

# FLOURISH Community Listening Sessions

## Summary

### Purpose

The FLOURISH community listening sessions were conducted as part of the larger FLOURISH St. Louis infant mortality reduction initiative. FLOURISH St. Louis is a collective impact effort seeking to bring the community together in new ways to address why too many babies in the St. Louis region are dying, born too early or too small. The purpose of the listening sessions was: 1) to gain insight from community members related to the factors that they see as contributing to or causing infant mortality; 2) Build awareness of community needs and assets impacting the health of women and infants in the St. Louis region; 3) Increase shared understanding of infant vitality and emerging trends pertinent to the health of women and infants; and 4) Establish a foundation of community trust, ownership, and involvement of impacted families. In order for FLOURISH to make a significant and sustained impact on infant mortality in the St. Louis region, the initiative must be grounded in and driven by the needs of the community, as the community sees those needs to be. The information collected from the listening sessions will be presented to the FLOURISH Cabinet, which will use this information along with other data and lessons from other cities to help set the overall priorities of the FLOURISH St. Louis initiative. There were six smaller listening sessions held at various community agencies and organizations, as well as one large listening session that was open to the general public.

### Listening Session Context

The planning process for the listening sessions began in June 2015. The Maternal Child and Family Health Coalition (MCFHC) in St. Louis compiled a list of their community partners who were thought to have a client base impacted by the issue of infant mortality that would be appropriate for participation in the sessions. The target audience was mothers, fathers, grandparents, aunts, uncles, friends, etc. who had either directly experienced an infant death or premature birth, knew someone who had, or was in some other way affected by infant mortality. The MCFHC reached out to these partners and asked whether they would be willing to engage in an ongoing relationship and conversation with the FLOURISH initiative. This relationship would involve not only allowing the MCFHC to host a listening session with their clients or to promote the large community listening session, but also to continue to support and work with the initiative going forward. The MCFHC emphasized to all the community members who attended the sessions that the information they provided is valuable and will be used to start a conversation with the community that will be ongoing as FLOURISH identifies priorities and works toward a significant and sustained reduction in the St. Louis region's infant mortality rates.

## Involved Partners

The MCFHC would like to thank the following partners, who opened the door to conversation with their clients, graciously provided use of their space, and helped to make all of the smaller listening sessions to go as smoothly as possible.

- BJC - Raising St. Louis
- Matthews-Dickey Boys and Girls Club
- Queen of Peace Center
- Kingdom House
- St. Louis Crisis Nursery
- Normandy School District Parent/Teacher Organization
- Beyond Housing
- Parents As Teachers

