women and to women who recently had their babies.

#### Who can participate?



#### What will you do?

You will participate in an interview with a Voices team member. The interview will last approximately 45 minutes to one hour. We'll conduct the interview by phone to make sure you feel safe in this time of COVID-19.

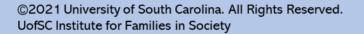
#### What will you receive?

You will receive a \$50 gift card to thank you for your time.

If you are interested in participating or would like more information, please call us at (833)286-4237 or (833)2VOICES or email ifsreports@mailbox.sc.edu.





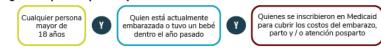




#### ¿Está embarazada? 0 ¿Tuvo su bebé en los últimos 12 meses?

¡Nos encantaría hablar con Ud! El Proyecto Voces valoraría escuchar sus experiencias. Estamos trabajando en todo Carolina del Sur para brindar un mejor apoyo a las mujeres embarazadas y a las mujeres que recientemente tuvieron sus bebés.

#### ¿Quién puede participar?



#### ¿Cómo participar?

Participará en una entrevista con un miembro del equipo de Voces. La entrevista durará aproximadamente de 45 minutos a una hora. Realizaremos la entrevista por teléfono para asegurarnos de que se sienta segura en este momento de COVID-19.

¿Oué recibirá?

Recibirá una tarjeta de regalo de \$50 para agradecerle por su tiempo.

Si está interesada en participar o desea obtener más información, llámenos al (833)286-4237 o (833)2VOICES o correo electrónico ifsreports@mailbox.sc.edu.

Deje que se escuche SU voz. ¡Póngase en contacto con el proyecto Voces hoy!





# Methods (January 2020 – August 2021)

- Qualitative Methods and Approaches
  - Semi-structured interviews (English and Spanish), Verbatim transcription
- Recruitment: Health Care and Social Service Leaders
  - Purposive sampling: experts and leaders in maternal health care, social services, community leaders
  - Participants (N=33) completed interviews by zoom with a trained member of study personnel
- Narrative Analysis





#### Who are we?

The project, Pregnancy and Birth Inequities in the Context of the COVID-19 Pandemic is being undertaken by The Institute for Families in Society at the University of South Carolina with partial funding from the South Carolina Department of Health and Human Services (SCDHHS). (UofSC IRB approved Pro00100005)

#### What issues guide the Voices Project?

As pregnancy, birth, and postpartum inequities continue to exist across South Carolina, particularly within the state's most vulnerable and resource-disadvantaged populations, the COVID-19 pandemic has presented new challenges. We recognize that health care and social service leaders throughout the state are working hard in these unprecedented times to provide services to these women and their families throughout their pregnancy, birth, and postpartum experiences. This critically important work offers insights surrounding maternal and newborn care delivery that need to be heard.

#### What is the Voices Project doing?

We are conducting interviews with women and service leaders throughout South Carolina who participate in the Medicaid program to cover the costs of pregnancy-, birthing- and postpartum-related care.

#### Why are the interviews important?

We want to bring the voices of currently or recently pregnant women, along with those of health care and social service leaders, directly to discussions about policies and practices related to Medicaid and pregnancy-, birthingand postpartum care, especially as new solutions and approaches are tried during the pandemic.

#### Who should participate?

Health care and social service leaders and stakeholders throughout South Carolina—including ObGyn, Pediatric, and Family Medicine providers, community organization leaders, and Community Health Workers—who provide care to pregnant, birthing, and/or postpartum women who use Medicaid to cover the costs of their care.

#### What will you do?

You will participate in an interview with a Voices Project team member. The interview will last approximately 30 to 45 minutes via phone or Zoom to make sure you feel safe in this time of COVID-19.

If you would be willing to participate in an interview call or would like more information, please contact us at (833)286-4237 or (833)2VOICES or at ifsreports@mailbox.sc.edu.



