

REDUCING THE INFANT MORTALITY RATE IN HAMILTON COUNTY



Infant Mortality Collaborative Focus Groups

Summary Report

Prepared for
Cradle Cincinnati
The Center for Closing the Health Gap

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Infant Mortality Collaborative Focus Groups Executive Summary

The most important factor

The 47 focus group participants determined that the most important factor in reducing infant mortality in our community is: *access to education and information that is relevant to cultural, social, spiritual, and economic needs of the targeted group, including respect for the individual's values, preferences and expressed needs, approach to problem-solving, communication needs, involvement of family, emotional support and alleviation of fear, anxiety and mistrust.*

Major Themes

The following major themes describe the factors of the high infant mortality rate in Cincinnati and Hamilton County.

1. Alcohol, tobacco, and other drugs is the number one factor affecting a woman's health BEFORE pregnancy.
2. Alcohol, tobacco, and other drugs is the number one factor that affects a woman's health and her baby's health DURING pregnancy.
3. Visiting the doctor is the number one factor that affects a baby's health AFTER it is born
4. Self-directed healthcare management
5. Fear, anxiety, or mistrust of healthcare systems
6. Male and Female Relationships
7. Cultural and social pressures
8. Lack of education, information, and access to healthcare system

Recommendations

"Knowledge is power. When you know better, you do better."

1. Provide access to education and information that addresses the specific cultural, social, spiritual, and economic needs of the targeted group, including respect for the individual's values, preferences and expressed needs, approach to problem-solving, communication needs, involvement of family, emotional support and mitigation of fear, anxiety and mistrust of healthcare systems.
2. Accurate, timely, and relevant healthcare information should be accessible using a "trusted" website.

Introduction

Cradle Cincinnati brings together diverse partners who refuse to accept the high infant mortality rate in Cincinnati and Hamilton County. The Center for Closing the Health Gap leads the effort to eliminate racial and ethnic health disparities in Greater Cincinnati through advocacy, education, and community outreach.

Together Cradle Cincinnati and the Center for Closing the Health Gap have combined forces to answer: What factors do community members see as the most important reasons for our community's high infant mortality rate? The focus groups followed these three themes: what factors keep women from being healthy enough to start pregnancy, what factors keep women from having a healthy pregnancy where the baby is born full term, and what factors keep babies from reaching their first birthday healthy.

Methodology and Participant Profile

The goal of the Infant Mortality Collaborative Focus Groups was to gather information from Cincinnati urban residents about their perceptions about: *What causes our community's infant mortality rate to be so high?*

Because of the inequalities when it comes to birth outcomes in the African American community, six focus groups were made up of African American women ages 18-44 and one was made up of men ages 20-44. Recruitment efforts included vulnerable women in Appalachian and Hispanic communities. In addition, a health questionnaire (Appendix P. 33) gathered information about decisions women make when accessing health care services for themselves and their baby.

Instrument Development

A ten-question instrument (Appendix P. 37) was designed for the 90-minute focus groups. The questions ranged from open-ended designed to obtain ideas and opinions or big-picture thinking to forced choice questions designed to determine if a member is drawn to a number one choice on a topic. Each open-ended and forced-choice question was fully discussed.

Profile of 47 Participants

Group 1: 8 women ages 18-20 from the Clifton Area

Group 2: 8 women ages 30-44 from Winton Terrace, Price Hill, Corryville, Northside, Cumminsville, and Avondale (one participant left midway through the focus group because she felt she was too old for the discussion).

Group 3: 7 women ages 18-24 from Carthage, St Bernard, Symmes Township, and Price Hill

Group 4: 6 women ages 18-24 from Clifton, Northside, Avondale, and Evanston

Group 5: 7 women ages 18-24 from Clifton, Westwood, Over-the-Rhine, and Avondale

Group 6: 7 men from Avondale and Mt. Auburn

Group 7: 4 women ages 23-31

Focus Group Location

All focus groups were conducted at the Center for Closing the Health Gap, 3120 Burnet Avenue, Suite 201, Cincinnati OH 45229, 513-585-9872.

Focus Group Results

For each question, the participant’s actual comments follow by focus group.

1. In general, how do you get information about healthcare for you and your family? (Multiple responses were made to this question).

<p><u>Group 1</u></p> <ul style="list-style-type: none"> • Doctor’s office • News: television news • News: print • Internet/websites (6x) • Family/parents 	<p><u>Group 2</u></p> <ul style="list-style-type: none"> • Websites/online • Doctor • Word of mouth or other people • I haven’t been to the doctor in 11 years. I talk to my sister (for health information). My children have insurance, I don’t • I work at St. Vincent DePaul, so I get information from their resources • Family, mail, friends • Health care provider; clinic
<p><u>Group 3</u></p> <ul style="list-style-type: none"> • Internet (3x) • Doctor (2x) • Dentist office • School, classes, discussions • Library—I am a pamphlet junkie • Pamphlets at doctor office or like in Kroger • Clinic, Health Clinic (2x) • Hamilton County JFS 	<p><u>Group 4</u></p> <ul style="list-style-type: none"> • My own research on Internet (4x) • Mayoclinic.com website • Family and friends (2) • School wellness center • Health promotions on television • Word of mouth
<p><u>Group 5</u></p> <ul style="list-style-type: none"> • Internet • Television • My mama and family • Newspaper • Neighborhood friends • Books/class/school • Pediatrician/hospitals/health professionals • Minority practitioners who have information relevant to my race 	<p><u>Group 6</u></p> <ul style="list-style-type: none"> • Internet (3) • Television (3) • Mental health professional (2) • Parents (2) • Doctor

2. Thinking about seeing a healthcare professional in the last year, have you ever felt uncomfortable or believed you were treated badly because of your race or income level?

Group 2 – group agreement that it is more about income than race

- I am looking for a different provider right now because my doctor serves low-income people. I don’t feel like I get real answers to my questions
 - “I felt this before and then changed doctors/clinic”
- It depends on the type of insurance you have and how they treat you, they don’t tell you everything they could
- With private insurance, the doctor spends more time with you

- The issue is an economic one causing the differences, and not race
- It's about color... and the color is green!

Group 3

- I went to the emergency room ; they were slow to provide care until someone I knew (a white nurse) acknowledged me, and she knew they were not providing the right treatment; then the treatment got better
- “My doctor doesn't understand the cultural needs [prevalence of disease in AA community]. If I ask for a screen to know my levels, she doesn't take it seriously – e.g., diabetes runs in my family and she said no because she felt I was too young, saying you don't have to worry. But I want to know in order to [manage my health] prevent issues.”

Group 5

- Hospital discriminated a lot against (1 person)
- Another woman: I went to the hospital with extreme pain and the doctor did not listen to me describe how it started. He said I had food poisoning, gave me medicine, and sent me home. After 6 hours of pain, I went back to the hospital. They took a CAT Scan [CT computerized tomography] and discovered that my appendix had ruptured. Because of the length of time it took, I ended up with infection throughout my body. Then the same doctor changed his order for a leg pump [Sequential Compression Device (SCD)] that would keep me from getting a blood clot in my leg after the surgery. I felt bad from being sick, and felt worse because I don't feel the doctor listened to me or cared about what I.
- I had my first baby at age 16 and after two visits, the hospital told me not to come back because I did not have insurance, so I did not have prenatal care based on my financial status.

Group 6

- No medical insurance
- Social security benefits have been denied three times; I am depressed and cannot work
- Health problems deteriorating – trying to get SSI and doctors questioned me about my medical records and why he needed SSI
- I don't have problems because the Veterans Administration makes it simple.
- I have degenerative joint disease, when weather conditions change, my joints get extremely stiff; I have depression because of the severity of my disease and because I have no control over the condition—doctors do not understand why I have a problem accepting the disease. I do exercises and use home remedies that sometime make it feel a little better. I have been off work 50 weeks.
- No insurance so I have to go to clinic to get medicine

Focus group participants were provided the following definition and statistic about infant mortality. Each participant assured the facilitator that they understood the information, and was ready to proceed.

Infant Mortality Definition and Statistic

The definition for infant mortality is 'the death of children under the age of one year.'

The national average for infant mortality is 6%.

The Cincinnati average is 13%.

Babies under the age of one year old in Cincinnati die at twice the rate of other cities across the United States.