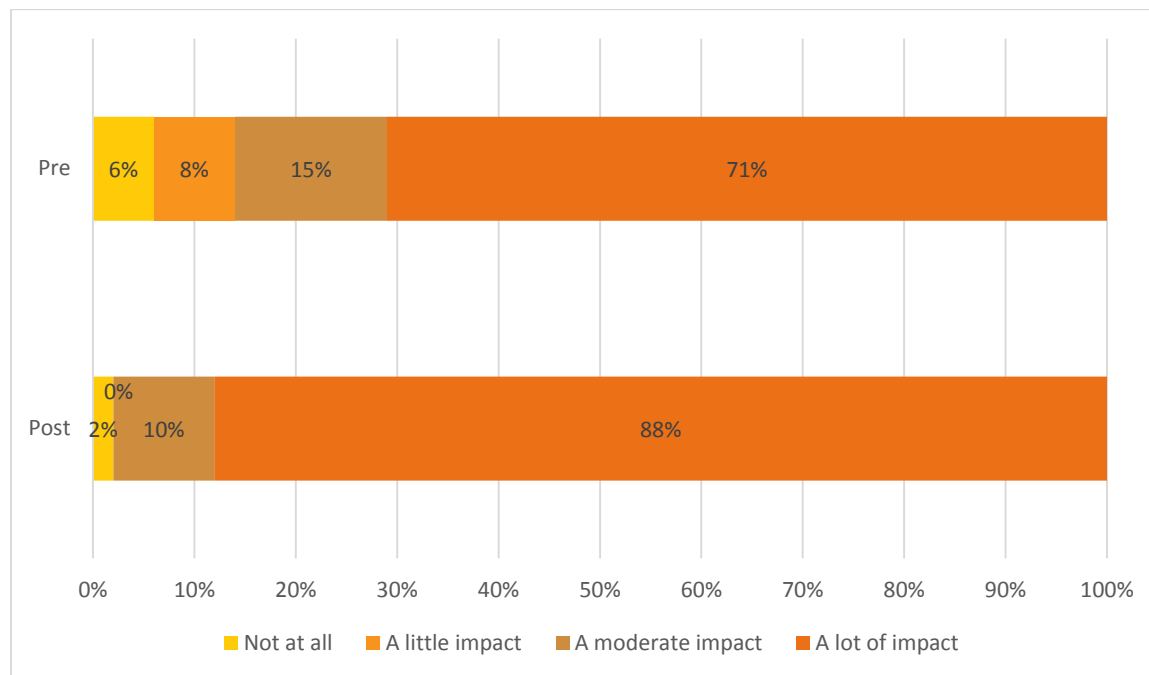
## Participant Demographics

In the process of conducting the seven listening sessions, the perspectives and insights of 126 community members were gathered. The participants ranged in age from 11 to 76. In terms of race and ethnicity, participants were predominately African American, with representation of Caucasian, Hispanic, and Asian American individuals as well. For the individuals who provided their race/ethnicity, there were 102 African Americans, 12 Caucasians, 4 Hispanics, 1 Asian American, and 1 individual who reported their race as Mixed. Participants were overwhelmingly female, although there were a handful of males present at three of the listening sessions (Kingdom House, Normandy, Open Session).

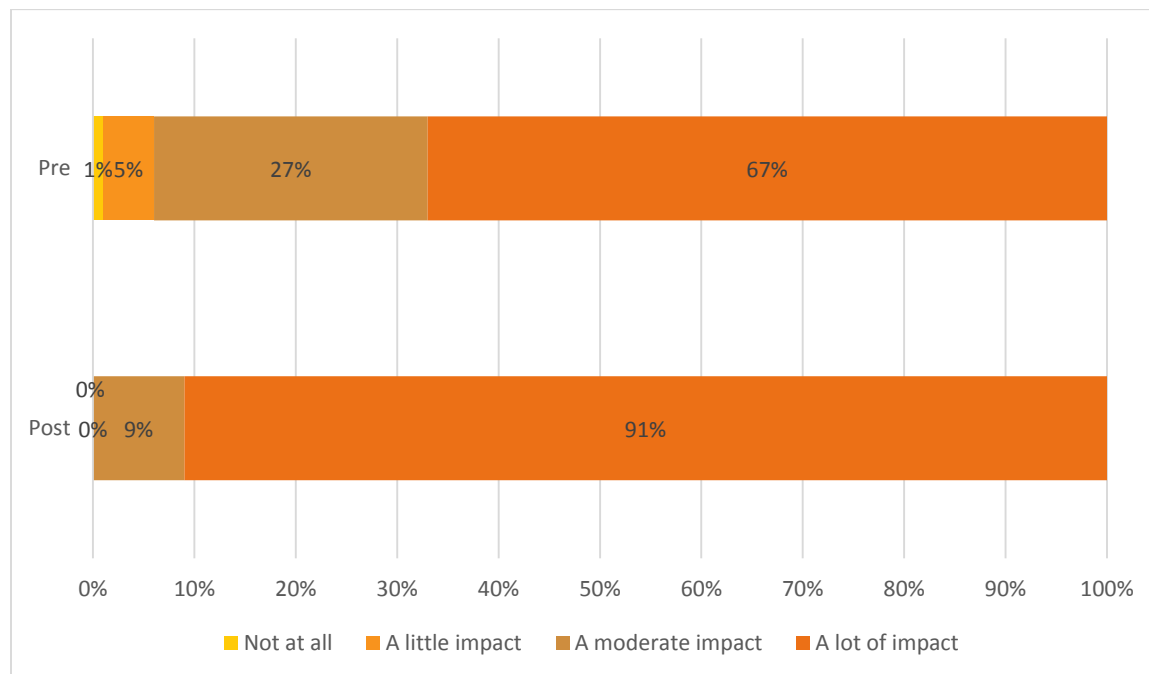
## Current Understanding of Infant Mortality-Related Issues

As part of the listening sessions, participants were asked to complete a pre- and post-test, in which they placed stickers on a poster to represent their response (on a scale of 1 to 10) to three questions related to infant mortality. The charts below represent a compilation of the data from all of the listening sessions. The data shows that as a result of participating in the listening sessions, participants generally experienced an increase in their overall understanding of infant mortality and expressed a desire for awareness to be raised and for there to be more community education around the topic.