#### Who are we?

The project, Pregnancy and Birth Inequities in the Context of the COVID-19 Pandemic is being undertaken by The Institute for Families in Society at the University of South Carolina with partial funding from the South Carolina Department of Health and Human Services (SCDHHS). (UofSC IRB approved Pro00100005)

#### What issues guide the Voices Project?

As pregnancy, birth, and postpartum inequities continue to exist across South Carolina, particularly within the state's most vulnerable and resource-disadvantaged populations, the COVID-19 pandemic has presented new challenges. We recognize that health care and social service leaders throughout the state are working hard in these unprecedented times to provide services to these women and their families throughout their pregnancy, birth, and postpartum experiences. This critically important work offers insights surrounding maternal and newborn care delivery that need to be heard.

#### What is the Voices Project doing?

We are conducting interviews with women and service leaders throughout South Carolina who participate in the Medicaid program to cover the costs of pregnancy-, birthing- and postpartum-related care.

#### Why are the interviews important?

We want to bring the voices of currently or recently pregnant women, along with those of health care and social service leaders, directly to discussions about policies and practices related to Medicaid and pregnancy-, birthingand postpartum care, especially as new solutions and approaches are tried during the pandemic.

#### Who should participate?

Health care and social service leaders and stakeholders throughout South Carolina—including ObGyn, Pediatric, and Family Medicine providers, community organization leaders, and Community Health Workers—who provide care to pregnant, birthing, and/or postpartum women who use Medicaid to cover the costs of their care.

#### What will you do?

You will participate in an interview with a Voices Project team member. The interview will last approximately 30 to 45 minutes via phone or Zoom to make sure you feel safe in this time of COVID-19.

If you would be willing to participate in an interview call or would like more information, please contact us at (833)286-4237 or (833)2VOICES or at ifsreports@mailbox.sc.edu.



# Findings

### Interviews with Women\* participants and Leaders

\*All participants identified as women



#### TABLE 3. VOICES/VOCES WOMEN/CONSUMER PARTICIPANTS (N=30)

Descriptor	Ν
Race/Ethnicity (self-defined)	
Black/African American	22
Latina/Hispanic	7
Bi-racial	1
Age (mean)	
Black/African American/Bi-racial	28 years (n=22)
Latina/Hispanic	37 years (n=7)
Bi-racial	25 years (n=1)
Number of pregnancies, with current (mean)	
Black/African American	3
Latina/Hispanic	4
Bi-racial	1
Number of children (mean) <sup>1</sup>	
Black/African American/Bi-racial	2
Latina/Hispanic	3
Bi-racial	1
Primary language (language of interview)	
English	23
Spanish	7
Country of origin	
Mexico	4
Guatemala	1
Honduras	2
Pregnancy status at time of Interview	
Pregnant	16
Postpartum	14
Housing status during pregnancy	
With stable housing	28
Without stable housing	2*
Intimate partner violence during current pregnancy	
Yes	2*
Substance use during current pregnancy	
Yes	2

\* In both cases, women experienced unstable housing while escaping intimate partner violence.

©2021 University of South Carolina. All Rights Reserved. UofSC Institute for Families in Society



Institute for Families in Society Improving Policy, Advancing Practice. Strengthening Communities and Family Well-Being.

