**SUPPLEMENT MATERIAL**

**Interview Guide**

**Narrative and understanding:**

* I want to hear your story.
  + First interview: When did you first find out that your baby could have a heart problem? How did you get to the Fetal Cardiology Clinic?
  + Second interview: I want to hear your story since your first visit to the Fetal Cardiology Clinic. What has happened?
* What did you learn from your appointment?
  + Can you describe what is going on with your baby? What is your understanding of your baby’s diagnosis and how it might affect his life and your family’s life?
  + Can you describe the options you have in your own words?
  + Do you have questions about what is going on?
  + Are there things you wish you knew or did not know?

**Role of the providers:**

* What was your experience at the Fetal Cardiology Clinic?
  + How did you feel during the ultrasound? During counseling?
  + Did you feel like you understood what was going on?
  + How do you feel about the amount of information you were given?
    - What was important?
    - Are there things you wish had been communicated differently?
  + Some parents say that when they hear a diagnosis, they then go blank and hear nothing else. Others say that they become extra focused and remember every word. How did you respond to hearing the diagnosis?
* What do you remember most about the providers in Fetal Cardiac Clinic?
  + Was there anything that stuck out to you?
  + Is there anything that could have gone differently?

**Anticipation:**

* What is the next step?
  + How will you prepare?
  + What will be your role?
  + What does this problem mean to and for you and your family?
* You are going through a clearly stressful time in life.
  + What is your greatest fear? What are you most worried about?
  + What are you and your family hoping for?
  + What do you imagine for your child?

**Influencing factors:**

* On a 1 to 10 scale, how much control do you feel like you have? Why?
* On a 1 to 10 scale, how stressed are you currently? Why?
  + What are some of the other things going on in your life?
  + How has the stress been affecting your family?
    - Do you have any other children?
    - Do you care for anyone else?
  + How is this affecting your job?
  + Is there anything in your personal medical history or in your family’s medical history that has prepared you in any way for this experience?
* On a 1 to 10 scale, how well do you think you are coping?
  + How are you coping?
  + How do you typically respond to stress or difficult times?
  + How are you now coming to accept this diagnosis and move forward in life?
* On a 1 to 10 scale, how supported do you feel?
  + Where are you getting support from?
  + Family? Friends? Internet? Church?
  + Have your relationships been impacted during this pregnancy?

**Resilience and empowerment:**

* How difficult has this experience been for you? For your family?
  + Does anything make it better?
  + Can you think of anything your provider could do to make it better?
    - Identify another parent to talk with?
    - Give you a letter that details your child’s condition simply?
    - Provide a list of reputable websites?
    - Identify a specific support group?
* Imagine a parent like you was referred to Fetal Cardiac Clinic for evaluation of a similar diagnosis:
  + What would you tell them to expect?
  + What questions would you suggest they ask?
  + What would you want the physician to make sure to say or do?