



# 2016 FLOURISH Community Listening Sessions Summary

## Purpose

*FLOURISH* St. Louis is bringing together families, as well as leaders from across the education, faith, business, and health care communities to accelerate change. The initiative goal is to create substantial and long-lasting change throughout our entire region by changing the conditions in our community. This is a collective impact approach to solving the complex challenge of why too many babies in the St. Louis region are dying before their first birthday.

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. The information collected from the listening sessions was presented to the *FLOURISH* Cabinet, and will use this information along with other local research to help identify the top priority areas for addressing infant mortality in the St. Louis region.

Community listening sessions were conducted in the fall of 2016 as part of the *FLOURISH* St. Louis infant mortality reduction initiative. The purpose of the listening sessions was to:

- 1) Deepen understanding of the priority areas to assist the *FLOURISH* Cabinet in making initial decisions for reducing infant mortality;
- 2) Increase awareness of community needs impacting infant mortality in the St. Louis region;
- 3) Develop a shared understanding of systematic influences impacting the health of women and infants; and
- 4) Foster the ongoing foundation of building community trust, ownership and involvement with impacted families.

Nine listening sessions were held at various community agencies, as well as one large listening session that was held at the Generate Health's Quarterly Coalition meeting and consisted of primarily service providers. Generate Health, formerly known as the Maternal, Child and Family Health Coalition, is the backbone organization which provides support and coordination to the *FLOURISH* initiative. Generate Health is dedicated to improving birth outcomes, promoting health families and building healthy communities.

## Listening Session Context

*FLOURISH* St. Louis continued its series of community listening sessions to discuss and better understand St. Louis' infant mortality crisis. In 2014 and 2015 a series of open and targeted listening sessions were conducted with community partners, including Missouri Foundation for Health Infant Mortality Reduction Grantees, who had a client base impacted

by the issue of infant mortality. For the 2016 listening sessions, Generate Health again reached out to a broad-base group of community partners to host a listening session and expanded the number of collaborative partners and community members respectively reached in 2014 and 2015. The target audience was families with lived experience, 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 approach was kitchen table-style conversations where priority areas were discussed and a survey completed by participants. An emphasis was made to all community members who attended the sessions that the information they provided was valuable and will be used to deepen the understanding of priority areas that data has pointed to as critical to the health of moms and babies. Ongoing community feedback will help *FLOURISH* better understand St. Louis's infant mortality crisis and work toward a significant and sustained reduction in the St. Louis region's infant mortality rates.

## Involved Partners

Generate Health would like to thank the following partners, who opened the door to conversations with their clients, graciously provided use of their space, and helped to make the listening sessions go as smoothly as possible.

- Almost Home
- Beyond Housing
- Big Brothers Big Sisters
- Kingdom House
- Making Change Happen Leadership Academy
- Matthews-Dickey Boys and Girls Club
- New Northside Baptist Church
- Normandy School District Parent/Teacher Organization
- Our Lady's Inn
- Parents As Teachers
- Queen of Peace Center
- St. Louis Crisis Nursery
- United 4 Children

## Participant Demographics

In the process of conducting the ten listening sessions, the perspectives and insights of 220 participants were gathered. The participants ranged in age from 14 to 74. In terms of race and ethnicity, participants were predominately African American, with representation of Caucasian and Hispanic individuals. For the individuals who provided their race/ethnicity, there were 58% African Americans, 22% Caucasians, and 8% Hispanics. An overwhelming percent of the participants were female (86%), while (9%) males were in attendance. Targeted efforts were made to ensure geographic diversity. Listening session participants reside in 34 separate zip codes.

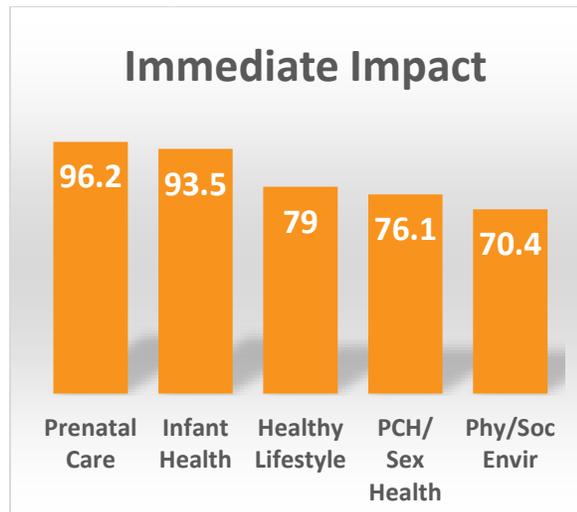
## Overview of Infant Mortality-Related Priority Areas

Listening session participants were given the latest statistics and contributory factors to the high rates of infant mortality in our region during the introductory portion of the session. Information about racial health disparities and a definition of racial equity was shared and discussed. The lack of racial equity is an important factor believed to influence health disparities across all priority areas, which community feedback would later affirm. Next, the facilitator shared the five initial priority areas to help reduce the number of babies dying in St. Louis. These areas were derived from issues raised by residents in earlier community listening sessions and data analyzed by the Think Tank. Each priority area had an associated infographic for participants to refer to throughout the session. The five priority areas presented were prenatal care, infant health, healthy lifestyles, preconception health/sexual health, and physical/social environment.