### WOMEN'S PARTICIPATION BY COUNTY (N=30)

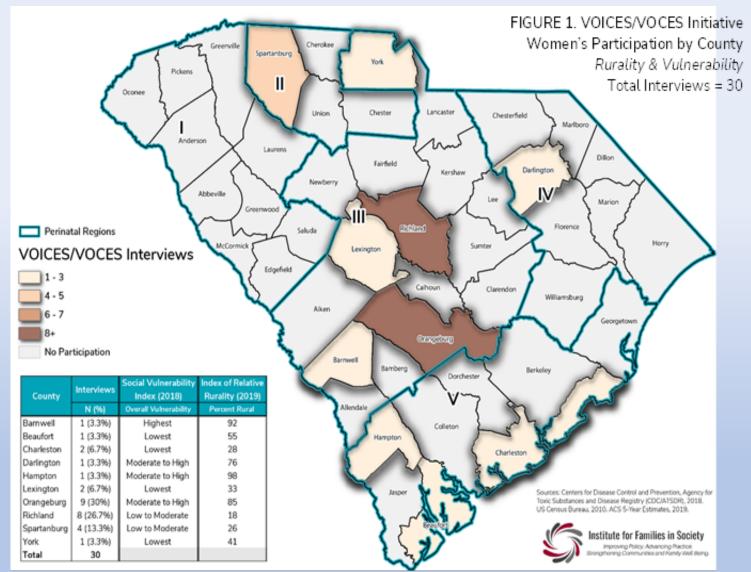
County	N (%)	
Spartanburg	4 (13.3%)	
Charleston	2 (6.7%)	
Richland	8 (26.7%)	
Orangeburg	9 (30%)*#	
Barnwell	1 (3.3%)#	
Hampton	1 (3.3%)*#	
Lexington	2 (6.7%)	
Beaufort	1 (3.3%)	
York	1 (3.3%)	
Darlington	1 (3.3%)*#	
Total	30 (100%)	

#### **NOTES:**

- Indicates a county that is in the Top 2 Quartiles of the CDC Social Vulnerability Index (SVI), 2018. Source: <u>storymaps.arcgis.com/stories/</u> <u>691f93b9a82e4fb4a64c336460974653</u>
- # Indicates a county that encompasses "High Need Areas" (additive scores of 7-8; 9-11).

Source: ifs-mpr.maps.arcgis.com/apps/MapSeries/index.html?appid=62df61343f4e432698523d15726098b7





Map developed by Institute for Families in Society (IFS) - Data Science & Visualization Team. Created August 2021



#### LEADER PARTICIPANT INTERVIEWS

Participant/Participant Organization	SC Location	# People interviewed
South Carolina Hospital Association	Columbia	1
University of SC School of Medicine	Columbia	1
Alliance for a Healthier SC	Columbia	1
Family Solutions	Orangeburg	1
Center for Community Health Alignment	Columbia	1
SC Community Health Worker Association	Columbia	1
Prisma Health-Midlands	Columbia	1
South Carolina Office of Rural Health	Lexington	1
PASOs Statewide	Columbia	2
PASOs Greenville	Greenville	1
PASOs Spartanburg/ CHW Reproductive Health	Spartanburg	3
PASOs Beaufort/Jaspar	Beaufort	1
PASOs Richland	Columbia	1
Good Samaritan Clinic	Columbia	1
Outreach specialist, Midlands Healthy Start, Prisma Health, Midlands	Columbia	1
BirthMatters	Spartanburg	3
MUSC Women's Reproductive Behavioral Health Division	Charleston	10
Independent Doula	Columbia	1
Independent Pediatrician	Columbia	1
TOTAL	33	



# Results Highlights

Inequitable treatment

### Awareness of inequities

Respectful, culturally appropriate care

Access to resources

Mental health concerns and access

### Inequitable Treatment

"I felt so judged and like belittled and like a statistic that I just stopped going to my appointment, and I just ended up giving birth...But that wasn't good, because that could've possibly been a DSS case."



## Awareness of Inequities

"A lot of my patients know about the maternal mortality rate being higher in Black women. They are in these mommy blogs. They're online. They're reading their own information. They have their support group. And so it's not really a secret anymore that Black women are treated differently in labor and so they were scared." (Health care provider)

"...then the social pandemic hit of the killing of Breonna Taylor and George Floyd and Ahmaud. And that stressed me out seeing it all over social media. I was so bad that my blood pressure was almost in the 200s. It was so high. I was so stressed out every night because I would look and it was like a new case was coming or somebody just opened up an old case."



## Respectful, Culturally Appropriate Care

"My most important recommendation is that there be a person physically present in Medicaid offices who speaks Spanish, one or two people. I don't think the volume is that high for-but a lot of people do go daily. And they stop going to the offices because there is no one to attend to them in Spanish. That's very important to me. We have all the information, because we print it directly from the website, but it's us who look for it [the information], we look for it in Spanish. But in the [Medicaid] offices there is no information in Spanish." (Social service leader)



### Access to Resources

"I have a doula through BirthMatters....She would come and talk to me. She got me a counselor that I could talk to, also. And she would help me get things for my baby."