3. Preconception/Before Pregnancy. As far as you know, what causes unplanned pregnancies?

Group 1

- Unprotected sex
- Lack of knowledge about contraceptives
- Misuse of contraceptives—condom breaking or slipping off
- Multiple sex partners
- Participating in sex without thinking about the consequences

Group 2

- Lack of knowledge: “In my day, we had sex education in home economics classes at school. Our kids are not being educated, and it is not talked about at home or in school.”
- My parents “set me up” – they made parenting look easy so I thought it would be easy (NOTE: two parents raised her, her father was engaged in the family, there was love, and they were middle class.)
- I went through a molestation; I sought love (from the man and the baby); my lack of knowledge was not really understanding what it meant to be a mother
- We women are bottom line; we have to protect ourselves. I don’t think we love ourselves like we should
- Women are not strong enough to say NO and mean it when they say it.
- I wanted to fit in and feel loved. I wanted and sought out male affection. I didn’t have (a dad) in my home (growing up). NOTE: this woman got pregnant at 17
- Yes, my dad wasn’t around either
- Not using condoms
- No one talked about sex in my house growing up
- Not asking doctor about options like tying tubes
- I didn’t want to have side effects of birth control drugs
- Lack of communication with boyfriend is a big problem; when I’m pregnant is when he decides he wants to (finally) talk and (that is) he does not want the baby

- I think he loves me; he's thinking I'm a piece of meat
- Rape is unplanned pregnancy too
 - Girls and women need to tell (and they don't tell) when they have been raped because they get scared off by the person who raped them or they don't want the shame or they feel it is their fault
- Parents not talking/ teaching about sex
- I didn't have a clue of the consequences of sex; I got pregnant right out of the shoot, first time
- Un-natural sex was going on in my house...molestation and stuff. No one talked about sex because then I would know that what they were doing was wrong
- Not making the man wear a condom
- Women need to make their own decisions about having sex
- You can not only get pregnant, you can catch something you can't get rid of

Group 3

- Alcohol: one night on the town, meet a guy, and then wake up the next morning, and "the lady doesn't come to you for the next month" (slang term for missing monthly cycle.)
- Ohio doesn't teach sex education, so girls and guys don't know how to use a condom, not choose best birth control
- Rape by a partner or a known relationship (2 shook their head affirming this)
- Some men feel they can trap you or keep you if you are pregnant; that's how they control you
- Lack of parental guidance – you don't have anyone to turn to, so they hide it a long time
 - A family member hid her pregnancy until the baby was born
- Lack of planning: as females, we have to be prepared, not just the male; condoms are available to everyone
- Even in committed relationships, plan your future, babies should come in the right time span
- Lazy, unprotected sex without planning on it

Group 4

- Lack of birth control for women
- Rape is a cause when women don't know about 'Plan B Pill'
 - Religious reasons for keeping a baby after rape
 - If not forced by rape, then abortion is not an option
- Impoverished populations of women don't have the right information and education, they don't always realize what's at risk when having more sex and more early and unplanned pregnancies
- Belief that it [pregnancy] won't happen to me. I won't get pregnant, especially the first time
 - If he pulls out, I am safe
 - I had my baby early, but if I had it to do over, I'd do it different
- The cost of birth control is a burden/issue for some girls unless Medicaid or insurance is accessible
 - The shot and pill are expensive unless you have Medicaid or insurance

- Lack of sex education and communication
 - Not enough information commonly shared between partners
 - He thinks she is on birth control and she is not and she thinks he has condoms and he doesn't
 - Couples don't know who is responsible for what and they don't discover it until it is too late
- Lack of resources and opportunities
 - People act within what they know
 - College-rich communities have programs and information, but areas where there aren't institutions of higher education, the information is limited
 - Communities don't have money for youth programs

Group 5

- Unprotected sex
- Maturity level
 - Not understand or take responsibility for the consequences [baby] of their actions [sex]
- Based on how you are raised, the outcome of unplanned pregnancy
- Kids not having enough to do
 - Out of school, hanging out with local guys and get into trouble
 - Guys on the corner hounding after girls
- Thinking it won't happen to me
- Lack of knowledge about sexual health: I was never taught sex education
 - No sex education classes; low budgets in school don't allow for extra topics
- Social class: health and wellness has to do with your social economic class
 - Who raises you (parenting)
 - What you are taught (parenting)
 - Your parents don't have the information that you need
- Media: what's on television
 - You copy what you see; there is so much sex on television
- Then again, sometimes people make a decision opposite what they were taught—they make individual decisions

Group 6

- Lack of education
 - Girls and boys don't get information about sex education today the way I got it in high school years ago (3)
 - Kids today do not know about contraceptives
 - They don't know about parenting
 - High exposure to sex in the culture without a mature understanding about the responsibility and consequences
 - Not have information about the high rate of STD; syphilis and gonorrhea among ages 13-30 year-olds
 - Kids are having kids and raising kids without really knowing how to parent (4)

- Men are stubborn: they don't want to go to the doctor when they first feel that 'burning' sensation, they don't believe it is serious before they go to the doctor, and in the meantime, they continue to have sex
- Mis-education: men and women feel sex is better without a condom
- We blame unplanned pregnancy and too much sex on everything but what it is: no moral ethics or codes
 - We need to bring moral codes back into families
 - Codes like the 'bro [brother] codes' or code of honor among men: you don't date a girl in your best friends family and you don't date a girl that your best friend used to date, you don't run [pass] a girl through your group of friends and family
 - Today boys and young men feel: "get in where you fit in" which has no purpose or intention other than just plain having sex—no moral or ethics to this thinking
- There is peer pressure on girls and boys that have not had sex by a certain age

4. Name one issue from the list below that you think most affects a woman's health BEFORE Pregnancy. First, vote, and then we will discuss your choices as a group.

Focus Groups 1-7							Factors
3	3	1	4	1	0	2	Stress. Some people say that stress can affect a woman's health even before pregnancy, what do you think?
0	0	0	0	0	0	0	Weight. Some people say that being overweight or being too thin affects a woman's health before pregnancy, what do you think?
0	0	2	0	1	2	0	Support from loved ones. Some people say that an important part of a woman's health before pregnancy is how supported she feels by her family, friends and community, what do you think?
0	0	1	0	0	0	0	STDs. Some people say that whether or not a woman has a sexually transmitted disease like chlamydia, gonorrhea or syphilis before pregnancy affects her health, what do you think?
1	4	0	1	4	3	2	Alcohol, Tobacco, and Other Drugs. Some people say that smoking and/or drinking too much or using drugs can lead to poor health before pregnancy, what do you think?
0	0	3	0	0	0	0	Housing. Some people say that having a safe place to stay can affect your health before pregnancy, what do you think?
3	1	0	0	0	1	0	Going to the doctor. Some people say that regularly going to the doctor is important for a woman's health before pregnancy, what do you think?
0	0	0	0	0	0	0	Having another baby too soon. Some people say that if you get pregnant too soon after having one baby, the next baby will not be as healthy, what do you think?
1	0	0	1	1	0	0	Planning. Some people say that whether a woman gets pregnant on purpose or by accident can affect the health of her baby, what do you think?

Why did you choose the item you selected about what most affects a woman's health BEFORE Pregnancy? NOTE: Even though we required a forced choice response, when we opened the topic for discussion, women had multiple feelings about some factors as seen with the responses below.