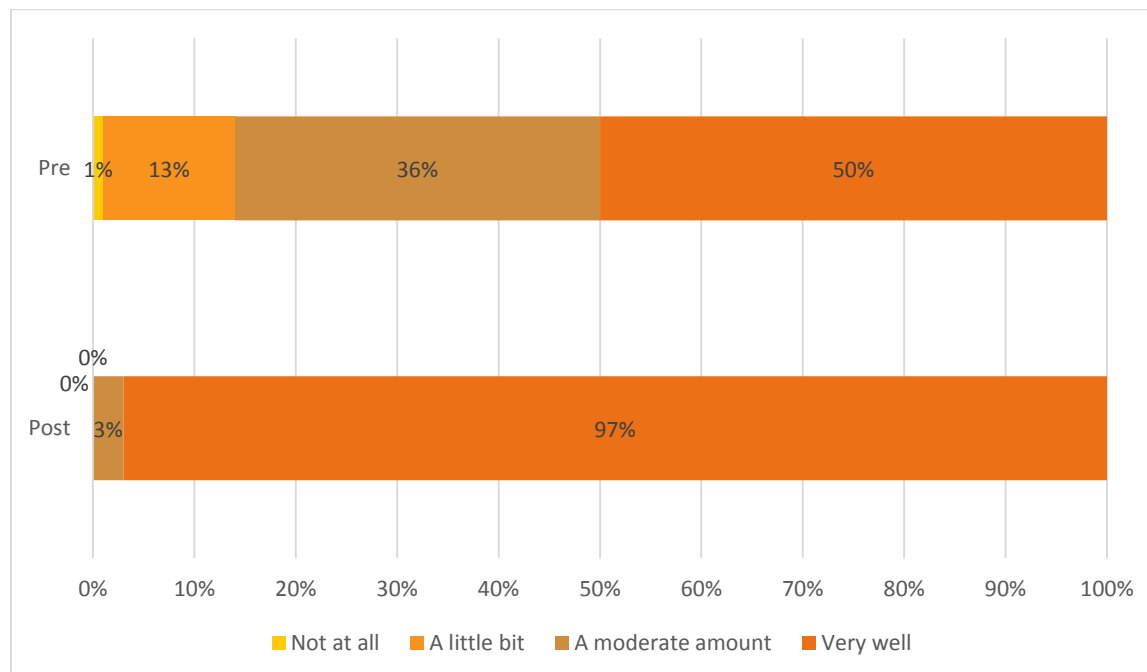
**FIGURE 1. HOW MUCH DO INFANT DEATHS AFFECT YOU?**



**FIGURE 2. HOW MUCH DO INFANT DEATHS AFFECT THE COMMUNITY?**



**FIGURE 3. I UNDERSTAND THE CAUSES OF INFANT DEATHS.**



## Information Gathered

The listening sessions were structured as a dialogue between the facilitator and the participants. The sessions began with the facilitator describing the purpose of the listening session, how the information was going to be used, and laying some basic ground rules. The facilitator then briefly presented some background and data about infant mortality in the St. Louis region. The information was then gathered via a series of questions that participants were asked to respond to based on their lived experience. A scribe wrote all information on flipchart paper so that participants could see what was being recorded. There were eight main questions that were asked of all participants. The questions and a summary of all the responses gathered follow.

### How does the death of an infant impact you?

In response to this question, many participants expressed that they often do not think about infant deaths because it is something that is sad and emotionally draining to consider. Babies are innocent and vulnerable, and it seems very unfair that they should die before even having a chance to live. Participants said that babies dying is devastating, and that discussing it makes them feel hopeless and helpless. Thinking about infant deaths means thinking about so many futures that have been lost. When a woman loses a baby it is hard to even know what to say to her. Several participants spoke about babies that their mothers or other family members had lost, and how that

loss had, and continues to have, a significant impact on all of their family members. Women who had premature babies spoke about the difficulty of seeing their babies in the Neonatal Intensive Care Unit (NICU), and how so many mothers have to go through this experience alone. One mother mentioned how she was shocked that there are babies in the NICU dying every day, and how it was hard to be happy about her baby getting better when she saw other mothers losing theirs.