"...COVID is, honestly, just really messing stuff up because I still haven't even been able to get to my appointments to get back on seizure medications so I can get cleared to go back to work."

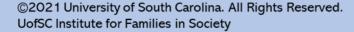


## Mental Health Concerns and Access

"It was – honestly, when this whole COVID thing just came, I was scared. Honestly. It scared me, because I was on social media seeing how it was affecting pregnant women and I didn't even leave my house. I was scared."

"I was even scared to go to my doctor's appointment. I'm like, "What if I go and I contract it from a doctor, from my nurses, you know?" I didn't even want to go to the grocery story. I was sending my husband out."

"And so, it's even another layer of sort of frustration and inconvenience that we've got this program that's ingrained in our OBGYN field, but then we can't help a significant minority of their Medicaid patients because they don't cover any type of mental health services whatsoever." (Mental health professional)





## Part II: Theatrical Performance October 2021



©2021 University of South Carolina. All Rights Reserved. UofSC Institute for Families in Society

## **VOICES/VOCES:**

### Pregnancy, Medicaid, & COVID-19

A play in Spanish and English based on interviews with women using Medicaid for pregnancy-related healthcare

#### Written and directed by Patti Walker

With Adeline Badillo, Aaliyah Broadwater, Jasmine Davis, Kristen Javis, Charlene Jones, and Miranda McDermott



Booker T. Washington Auditorium 1400 Wheat St. Columbia, SC 29201

NOTE: Seating is limited to 131 as a COVID-19 precaution.



#### Free Admission

Please register through EventBrite at **tinyurl.com/ncasa22r** 



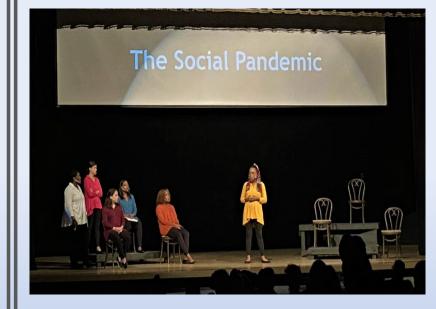
VOICES Project @ IFS

Improving Policy. Advancing Practice. Strengthening Communities and Family Well-Being. ©2021 University of South Carolina. All Rights Reserved. UofSC Institute for Families in Society

Yes. I think it was the most sad thing of my life, because I started to feel nauseous, I started -I mean, I didn't feel good anymore, because I've never been like this with my pregnancies, I've not had symptoms of anything.