Group 1

- Stress: I saw someone miscarry from stress – I was living in the same house with her
 - Stress can be the lack of eating, weight loss, I get sick when I am stressed
- Going to the doctor: Baby can be born of retardation if you don't know your own health
- ATOD: Drugs stay in your body and have effects on your organs
- Planning: Not supposed to have a baby within a year of the first one – I learned this at a class at UC

Group 2

- ATOD: changes you and your body and causes you not to be healthy
 - It affects your mental health
 - It alters your thinking – can't make best decisions
 - Could sleep with lots of people and get STDs
- Stress: can bring on a lot of things health-wise, due to my molestation, my first baby came through rape. I was not thinking about the baby, so when it came, it was like “bam,” and I wasn't prepared. I was an athlete, running track and going to school, trying to stay active, and the boy raped me at school. I was pregnant 5 months before I even knew it (NOTE: she was used to not getting periods as an athlete)
 - Another woman accounted: My house was stressful already and then to have a pregnancy as a teen, the wrath and shame from my mom, grandma, aunt and uncle, the stress was huge; I had high blood pressure and diabetes. I was on bed rest for 6 months.
- Going to the doctor: My daughter-in-laws had miscarriages and they didn't go to the doctor. If they had gone, they may have known why they couldn't carry their baby full term because their bodies were not healthy.
 - I haven't been to the doctor in years. I just pray a lot (This is the woman who said she hadn't been to doctor in 11 years previously)
 - Got to take care of self. I've always been more into herbal/natural food and stuff—I've done research to make decisions about natural medicine
 - *I had STD when I got pregnant; it was transferred to the child. If I had gone to the doctor before the birth, I would have known that gonorrhea would show up in my baby's eyes at birth (and could do something for the baby ahead)*

Group 3

- Housing: A roof over your head is the first thing. Not having a stable place can be stressful to a baby
 - Housing can affect baby – Cincinnati Metropolitan Housing Authority and Section 8 are stressful – rigorous process is stressful. And if your income changes it can affect your home
 - Housing should be #1 because it is the protection of your child; some places still have lead-based paint which is unhealthy for your baby
 - Your child needs room to grow and develop like it should
- Stress: greatly affects health, work, family, school, housing and every other part of life
 - Our society waters down the racial stress in our community—it is a constant part of our lives. Some whites will ignore me when I am shopping, but they don't ignore my white

neighbors. (I am profiled) I was in grocery store in my neighborhood and they are always stopping my lane with stupid questions; in school, teachers are constantly questioning my intelligence, constantly double checking my information

- If father is not present, it is stressful (financially and emotionally). If you feel alone, abandoned, you end up with strangers raising your child.
- Support from loved ones: you need a village to raise a child. If father not present, that is detrimental – prenatal appointments (don't happen), financial (lack).
 - Family helps you from feeling alone and abandoned
- STD is top for me because it can have effect on your reproductive systems

Group 4

- Stress: when stressed, I can go 4 months without a period, I'm tired and loose or gain weight
 - Can be the reason for all the other choices on the list
 - Bone density issues
 - Diabetes
 - Heart disease
- ATOD – stood out more to me
 - Drinking and any of the things on choice in excess is not good for you or a baby
- I was split on this decision because I think going to the doctor is also important. STD's that go too long can leave you sterile; I got chlamydia and had no clue about it
- Planning – if you know you are pregnant, you'd have habits that you would otherwise stop

Group 5

- ATOD
 - Takes a toll on the body whether you realize it or not – it hurts the baby especially when you don't know you are pregnant yet
 - This is also the root cause of so many STDs
 - Habits are hard to break—don't want to stop, can't stop, people say, “Oh, it will be okay.”
 - I used ATOD with my last 2 children – marijuana with one and alcohol with the last one. Stress caused me to take drugs alcohol. ‘I'm one of the lucky ones’ because both are healthy. I knew marijuana was bad but I did it anyway. I stopped after research about what alcohol can do to a baby
- Stress from abuse: when a man beats on a woman when he doesn't know she is pregnant; it affects the body
- Support of loved ones—something is causing the stress because you are not feeling the love in the family
 - ATOD fills the void—trying to be happy and using ATOD to substitute for love
- Planning – when pregnancy is unplanned, mom can be so stressed that she doesn't care about the baby at all.

Group 6

- ATOD

- Girls and young women smoking blunts (marijuana rolled into cigar or cigarillo wrappers rather than regular cigarette paper) and they get taken advantage of because they get so high
- Allowing drug dealers move into their apartment so they have access to more drugs
- With getting high being so casual—kids get drunk, smoke weed all night, which makes it easy to make bad decisions
- Support from loved ones
 - Today young mothers are raising young mothers because their own girls are getting pregnant in their early teens
 - Young mothers don't know what it takes to raise kids the right way because they themselves were not raised the right way
 - If you are not raised to have strong family foundation with values, then you will not be strong and you have nothing to pass down to your own kids
- Going to the doctor
 - Men don't go, they don't want to discuss things with their doctor
 - They are not honest with the doctor, not open because they feel ashamed or embarrassed, they think the doctor won't relate to what is going on so they don't share the truth
 - a man's doctor almost has to be a mind reader to figure out what is really going on because the man won't tell (4 participants nodded and voiced agreement)
 - Men believe they are not supposed to cry so they see the doctor as a place they have to be vulnerable, so they don't go

5. **Now we are talking about DURING Pregnancy. What are some of the reasons a pregnant woman does not always get the social and emotional support she needs?**

Group 1

- When baby is not the first priority of anyone having to do with the baby
- A person in her life may not understand her needs, like a man
- Some fathers of babies are not around
- Family may not agree with the decision to keep the baby
- Lack of resources – not know where to go if, say, she has depression
- Some people in her life may lead her to a negative route (i.e., abortion)
- (Then another woman said): Sometime having an abortion can be the right thing
- Some people may judge you because you are pregnant (implying that to avoid judgment, mom may avoid getting the support she needs)
- If the guy (father) doesn't want to keep the child

Group 2

- I did not know the consequences of sex the first time. He said he loves me—I was just a body to him
- He does not want to have the child

- They (other family members and friends and others) are judging you, they forget they were young once.
- Some of the stuff that was done to me (i.e., rape/molestation) was from friends of (my) brothers in the house where I was raised, and still I was judged
- My father told me as long as you are alive, I will make sure you and your baby will be okay (this is from the woman who felt that the life her parents created for her “tricked her” into thinking parenthood was easy)
- I was 26 when I got pregnant – made me grow up a lot faster. My number one worry was how I would take care of this baby.
- I was raped at 14 (at school) I didn’t have support. My next (male) relationship was abusive—he busted my lip. I was looking for love after being raped and I got pregnant again.
- Some women believe that if she gets pregnant, she might be able to hold on to [control] the man
- Self-esteem, mental health problems can keep you from being close to other people

Group 3

- Loss of home, sometimes homeless,
- Living place to place
- Unaware of public housing
- Issues with the father of the child and chooses to remove herself –something causes her to leave
- Mom comes from a broken home in the first place so she doesn’t know how to make places to be well
- Loss in general—job or husband
- Mental Illness
- Poverty
- Doctor may not provide the pamphlets needed
- Don’t have information – counseling, Tai Chi to calm nerves,
- [Judgment] because you disappointed family – “You gonna take care of the baby yourself,” e.g. I got pregnant and then immediately got pregnant again

Group 4

- People judge you when you are too young or even when you are too old because sometimes your baby can be at risk either way
- If people don’t approve of the partner—family, friends, community, different religion, inter-racial—it all depends on how closed or small is your community of family and friends
- LGBTQ: at school, I learned that the lesbian, gay, bi-sexual, transgender, and questioning community struggle with the same issues of sometimes not having emotional and social support at home
 - They have high rates of homelessness; their families ostracize them when someone within that group chooses to get pregnant
- Lifestyle: a 22 year-old, pregnant with no job, and the boyfriend is a bum
- Stress: religion shuts you out and then family shuts you out
- Based on who the partner is—will they stay with you—a pregnant woman when the man is not part of your life
 - When the father denies the baby and perhaps denies other children

Group 5

- People don't agree with your pregnancy or your age or the person the mom is with
- Domineering parents, don't communicate, parents tell their children, "do what I tell you to do."
- Health care is not accessible
- One woman said her mom put her on birth control at age 16 even though she was not sexually active because getting pregnant is not an option, "We don't want to pay for abortion or take of any baby."
- There is a cultural difference in what black and white mothers tell their daughters. It all boils down to how a girl is raised and what her mother tells her about teen pregnancy

Group 6

- Unrealistic expectations—we can't read a woman's mind we don't always know what she wants emotionally and socially, especially when she is on her period [menstrual cycle]
 - Men need a plan for what a woman wants
 - I walk on eggshells when my woman is on her period [menstrual cycle] because I don't know what will set her off
 - Women—are not proactive, do not ask for what they want, they don't tell what's on their mind
- Anything the man [man in her life at the time or the baby's father] or the mother does effects the baby
- I used to sleep with my son on my chest—I could feel the rhythm of his breathing connected to mine—a lot of men don't understand or know about that kind of emotional connection because no man ever connected with them in that way
 - Another man said: I rubbed my woman's feet when she was pregnant, I didn't want her to do anything that stressed her out emotionally
- Stress is bad for the baby, the woman needs that person who is supporting them, she needs someone emotionally
 - Young girls are stressed
 - Stressed when she is telling the guy she is pregnant
 - One guy told the pregnant girl, "here is \$2,000, so what are you going to do?"
 - A girl I know lost a baby due to miscarriage because she was so stressed out about whether to keep it or abort

6. Name one issue from the list below that you think most affects a woman’s health and her baby’s health DURING pregnancy. First, vote, and then we will discuss your choices as a group.