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*“My son was born at 27 weeks. The doctors gave me everything to try to stop it. I still remember my doctor’s heels running to the room to deliver my child. She was wearing a white cashmere sweater because she didn’t even have time to change.”* –Open Listening Session Participant

*“In the NICU I saw moms staring off into space or just crying and didn’t know what to say to them and they didn’t know what to say to me.”*  
–Open Listening Session Participant

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## How does the death of an infant impact our neighborhoods and community?

Participants described the trauma of the loss of an infant on a parent and how it drastically impacts their behavior, often leading to self-medication and other unhealthy coping mechanisms. These parents are so sad and broken due to their devastating loss that they are often unable to contribute to the neighborhood. This often breaks the community apart because any loss is impactful, but the loss is felt even more deeply when a vulnerable baby dies. All of these losses create a void and have a negative impact on the future potential of our neighborhoods and communities. In spite of all of this, a lot of people are not aware of infant mortality because no one talks about it. One participant thought this might be because of the cultural norm that “family business should be kept at home”. People in the community do not know what to do or how to approach someone or bring up the loss of an infant. As a result, the problem often gets slipped under the rug.

## Does the data about infant mortality that was presented seem accurate to you? Why or why not?

The majority of participants agreed that the information about the high infant mortality rates in the St. Louis region, as well as the disparities in infant mortality and premature births between African American and White residents was accurate. Many also expressed anger or frustration that the numbers were so high and the disparities so extreme. Participants were concerned with why this reality exists, and described it as “disturbing”, “alarming”, “shocking”, and “a silent cry”. Others felt that the rates may be

even higher due to unreported cases and expressed surprise that the disparities between Whites and African Americans were so extreme.

Some of the reasons given for the why the data seemed accurate included the fact that many neighborhoods in the St. Louis region are very poor, especially many African American neighborhoods. Participants also mentioned the persistence of residential segregation in St. Louis, as well as how infant mortality is a symptom of larger, deeply rooted issues in the region. Many expressed the importance of addressing the deterioration of the family unit, cultural values, and taking the African American community's perspective into consideration as priorities are set.

### What impacts the health of moms and babies in our region?

There were a multitude of factors that participants listed in response to this question. Factors that appeared time and again included: drugs, alcohol, lack of access to fresh foods, lack of transportation, stress, undiagnosed or untreated mental illness, lack of education/knowledge, lack of access to resources, poverty, homelessness, and the larger physical and social environment. Other common answers included a lack of social support (from a partner, extended family, or friends), lack of access to/awareness of resources, inflexible work schedules, and fear/difficulty related to navigating social service systems. Participants discussed the importance of vitamins, prenatal care, healthy nutrition, exercise, self-care, and making smart sexual health decisions. After babies are born, major factors impacting their health were safe sleep, bonding and connection between mothers and babies, parenting approach, and the amount of love and care that they are shown.

### What currently exists in our community to help the health of moms and babies?

Participants listed a number of different agencies and organizations that they felt had a positive impact on the health of women and children in the St. Louis region. Some of these resources included Matthews-Dickey Boys and Girls Club, United Way, the Community Action Agency, St. Louis Crisis Nursery, Thrive, Planned Parenthood, Nurses for Newborns, Almost Home, SIDS Resources, Kingdom House, Better Family Life, Father Support, Beyond Housing, and many more. Participants also described a number of educational classes they knew of, such as car seat safety, parenting classes, prenatal yoga, CPR, and personal responsibility. Other resources included pediatricians and other healthcare providers, CenteringPregnancy meetings, food pantries, and childcare providers.