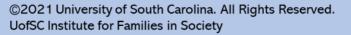




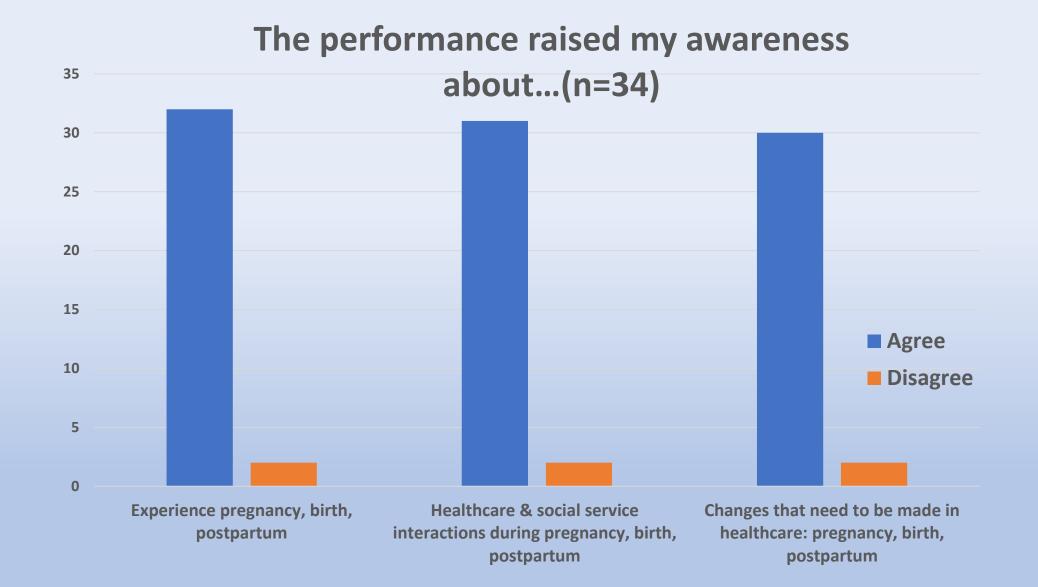
DISSEMINATION THROUGH THEATER SHARING RESULTS FOR IMPACT

Created and Directed by Patti Walker

## **Post-Performance Feedback**









I think that using research-based drama is an effective way to raise awareness among my peers (n=33)



**Number of Respondents** 



### Most important messages

- There is a need for more representation, access, and affordability for minority families.
- Advocating for patients needs and meeting them where they are.
- Child-bearing is expensive, inaccessible, and traumatic for many.
- No one knows their body better than themselves.
- Some of the same issues are the same I experience some 40 years ago.
- We need to believe women and their experiences and take the information we learn to make change and increase equity of care
- Listen! We need to listen/work on issues faced.
- Listening to your patients is one of the most important thing a physician can do
- The importance of empowering women to trust their intuition and use their voices. And that we all have a part in this empowerment. We can all take action and be of service.
- Black and Latinx women enter the hospital to give birth with the thought they may not live to walk out the door.



### Actions inspired for next six months

- This is motivating me to get more involved in research regarding MCH
- Right now, there is not much I can do but when I am working in the medical field, I will be able to work in collaboration with my patients rather than working "over," them.
- I will tell as many people as I can about the details I saw in the performance.
- Through the results of my academic research, I will promote the implementation of intervention programs, and government attention.
- To better communicate with pregnant, birthing, and post -parturition people.
- Share messages with family, friends, and associates.
- See all issues through the lens of equity
- Teach young women how to have a voice
- Make providers aware of the inequity when it happens
- I plan to reach out to birthing centers in my area to see how I can help.
- Listening more!
- Share the messages with others and explore policy issues, i.e., payment for doulas.
- First, encouraging others to listen to the voices of those experiencing these issues rather than making assumptions about their needs
- I want to say yes, but I don't know how I can be useful.



### Recommendations

Listen to women/consumers and incorporate their insights into strategies moving forward

"I do feel like Black women can get left at the wayside. I just think that that's so unfair. I feel like if I'm telling you that I feel like something's wrong or something is off, don't just kind of brush me off, even if you have heard it 1,000 times before."

*"I understand that you're the medical professional. But when I'm telling you, just please listen. Like, maybe it's something that I'm feeling that you can't see in my chart, just listen to me."* 



### Recommendations

- Engage community-care resources trusted by community members in strategies for improving access to SC Healthy Connections
- Invest in interventions that bridge the gap between community and health care: Community Health Workers and Doulas







### Recommendations

- Increase access through telehealth, especially for rural areas
- Ensure Medicaid information and language access
- Conduct outreach with information about Medicaid
- Increase access to prenatal and postpartum mental health services







### What's Next?



- Health care, social service, public health professional training (pre- and in-service)
- Informing policies and practices
- Ongoing Community engagement
- Connection and collaboration with local, state, national and global efforts toward implementing human rights standards in education, policy, and practice
- Ongoing processes to include consumers/beneficiaries in discussions and elaboration of policies and programs



## Thank you

We wish to acknowledge the valuable contributions made by the women who participated in these interviews shared their stories. We also acknowledge the health care and social service professionals and community leaders who shared their perspectives and insights to help us all better understand the pregnancy and postpartum experiences of women who use Medicaid.

For more information, please contact:

Ana Lòpez-De Fede, PhD Institute for Families in Society University of South Carolina 1600 Hampton Street, Suite 507 Columbia, SC 29208 adefede@mailbox.sc.edu (803) 777-2098