Focus Groups 1-7							Factors
5	2	3	5	4	3	1	Alcohol, Tobacco, and Other Drugs. Some people say that smoking, drinking too much or using drugs can lead to poor health during pregnancy, what do you think?
2	2	2	1	1	1	1	Going to the doctor: Some people say that it is important to go to the doctor regularly during pregnancy, what do you think?
1	0	1	0	0	0	1	Having the baby too early: Some people say that when a baby is born too early (before 39 weeks or 9 calendar months), it will not be as healthy, what do you think?
0	3	0	0	0	2	1	Disease: Some people say that if a pregnant woman has a disease like diabetes or hypertension (high blood pressure) during pregnancy, it is not good for her baby, what do you think?
0	0	0	0	2	0	0	Childbirth History: Some people say that if a pregnant woman has had other babies that were born too early (before 39 weeks or 9 calendar months), it is more likely to happen again, what do you think?

Why did you choose the item you selected? NOTE: For all items, even though we required a forced choice response, when we opened the topic for discussion, women had multiple feelings about some factors as seen in the responses below.

Group 1

- ATOD: I took a class and alcohol and drugs are not good for mom or baby
 - When ATOD is the priority, the baby is not first priority for mother
 - I had complications when my baby was born and everybody hated me because it was due to my use of alcohol and drugs
 - I used for 13 years; I went into treatment and I stopped using cocaine, but did not stop marijuana; the doctor explained the effects of it so I put myself into treatment
- Going to the doctor: doctor can help you with options in birth delivery
 - Child development disorders happen when the mother is not healthy during pregnancy; I could not stop smoking cigarettes and pot; I didn’t think my son would be born with diabetes and breathing problems—I was really selfish and did not want to stop what I had always done
 - Going to the doctor helps you find out about options—birth plan or delivery plan
 - Going to the doctor gets you vitamins
 - Going to the doctor helps you find out if you have diabetes or high blood pressure
 - Going to the doctor helps you find out if something is wrong with the baby
 - Older women go to the doctor to avoid problems occurring with the pregnancy
- Having baby too early: Miscarriages happen when mom is not healthy

Group 2

- ATOD because you are not in your full mind when still using drugs while pregnant
 - Smoking cigarettes and drinking wine compared to cocaine (and street drug usage) are so unrelated; it makes the question and the choice not good. Smoking does not do as much damage
 - One woman responded: I was addicted to everything and my baby was born addicted to everything. You are not in your right frame of mind – you do want to quit...you do the 90 day program but then someone (from drug circles) comes over to your house and you start again. My baby was born with all these complications. Then my baby was taken away and I was left in treatment center by myself. It's a whole (giant) mess. Everyone hates you and you already hate yourself. I will never forget where I've been.
 - Another woman responded: I was pregnant at 13—I was selfish, thinking I could smoke a joint, a cigarette, drink a beer, or a soda when I was stressed. I could not stop smoking marijuana—they explained the damage I was doing to my child—that is what finally gave me the mental capacity to stop and save my child. My child was born okay.

Group 3

- Side effects of medicine and vitamins that keep you from the doctor or from taking care of your illness

Group 4

- Going to doctor: because they can foresee a problem going on that will prevent you from going full-term
 - Sometimes doctors let you get a C-Section without a medical reason
 - Doctor is the most direct and immediate contact with the baby and the baby's vitals
 - Health care systems: pharmaceuticals are “in it to win it” they push medicine from their pharmaceutical reps
 - Medicines are so heavily promoted in the media and they ALL affect the baby's health and not always in a good way (3-4 women nodded agreement)
- ATOD:
 - Women are scared to hear what the doctor will say when they are using ATOD, so they won't go
 - Women are scared someone will call JFS
 - They don't know about personal health or of the baby without going to the doctor
- Having baby too early:
 - Most dangerous—too many medicines are dangerous to mom and baby

Group 5

- ATOD
 - Only a problem if you abuse it
 - That has a big effect on a baby. More likely to have a premature baby
 - I Know a girl who smoked and abused drugs her whole pregnancy and the baby was born with low birth weight
- Going to the doctor

- Will tell you what you should and should not do
- Childbirth history
 - Childbirth history along with abuse of drugs causes - premature babies
 - Your body was not ready for another baby yet

Group 6

- ATOD
 - Causes premature, low birth weight baby
 - Sometimes baby has to go through withdrawal
 - Girls and women smoking blunts—drinking alcohol to fit in even when pregnant
 - Lack of knowledge about the effects of ATOD on the baby and the mom
 - Changes mom’s mental capacity, her ability to cope is impacted by ATOD in utero, it slows down her reaction and good choices
 - Some girls are still smoking weed, and when doctors find out or at the hospital, they will take the baby away from her
- Going to the doctor
 - My woman is diabetic so she had gestational diabetes, our baby was born 9.2 pounds

7. Before we leave DURING Pregnancy, I want to ask about Pre Natal care. What are some of the reasons a woman would not get pre-natal care during pregnancy?

Group 1

- Medicine/medications are not natural. Manmade medicines have side effects. It’s better to eat organic food and food without pesticides
 - Note: There was a whole discussion around pre natal vitamins and how some women give theirs to friends as it helps to grow hair and make it soft.
 - Others said that non-pregnant women will buy them OTC for the same reasons
- You may not know that you are pregnant yet
- It may not be a priority to her
- Lack of resources or medical care
- If parents kick you out of the house (for being pregnant), you may have nowhere to go and don’t know what to do
- Another woman said that there was easy access to prenatal care but that some women choose not to get it – “If you are feeling good, why see a doctor?”

Group 2

- Lack of planning: planning happens when you have money
 - Another woman said planning, who does that?
- Lack of insurance – if you don’t have insurance, what do you do?
- Transportation (I can’t take 5 kids in the CareSource van and can’t find a baby sitter), so what am I going to do? The choice is between spending money on bus fare or spending it on food for my babies.
- Not enough supports or resources to get information about what your baby needs
- I don’t know where to go for a coat, a pair of shoes, there isn’t enough advertising about where to go to get what you need for yourself and your baby

- I don't have parents; I was raised in foster care. Who do I go to with questions?
- Lack of planning – how many people in our community actually says, “I'm going to have me a baby!” (and plan for it). We don't plan in our community

Group 3

- ATOD causes different health issues, even before pregnancy,
- Smoking can lead to low birth weight, fetal alcohol syndrome,
 - Smoking [weed] has a side effect that keeps you from the doctor or taking care of your illness
- Going to the doctor for prenatal care—gestational diabetes effects the mother and baby
 - The baby can come too early—odds are against the baby
 - Mental stress affects your stability—it can be devastating
- My baby weighed 3.9 at birth and I had a guilty conscious
- I could not keep food down, my water broke at 28 weeks
 - My cousin was pregnant with twins but had a spontaneous abortion at 18 weeks
- Multiple births like the Octo-mom – babies can't get all the nutrition needed in vitro.

Group 4

- Cost and access
 - The cost is not accessible to everyone
 - Out of pocket costs – the part the insurance does not pay
 - There are different levels of services based on what you can afford
- Access
 - Some places don't have access to private offices
 - Public transportation makes it hard for people to reach some offices
- Lack of education
- Lack of transportation

Group 5

- Lazy: sometimes I just didn't feel like going, even though the clinic was 23 steps from my house, I was too big, baby weighed me down, feet swollen, and I was too lazy to go
- Turned away because I did not have insurance
- Some women are not resourceful enough to find services that really are available
- Big vitamins – like horse pills—too big and make you sick
- Some religions talk against synthetic medicines. I prefer herbal and natural vitamins
- Some girls say prenatal care is not that important
- My sisters and mama say I don't need it
- You think you are fine so don't need to go for prenatal care
- When the first prescription tasted nasty, the doctor prescribed a different kind and they were fine
- One barrier is when you don't value the benefits of doctors or medicine, so you don't adhere to any medication when you feel it is not going to work

Group 6

- Any woman I ever had a baby with did her prenatal care (several men nodded agreement)

8. Now we are talking about the First Year AFTER BIRTH. Do you know anyone who lost a baby during pregnancy or within the first year of birth? What were the circumstances?