### What needs to change or be improved to make our community healthier for moms and babies?

Participants had numerous ideas related to changes that could be made to make the St. Louis region healthier for moms and babies. The number one suggestion related to

greater access to and awareness of resources. The resources for which there seemed to be the greatest demand included transportation, education, mental health, and the available/affordable fresh and healthy food. As far as increasing awareness of existing resources, many suggested that community workers or community resource specialists may be an effective way to meet this need. They also talked about the need for housing and job training programs in the St. Louis region. In terms of job training, the community felt that there should be less restrictions on getting jobs (credit history, misdemeanors), as well as measures in place to help facilitate attending job training (weekly bus passes).

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*“It shouldn’t be the case that only a handful of African Americans are able to ‘escape the cycle’ and thrive.”*

*-Open Listening Session Participant*

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Other changes that need to be made included mentorship, empowerment, and leadership programs, especially for young African Americans. Participants described the need to create motivation to change in the African American community, which will only occur once people begin to have hope that things can get better. Re-engaging fathers and strengthening the family unit were other proposed solutions. Some took this a step further, and expressed a desire to strengthen larger social networks as well, since it “really does take a village” to raise a happy and healthy child. Many also expressed a desire for greater communication in the community, which can only happen after fear and shame are reduced and mutual respect is increased. They felt that until people learn how to use their voices effectively and take ownership of the problem, it will be difficult to create real change.

Many also expressed the positive impact that Medicaid expansion would have on the health of women and children in the St. Louis region, as well as working to provide insurance for eye care and dentist appointments. There is a need to make going to the doctor a more pleasant experience (see the same doctor every time, decreased wait time, no bias related to type of insurance you have). Others felt that more home visitation programs, perhaps up to age 5, would also have a positive impact. There is a need for more birth control education and access for teens, as well as more resource centers for them to go to, especially for things that they may not want to talk to their parents about. Participants expressed an interest in expanded sex education in schools so that teens are informed about their bodies and can make safe, educated decisions related to sex.

There was also a communicated need for greater understanding of the important of keeping prenatal appointments, as well as encouraging women to attend prenatal classes. Many participants also spoke about the power of support groups for mothers, and thought that more of these would be helpful.

## What would it take to make needed changes happen?

Participants had many different ideas about how to go about making needed changes happen in the community. One major theme that emerged was related to encouraging increased collaboration among various agencies, systems, and individuals in the community. This collaboration would allow gaps to be identified, for community outreach and engagement to be increased, and for focus to be directed to areas where the needs are greatest. Community members also expressed a desire for greater access to decision makers and for access to information about resources so that they could share it with others.

In order for positive changes to be made, there is also a need for greater education of the community related to the responsibility of raising a baby, and about the importance of offering help when you are able to give it, as well as of asking for help when you are in need of it. Participants also described how systems such as SNAP often force families apart (as a single parent is eligible for more assistance), rather than encouraging/rewarding families for staying together. Significant investment needs to be made in many communities, in terms of money, businesses, transportation, etc. in order to rejuvenate and positively impact the people living in them.

## If your dream for a happy, healthy St. Louis region came true, what would it look like?

The answers to this question were varied and inspiring. People spoke about their desires for a safe, supportive community in which everyone looks out for each other and where there is unity and peace. They described healthy people, laughter, and children playing outside with their families. Violence, drugs, abuse, and guns were no longer part of the picture. There was unlimited access to healthcare, transportation, and nutritious foods. Family units were intact and neighborhood networks were strong. People described community centers, businesses, yoga studios, and quality schools with full classrooms. They talked about paid family leave, and parents who do not have to work all the time, but can actually spend time with their children. The community was trusting, clean, friendly, and allowed for open and effective communication. In the dream community, all neighborhoods were true melting pots, where love and hope were extended to everyone.

## Conclusion

Conducting the FLOURISH St. Louis community listening sessions was an extremely informative and humbling experience. The opportunity to talk to and learn from over 100 community members has provided a wealth of information that will allow the next steps of the FLOURISH St. Louis initiative to be driven by the needs of the community as the community sees those needs to be.



Opportunities for intervention in order to make a significant and sustained reduction in infant mortality in the St. Louis region include increasing collaboration among existing community agencies, increasing access to healthcare, increasing access to transportation and nutritious foods, raising awareness of existing resources, and working to reinvest in as well as empower African American communities.

Community members expressed a real desire to continue to be involved in the FLOURISH St. Louis initiative, and to continue to offer their knowledge and insights related to how to make St. Louis a place where all babies celebrate a happy and healthy first birthday.