Group 2

- My friend rolled over on her baby when it was 2 months old and it died (the woman was 17 when this happened)
- My baby cousin died in his sleep at night
- All 4 of my babies were born premature
- My daughter had two miscarriages. Her first one while I was doing drugs at the time and her life was stressful. She has four girls now.

Group 4

- Internal bleeding happened while my friend was pregnant and the baby did not make it
- Baby died of SIDS at 7.5 months old
- Baby died of SIDS at 3 weeks old

Group 5

- 2 babies died of SIDS in one family at only 5 months old
- SIDS at 4-5 months old
- SIDS at 6-7 months old
- A baby died within a day when its bile started leaking
- A baby died at 7 months old after living in an incubator because it was born premature

Group 6

- My first child occurred during a rough divorce and the stress caused my wife to miscarry
- A woman felt she was on her own, no support, she was stressed and not eating like she should, she lost weight and miscarried
- I know a couple who were both alcoholics and she miscarried

Group 7

- All aware of at least one baby dying within first year of birth

9. Name one issue from this list that you think most affects a baby’s health AFTER it is born. First, vote, and then we will discuss your choices as a group.

Focus Groups 1-7							Factors
0	1	1	2	1	0	2	Sleep: Some people say that putting a baby down to sleep alone, on its back and in a crib is important to make sure the baby sleeps safely, what do you think?
0	1	1	1	2	1	0	Breastfeeding: Some people say that breastfeeding a baby will make it healthier, what do you think?
4	2	3	1	3	4	0	Visiting the Doctor: Some people say that taking a baby back to the doctor for a checkup after it is born is important, what do you think?
4	3	1	2	1	1	2	Mom’s happiness: Some people say that if a baby’s mom is depressed, it can affect the health of her baby, what do you think?
0	0	1	0	0	0	0	Getting outside help: Some people say that a baby will be healthier if its mom has help from a social worker or a home visitor, what do you think?

Why did you choose the item you selected? NOTE: Even though we required a forced choice response, when we opened the topic for discussion, women had multiple feelings about some factors as seen in the responses below.

Group 1 (doctor and mom’s unhappiness (stress) vie for the number one vote because they each influence the other)

- Doctor: My doctor told me that age 0-1 years is when baby has the most doctor visits, so causes stress if unable to make all the visits
 - A (pregnant) woman responded that she uses Care Source
 - Mom’s happiness: stressed because I couldn’t get to the doctor (no car), unhappy
 - She may feel like the baby is doing well, is healthy, so no need to go to doctor
 - Some people mistrust the healthcare system – e.g., vaccine (like the Flue shot) make your baby sick—can cause stress because of pressure to get vaccines even though she does not trust them
 - A discussion followed about immunizations (live vs. dead cultures)—stressful choices
 - Some feel they only take them when required by schools—stressful choices
 - Pharmaceuticals “push” medicines off on people
 - There is a perception that doctors are pushing drugs, so the mom/woman choose not to take them (all agreed to this)
 - Don’t want to be judged if baby is not meeting milestones—causes stress
 - Don’t want to be told she did something wrong as a mom—causes stress

Group 2

- Mom’s happiness: If mom is unhappy those emotions transfer to baby. She is not getting up and caring for baby, feeding baby, she is not going to the doctor etc.
 - Mom is the head of the house. In my house if I’m not happy, no one is happy.
 - When the baby cries, she feels stress, her attitude and behavior falls back on the kids

- You set the tone for your baby: I was mean with my son; I was mad and now he's 3 and he's mean and mad and a bully
- Getting outside help would lighten the load so you are not alone, get a break some time, some help around the house

Group 3

- Going to the doctor: Important to pay attention to the baby's weight and nutrition
 - Immunizations – some people say that immunizations (the MMR vaccine) causes autism
 - Important to have a way to get vaccinations early—know when you are leaving the hospital
- Mom's happiness—baby's internal issues may not have been seen by mom if she is focused on being unhappy
 - Emotional stress
 - Mom's anger makes the baby fussy
- Sleep – I know several women whose baby died of SIDS
- Breastfeeding until one year old is very good—your baby will never get sick
 - I nursed my baby for 27 months
 - 'Breast is best' [international campaign message started by World Health Organization]
 - Canned milk—I questioned the effect on babies after a national recall
- Getting outside help—
 - When mom is feeling alone she needs family and friend support
 - No one is helping mom
 - Social worker, minister, family members can all help out

Group 4

- Sleep: because of SIDS
 - Proper crib; some moms don't have money to buy what they need
 - Moms want to sleep with their child
 - Not know how to position the baby – spit up can choke the baby when it's very young
 - A man once rolled over on my cousin's baby and killed it
- Mom's happiness
 - If not eating and breastfeeding, it will impact the baby
 - Mom's mood – the baby will miss feedings – she will not provide proper care
 - Depression –less likely take care of the baby
- Breastfeeding – nothing the market makes can replace what your body produces
 - Manufacturers cannot make what the baby needs naturally
 - Formula – baby can become malnourished or develop allergies – breast is best
- Visiting the doctor – get baby checkups to be sure everything is fine
 - Baby could fall off the bed
 - Brain bleeds – blood supply cut off from the brain and causes damage –
 - Baby becomes like a vegetable

Group 5

- Visiting the doctor
 - Monitor the baby's health and ensure immunizations
- Breastfeeding
- Sleep: pay attention if the baby is sick or stuffy or can't catch breath when sleeping or in the bed
- Mom's happiness: baby feeds off of mom's feelings

Group 6

- Going to the doctor
 - Need to know exactly what is going on with the baby
 - Not all babies are born healthy, even healthy babies should get their check ups
 - You need to know if something is wrong with the baby
- Mom's happiness
 - If she is not happy, she can treat the baby badly, no patience with the baby's needs and gets upset when the baby cries even a little bit
 - How she feels impacts how well she takes care of the baby
 - Shaking the baby comes from mom being stressed and unhappy

10. Of all of the things we discussed today, what would you say is the most important factor in reducing infant mortality in our community?

Group 1

- Close your legs
- Strap in (use a condom)
 - NOTE: there was a lengthy discussion of condoms – namely that the brand is critical. They noted that condoms were abundantly available; however, they won't use Lifestyle brand condoms or Trojan brand, only 'Magnum' brand
 - (When probed further after the session, this apparently has to do with "size". Magnum's are for big guys. The women also shared that if you are a woman and you pull out a non-Magnum brand condom, the guy looks on you poorly as well.)
 - IMPLICATION: are government and community programs giving out the wrong brand of condoms, such that they are not getting used and the good intentions, and good money wasted?
- It basically boils down to education – the more you know, the more you can be prepared
- There's a lack of resources and access to resources – create a website that people go to for information about pregnancy and the first year of birth and to find out where to go for services (would be a good solution)
- (To this, another responded): My momma showed me how to hustle. I knew all the loopholes (in my pregnancy) and I never spent a dime
 - (The same woman told others: There's a resource next to Kroger on McMillan. Go there and you can get clothes, food stamps, diapers etc.
 - NOTE: it's the Pregnancy Care Center. Other resources she mentioned were St. Mary's downtown and Every Child Succeeds home visitation

Group 2

- I feel if you fix alcohol, drugs, and housing, you can find the other resources for support

- We need to teach our kids knowledge – sex, how our body works, spiritual side, and the costs of a child to your life. (There was a quote about income/lack thereof during life time but I missed most of it)
- My sister allowed her son to watch pornography and he ended up molesting his 6 year old cousin, my daughter
- Must reduce the use of ATOD
- Knowledge and education about pregnancy, how the body works, self-esteem, mental and spiritual health, the financial costs to having a baby
- Educate boys and girls
- Talk to kids, tell them the truth

Group 3

- Education
 - Pregnancy prevention information
 - Women need pre-natal care
 - No ATOD during pregnancy
 - ATOD effects on the baby
 - How to put baby to bed/don't sleep with baby and car seat safety
 - Parenting and birthing classes should be mandated – no option
- Improve poverty – not a lot of grocery stores in some neighborhoods
 - Need vegetables, fruits, quality choices of foods
 - Prices are different, neighborhood to neighborhood

Group 4

- Education – knowledge is power
 - When you know better, you do better (2 people)
- Make the money to buy healthy food
 - WIC / SNAP don't allow families to buy junk foods with the stamps
 - Use of healthy corner stores like the program in Philadelphia
- How to be more creative with economic development
 - Teach everyone how to be a boss and create your own destiny
- Have the tools to take care of the child
- Stress – racism risks are everyday
 - It is the secret killer and people don't like to talk about it

Group 5

- Know the population you are dealing with
 - Have a solution that meets the social, emotional, spiritual, financial needs
 - Word of mouth – they can talk
- Pay attention to how the baby sleeps
- Get prenatal care
- Knowledge of how to take care of a baby
 - Education on what to do with a new baby

Group 6

- Mother and father's relationship with each other and the child

- Education about the entire process: before pregnancy, during pregnancy, and after pregnancy
- Without education, mom and dad might not have a healthy baby or a baby at all [miscarriage]
- Supportive family

Group 7

- Awareness of how to prevent infant death and keeping baby safe
- Resources that will help keep mom happy and feel supported

Major Themes

The following themes emerged as repeated responses across all focus groups.

Theme: Desire to self-direct health care management

I. Where women get information about healthcare for themselves and their family

- a. Internet and websites
- b. Print and television news
- c. Family and friends
- d. Doctor, health care provider, clinic, pamphlets at doctor's office
- e. School, books, library, classes

Theme: Fear, anxiety, or mistrust of health care systems

II. Belief that participant was treated badly by health care professional because of race or income in the past year

- a. It is more about income than race
- b. The issue is an economic one, not race. "It's about color and the color is green!"
- c. "With private insurance, the doctor spends more time with you."
- d. "I had my first baby at age 16. After two visits, the hospital told me not to come back because I did not have insurance, so I did not have prenatal care based on my financial status."

Theme: Lack of Education and Information, Culture, and Male Female Relations

III. Causes of unplanned pregnancies

- a. Lack of access to resources: sex education, information about contraceptives, and resources for where to go to get birth control if you don't have insurance.
 - "The shot and pill are too expensive unless you have insurance."
 - "I haven't been to the doctor in 11 years. I pray a lot, my children have insurance and I do not, so I do not have access to health care."
 - The brand of condoms is critical to the cultural context. Participants noted that condoms are abundantly available; however, they won't use Lifestyle or Trojan brand, only 'Magnum', having to do with "size."
 - i. IMPLICATION: are programs giving out the wrong brand of condoms that are going unused with the possibility of wasted good intention and money?
- b. Lack of knowledge about the consequences of sexual activity, especially for young girls
 - "I was naïve and thought it [getting pregnant] wouldn't happen to me."
 - "I thought if he pulls out, I am safe."
 - "One night on the town, you meet a guy, and then you wake up the next morning and "the lady doesn't' come to you for the next month" (slang term for missing monthly cycle.)
- c. Rape: date rape or by known partners or by family members or by neighbors or at school.
 - "Women are not strong enough to say NO. We have to protect ourselves. We don't love ourselves like we should."
- d. "I got pregnant at 17 because I wanted to fit in and feel loved. I wanted and sought out male affection. I didn't have a dad in my home growing up."

- e. Lack of communication with boyfriend: “I think he loves me and he’s thinking I am a piece of meat.”

IV. The Number One factor that affects a woman’s health BEFORE Pregnancy

Total	Factors
14	Stress. Some people say that stress can affect a woman’s health even before pregnancy, what do you think?
0	Weight. Some people say that being overweight or being too thin affects a woman’s health before pregnancy, what do you think?
5	Support from loved ones. Some people say that an important part of a woman’s health before pregnancy is how supported she feels by her family, friends and community, what do you think?
1	STDs. Some people say that whether or not a woman has a sexually transmitted disease like chlamydia, gonorrhea or syphilis before pregnancy affects her health, what do you think?
15	Alcohol, Tobacco, and Other Drugs. Some people say that smoking and/or drinking too much or using drugs can lead to poor health before pregnancy, what do you think?
3	Housing. Some people say that having a safe place to stay can affect your health before pregnancy, what do you think?
5	Going to the doctor. Some people say that regularly going to the doctor is important for a woman’s health before pregnancy, what do you think?
0	Having another baby too soon. Some people say that if you get pregnant too soon after having one baby, the next baby will not be as healthy, what do you think?
3	Planning. Some people say that whether a woman gets pregnant on purpose or by accident can affect the health of her baby, what do you think?

Theme: Alcohol, Tobacco, and Other Drugs ATOD

Why Alcohol, Tobacco, and Other Drugs is Number One factor affecting a woman’s health BEFORE pregnancy

- a. It alters your thinking so you don’t make the best decisions and it affects your mental health; it takes a toll on the body whether you realize it or not.
- b. “Habits are hard to break, you don’t want to stop, and you can’t stop.”
- c. “I used alcohol, tobacco, and drugs with my last two children—marijuana with one and alcohol with the last one. Stress caused me to take drugs and alcohol. I am one of the lucky ones because both of my babies are healthy. I knew marijuana was bad but I did it anyway. I didn’t stop until I researched what alcohol can do to a baby.”
- d. ATOD is the root cause of so many STD’s

Theme: Cultural and Social Pressures

V. What are some of the reasons a pregnant woman does not always get the social and emotional support she needs?

- a. Judgment: “People judge you when you are too young or too old or when they don’t approve of the father (he’s a bum, inter-racial, different religion, etc.)”
- b. Based on the partner [father of the baby] when the man is not part of your life.

- c. Parents throw you out so you are homeless, living place to place, unaware of public housing
- d. “I was raped at 14 at school and I didn’t have support. My next male relationship was abusive, he busted my lip. I was looking for love after being raped and I got pregnant again.
- e. “Unrealistic expectations between a man and a woman—men don’t know what the woman wants, he can’t read her mind, so we walk around on eggshells.”

VI. The Number One factor that affects a woman’s health and her baby’s health DURING Pregnancy

Total	Factors
23	Alcohol, Tobacco, and Other Drugs. Some people say that smoking, drinking too much or using drugs can lead to poor health during pregnancy, what do you think?
10	Going to the doctor: Some people say that it is important to go to the doctor regularly during pregnancy, what do you think?
3	Having the baby too early: Some people say that when a baby is born too early (before 39 weeks or 9 calendar months), it will not be as healthy, what do you think?
6	Disease: Some people say that if a pregnant woman has a disease like diabetes or hypertension (high blood pressure) during pregnancy, it is not good for her baby, what do you think?
2	Childbirth History: Some people say that if a pregnant woman has had other babies that were born too early (before 39 weeks or 9 calendar months), it is more likely to happen again, what do you think?

Theme: Alcohol, Tobacco, and Other Drugs

Why Alcohol, Tobacco, and Other Drugs is Number One factor affecting a woman’s health DURING pregnancy

- a. When ATOD is the priority, the baby is not first priority for mother, and the baby can be born premature or have low birth weight
 - “I had complications when my baby was born and everybody hated me because it was due to my use of alcohol and drugs.”
 - “I used [drugs] for 13 years; I went into treatment and I stopped using cocaine, but did not stop marijuana; the doctor explained the effects of it so I put myself into treatment.”
 - “I was pregnant at 13. I was selfish, thinking I could smoke a joint, a cigarette, drink a beer, or a soda when I was stressed. I could not stop smoking marijuana. They explained the damage I was doing to my child and that is what finally gave me the mental capacity to stop and save my child. My child was born okay.”

Theme: Lack of Access to Resources and Fear, Anxiety, Mistrust of Healthcare System

VII. Some of the reasons a woman would not get pre-natal care during pregnancy

- a. Lack of access: no transportation, no insurance, no money for ‘out-of-pocket’ copay

- “I can’t take 5 kids in the CareSource van and I can’t find a babysitter, so what am I going to do? There is the choice between spending money on bus fare or spending it on food for my babies.”
- b. Not want to use prescription medications:
 - Medicine/medications are not natural and they have side effects—it’s better to eat organic and food without pesticides—some women give their prenatal vitamins to their friends because it helps their hair grow and makes it soft
 - “My mama and sisters say I don’t need it.”
 - “The vitamins are too big, like horse pills, they make you sick”
- c. Don’t see the value or benefit of doctors or medicine.
 - a. “If you are feeling good, why see a doctor?”
- d. You may not know you are pregnant yet

VIII. Personal knowledge of the loss of a baby during pregnancy or within the first year of birth

- a. A 17-year-old rolled over her baby in the bed when the baby was 2 months old
- b. Participants are aware of 9 SIDS deaths
- c. A one-day old baby died due to leaky bile
- d. Participants are aware of 5 miscarriages

IX. The Number One factor that affects a baby’s health AFTER it is born.

Total	Factors
7	Sleep: Some people say that putting a baby down to sleep alone, on its back and in a crib is important to make sure the baby sleeps safely, what do you think?
6	Breastfeeding: Some people say that breastfeeding a baby will make it healthier, what do you think?
17	Visiting the Doctor: Some people say that taking a baby back to the doctor for a checkup after it is born is important, what do you think?
14	Mom’s happiness: Some people say that if a baby’s mom is depressed, it can affect the health of her baby, what do you think?
1	Getting outside help: Some people say that a baby will be healthier if its mom has help from a social worker or a home visitor, what do you think?

Theme: Lack of education, information, and access to healthcare system

Fear, anxiety, and mistrust in the healthcare system

Visiting the doctor is the number one factor that affects baby’s health AFTER it is born.

- a. My doctor told me that age 0-1 years is when baby has the most doctor visits, so that causes stress on the mother if she is unable to make all of the visits
 - Some people do not go to the doctor because they think immunizations cause autism (MMR vaccine)
 - Some people think the healthcare system, e.g. vaccines (Flu) can make your baby sick. Pharmaceuticals ‘push’ medicines off on people; there is a

perception that doctors are pushing drugs so the mom chooses not to take them

- Some moms don't take their baby to the doctor because she does not want to be judged if the baby is not meeting milestones or doesn't want to learn if something is wrong
- b. You have to pay attention to the baby's weight and nutrition, monitor the baby's health because even healthy babies need checkups.

Recommendations

One focus group participant said it best: “Knowledge is power. When you know better, you do better.”

The most important factor in reducing infant mortality in our community

Access to education and information that is relevant to cultural, social, spiritual, and economic needs of the targeted group, including respect for the individual’s values, preferences and expressed needs, approach to problem-solving, communication needs, involvement of family, emotional support and mitigation of fear, anxiety and mistrust.

The recommendation from the Infant Mortality Collaborative Focus Groups for reducing the high rate of infant mortality in Cincinnati-Hamilton County is:

1. Provide access to education and information that addresses the specific cultural, social, spiritual, and economic needs of the targeted group, including respect for the individual’s values, expressed preferences and needs, approach to problem-solving, communication needs, involvement of family, emotional support and mitigation of fear, anxiety and mistrust of healthcare systems.
2. Education and information topics should include:
 - Sex education (male and females)
 - Alcohol, tobacco, and other drugs
 - Male and female relations
 - Baby’s Journey from Preconception, Pregnancy, and to First Year of Life
 - Parenting
 - Accessing resources that support family health
3. Accurate, timely, and culturally relevant information regarding healthcare and the baby’s journey from preconception, to during pregnancy and after pregnancy should be accessible via the internet using a “trusted” website.
 - While more analysis is needed to determine how effective the ‘self-management and self-care’ efforts are that are mentioned by some focus group participants, it is evident that a significant amount of healthcare information is self-directed from internet, website, family and friends, and doctors.)

APPENDIX

- i. The Health Focus Group Questionnaire Pages 33
- ii. The Focus Group Instrument 37

How would you rate your stress level while you were pregnant?

Ages 18-24 (7 had children)	Ages 25-44
- 5 of 6 characterized stress level as moderate or high while pregnant.	- 9 of 14 characterized stress level as high or very high while pregnant.

How important is it for pregnant women to

Ages 18-24	Ages 25-44
Take pregnancy/ prenatal vitamins - All say very or extremely important	Take pregnancy/ prenatal vitamins - Most say very or extremely important
Visit the doctor once per month – - All say very or extremely important	Visit the doctor once per month – - All say very or extremely important
Eat healthy - Most say very or extremely important	Eat healthy - Most say very or extremely important
Exercise - Most say very or extremely important (16 of 20)	Exercise - Most say very or extremely important
Don't smoke - All say very or extremely important	Don't smoke - All say very or extremely important
Don't drink alcohol - All say very or extremely important	Don't drink alcohol - All say very or extremely important
Don't take drugs not prescribed by a doctor - Almost all say very or extremely important	Don't take drugs not prescribed by a doctor - All say very or extremely important

During your last pregnancy, about how often did you

Ages 18-24	Ages 25-44
Take pregnancy/ prenatal vitamins - 4 always; 1 never	Take pregnancy/ prenatal vitamins - Most say often or always
Visited the doctor once per month - All say often or always	Visited the doctor once per month - Most say often or always
Eat healthier foods - Most said often or always	Eat healthier foods - Half said often or always
Exercised - Half said always, other half sometimes/rarely	Exercised - Half said often or always
Smoked	Smoked

- Most say rarely or Not at all	- Most say rarely or Not at all
Drink alcohol Most say rarely or Not at all	Drink alcohol Most say rarely or Not at all (a few said always or often!)
Took drugs not prescribed by a doctor - Almost all said not at all	Took drugs not prescribed by a doctor - Almost all said not at all (a few said always or often!)
Ages 18-24	Ages 25-44
4 of 6 said no	More than half <u>breastfed</u> their first child.

What are the reasons you did or did not breastfeed?

Ages 18-24	Ages 25-44
	Child never made it her to breast feed.
	Parent died, too stressed couldn't produce milk.
	Baby wouldn't latch on.
	Very painful child wouldn't take nipple.

Did your first baby sleep in the bed with you at night? (check all that apply)

Ages 18-24	Ages 25-44
- All 6 said yes	11 of 15 said yes

What way or position did your first baby sleep when he/she was three months old or younger?

Ages 18-24	Ages 25-44
4 on back; 2 on stomach	6 of 13 said on back; 5 on stomach; 2 both

Which is the best way for a baby three months old or younger to sleep?

Ages 18-24	Ages 25-44
- Half – 9 on back; 9 on stomach	- 8 of 13 said back; 4 on stomach; 1

For each statement below, please check if you how much you agree or disagree?

Ages 18-24	Ages 25-44
What you eat and drink affects the baby during pregnancy - Most strongly agree 14 of 20; 4	What you eat and drink affects the baby during pregnancy - Almost all strongly agree

somewhat agree	
My baby's doctor advise is more reliable than my mother's - 12 of 20 agree; 6 are neutral; 3 strongly disagree	My baby's doctor advise is more reliable than my mother's - Half agree; most are neutral
It is not necessary to go to the doctor monthly while pregnant - 17 of 20 think it is necessary to go doctor;	It is not necessary to go to the doctor monthly while pregnant - 10 of 15 think it is necessary to go doctor
Overall I am healthy - Most agree	Overall I am healthy - Most agree
Breastfeeding leads to healthier babies - Almost all agree (3 do not)	Breastfeeding leads to healthier babies - Almost all agree (2 do not)
Breastfeeding is not for me - About are neutral; other half split	Breastfeeding is not for me - About half think breastfeeding is for them

For each statement below, please check if you how much you agree or disagree?

Ages 18-24	Ages 25-44
It is fine to smoke around a baby - All disagree	It is fine to smoke around a baby - All disagree
Smoking while pregnant is fine - Almost disagree; 2 agree	Smoking while pregnant is fine - All disagree
Doctors are trustworthy - 15 of 20 agree; 3 neutral	Doctors are trustworthy - 9 of 14 agree; 4 neutral, 1 disagree
It is important to get your baby vaccination shots on time - Vaccinations important to most	It is important to get your baby vaccination shots on time - Vaccinations important to most
Babies should visit a doctor at least five times before their first birthday - All agree	Babies should visit a doctor at least five times before their first birthday - 9 of 14 agree; 4 neutral

Are you aware of the term 'Infant Morality'?

Ages 18-24	Ages 25-44
15 of 20 say yes	About half are aware – confirmed by comments

Have you ever heard of Sudden Infant Death Syndrome?

Ages 18-24	Ages 25-44
18 of 20 say yes	Almost all have some awareness of SIDS.

Center for Closing the Health Gap Focus Groups November – December 2013 Process and Script

Draft timed process agenda and potential focus group questions. The focus group questions are organized in flow from general to specific and by Preconception to First Year Model. I recommend we choose 2 questions from each: Preconception, Pregnancy, First Year.

8 Minutes: Introduction

Welcome

Good evening (afternoon) and welcome to our focus group. Thank you for taking time to join us to talk about infant mortality in our community. To clarify what we mean by community, we are referring to the City of Cincinnati and Hamilton County.

My name is Diane Jordan-Grizzard and assisting me is Traci Sippel. I represent my consulting firm, Thembi Speaks and Traci represents Closing the Health Gap. [Cradle Cincinnati and the Center for Closing the Health Gap] asked both of us to help them get information from Cincinnati residents about your perceptions about *“What causes our community’s infant mortality rate to be so high?”*

We are having six discussions like this with several groups around the city. You were invited because you are of childbearing age, you have valuable information about accessing health care services for yourself and your baby and you live within the urban community.

There are no wrong answers but rather differing points of view. Our desire is to get an intimate understanding of your perceptions of the high rate of infant mortality, so please feel free to share your point of view even if it differs from what others have said. Keep in mind that we are just as interested in comments perceived as negative as positive comments, and at times, the negative comments are the most helpful because we can learn from them.

You have probably noticed the microphone. We are tape-recording the session because we do not want to miss any of your comments. People often say very helpful things in these discussions and we cannot write fast enough to get them all down. We will be on a first name basis, and we will not use any names in our written reports. You may be assured of complete confidentiality, and we ask you do the same for each other. While your comments will be captured, no attribution (mention) will be made to any individual. The answers to the questionnaire you completed earlier today along with the information shared during this focus group, will be summarized in a report that will go back to the [Cradle Cincinnati and the Center for Closing the Health Gap] staff to help plan future health initiatives and programs.

Ground Rules (will post these on flip chart paper for each group)

- ✓ Remember, first name basis. Additionally, do not name other family members, friends, or healthcare providers.
- ✓ Please listen respectfully and speak one at a time.
- ✓ Avoid side conversations with your neighbors.
- ✓ I need to hear from everyone during the session but you do not have to answer each question.
- ✓ Say what is true for you.
- ✓ Don't let the group sway you, and don't sell out to group opinion or to a strong talker. It is OK, however, to change your mind during the course of the session because of something you hear or see.
- ✓ Talk to each other.
- ✓ Don't interrupt or talk over anyone
- ✓ We ask that you turn off your phones or pagers. If you must respond to a call, leave the room as quietly as possible and rejoin us as quickly as you can.
- ✓ My role as moderator will be to guide the discussion, make sure we stay on track with each question, and manage our time together.

Any questions? Let's get started.

1. **2 Minutes:** We've placed name cards on the table in front of you to help us remember each other's names.
2. **5 Minutes:** Opening Question (round robin provides enough structure to relax and establish group rapport for talking)
 - a. Let's find out some more about each other by going around the table. Tell us your first name and the neighborhood you live.
3. **6 Minutes:** Introductory Question (ask one of these questions in round robin fashion).
 - In general, how do you get information about healthcare for you and your family?
 - Thinking about seeing a healthcare professional in the last year, have you ever felt uncomfortable or believed you were treated badly because of your race or income level?

REVIEW INFANT MORTALITY DEFINITION AND STATISTIC

Infant Mortality definition is 'the death of children under the age of one year.'

National average 6% and Cincinnati average is 13% -

Babies under the age of one year old in Cincinnati die at twice the rate of other cities across the United States.

4. **61 Total Minutes:** Key Questions (open responses, group should be comfortable with each other by now)

Preconception/BEFORE Pregnancy: (20 Minutes)

a. As far as you know, what causes unplanned pregnancies?

5. Name one issue from the list that you think most affects a woman's health **BEFORE** Pregnancy. First answer at your seat. Then we will discuss. **Count the number of answers for each item.**
- a. **Stress.** Some people say that stress can affect a woman's health even before pregnancy, what do you think?
 - b. **Weight.** Some people say that being overweight or being too thin affects a woman's health before pregnancy, what do you think?
 - c. **Support from loved ones.** Some people say that an important part of a woman's health before pregnancy is how supported she feels by her family and (friends) community, what do you think?
 - d. **STDs.** Some people say that whether or not a woman has a sexually transmitted disease like chlamydia, gonorrhea or syphilis before pregnancy affects her health, what do you think?
 - e. **Alcohol, Tobacco, and Other Drugs.** Some people say that smoking, drinking too much or using drugs can lead to poor health before pregnancy, what do you think?
 - f. **Housing.** Some people say that having a safe place to stay can affect your health before pregnancy, what do you think?
 - g. **Going to the doctor.** Some people say that regularly going to the doctor is important for a woman's health before pregnancy, what do you think?
 - h. **Having another baby too soon.** Some people say that if you get pregnant too soon after having one baby, the next baby will not be as healthy, what do you think?
 - i. **Planning.** Some people say that whether a woman gets pregnant on purpose or by accident can affect the health of her baby, what do you think?

Why did you choose the item you selected?

6. **Now we are talking about DURING Pregnancy: (20 Minutes)**

- a. What are some of the reasons a pregnant woman does not always get the social and emotional support she needs?

7. **Name one issue from this list that you think most affects a woman's health and her baby's health DURING pregnancy. First answer at your seat. Then we will discuss your selection. Count the number of answers for each item.**

- a. **Alcohol, Tobacco, and Other Drugs.** Some people say that smoking, drinking too much or using drugs can lead to poor health during pregnancy, what do you think?
- b. **Going to the doctor:** Some people say that it is important to go to the doctor regularly during pregnancy, what do you think?
- c. **Having the baby too early:** Some people say that when a baby is born too early (before 39 weeks or 9 calendar months), it will not be as healthy, what do you think?
- d. **Disease:** Some people say that if a pregnant woman has a disease like diabetes or hypertension (high blood pressure) during pregnancy, it is not good for her baby, what do you think?
- e. **Childbirth History:** Some people say that if a pregnant woman has had other babies that were born too early (before 39 weeks or 9 calendar months), it is more likely to happen again, what do you think?

Why did you choose the item you selected?

Before we leave DURING Pregnancy, I want to ask about Pre Natal care

- o What are some of the reasons a woman would not get pre-natal care during pregnancy?

8. **Now we are talking about the First Year AFTER BIRTH: (20 Minutes)**

- **Do you know anyone who lost a baby during pregnancy or within the first year of birth? Share circumstances.**

- a. Name one issue from this list that you think most affects a baby's health AFTER it is born. First answer at your desk, then we will discuss.
- b. **Sleep:** Some people say that putting a baby down to sleep alone, on its back and in a crib is important to make sure the baby sleeps safely, what do you think?
- c. **Breastfeeding:** Some people say that breastfeeding a baby will make it healthier, what do you think?
- d. **Visiting the Doctor:** Some people say that taking a baby back to the doctor for a checkup after it is born is important, what do you think?
- e. **Mom's happiness:** Some people say that if a baby's mom is depressed, it can affect the health of her baby, what do you think?
- f. **Getting outside help:** Some people say that a baby will be healthier if its mom has help from a social worker or a home visitor, what do you think?

Why did you choose the item you selected?

9. **5 Minutes:** Ending Question

- Of all of the things we discussed today, what would you say is the most important in reducing infant mortality in our community?

10. **2 Minutes:** Summary

Overall, you believe the most important contributing factor to our community's high infant mortality rate is _____ . Do you agree?

Thank you and Good Bye

90 Minutes Total