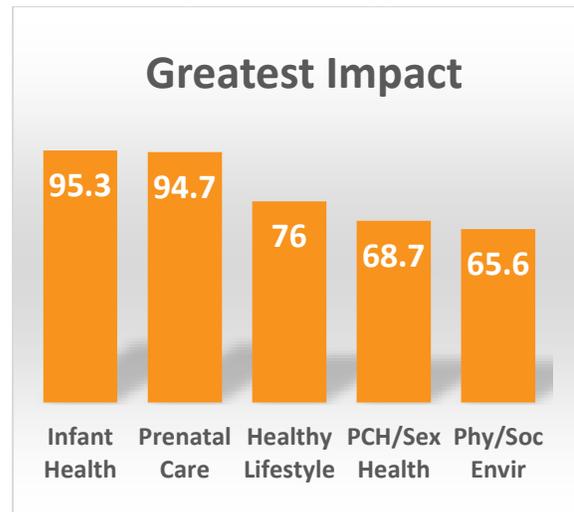
## Information Gathered

The listening sessions were structured as a dialogue between the facilitator/table hosts and the participants. Background about each priority area was presented one at a time by the facilitator and as outlined in a participant survey and infographic. Then information was gathered via a discussion of specific bullet points related to that area based on participants' lived experience. A scribe wrote all information on flipchart paper/questions sheet so that participants could see it was being recorded. After this discussion, participants were asked to rate the priority level regarding its potential for immediate impact and greatest impact for reducing infant deaths. Below are the results of the participant survey.

**FIGURE 1. MOST IMMEDIATE IMPACT FOR REDUCING INFANT DEATH**



**FIGURE 2. GREATEST IMPACT FOR REDUCING INFANT DEATH**



## Prenatal Care

Prenatal care refers to both the care a woman receives during pregnancy and the growth and development of the fetus. Prenatal care surveyed as one of the top priorities among community listening session participants for both having the most immediate and greatest impact for reducing infant death. The greatest challenges exist for families both in access to quality care and coverage. Some of the barriers to prenatal care most noted include:

- Inconsistent, delayed or denial of health coverage with overwhelming support for Medicaid expansion.
- Loss of health insurance for pregnant women, particularly after the 60 days postpartum visit.
- Limited access to quality care and providers who did not properly explain information, talked down to them, or mistreated them. Participants spoke about not feeling empowered to speak up or say no to doctors. It was an often occurrence to hear reports from women with Medicaid reflect on experiences they felt were treated differently than those with private pay insurance.

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*One participant shared that a male student was made to check her cervix without her permission during her prenatal visit. She felt violated and wished she was given a choice to ask for a female health provider.*  
- Listening Session Participant

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- Lack of information about available services or benefits, which makes it difficult to navigate resources available for pregnant or new moms.
- Inconsistent referrals and linkages to services by their providers.
- Lack of concerted efforts to include fathers during prenatal education and services.
- Difficulty getting to appointments due to lack of child care for moms with multiple children and unreliable transportation.

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*“The good doctors and quality care are outside of my neighborhood (St. Louis City). The good doctors are far away”*  
-Listening Session Participant

*“Researching services on your own is overwhelming.”*  
-Listening Session Participant

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## Infant Health

Infant health focuses on the well-being and care of babies during infancy, a period of rapid growth and development from birth to one year old. Key areas of concern voiced by participants include:

- A disconnect between providers and parents when it comes to understanding infant health care. Providers did not always take concerns seriously and advocates such as home visitors helped to empower parents.
- Education and resources are needed to help parents better understand developmental milestones and safe sleep practices.
- Outreach efforts to educate parents should be strengthened in the areas of drug and alcohol use, nutrition, breastfeeding and safe sleep.
- Safe sleep practices were cited in a recent Perinatal Periods of Risk (PPOR) data analysis of the St. Louis region as an area of excess or preventable infant deaths, yet was not well known by participants as a contributor to infant loss.
- Strong support for home visiting services to improve infant health and development and increase access to resources to promote the health of their families.

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*“My baby’s doctor kept saying wait a couple of months/years to see if there are changes when I felt/knew there was something wrong with my son. My parent educator gave me a voice. I sought a second opinion and my son was later diagnosed with cerebral palsy.”*

*–Listening Session Participant*

*“Home visitation should be a resource for all families.”*

*–Listening Session Participant*

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## **Preconception Health/Sexual Health**

Preconception health refers to a woman’s health before she becomes pregnant. The majority of participants overwhelmingly agreed that there should be comprehensive medically accurate sexual health education in schools. There was also strong support for access to and education about birth control, especially for teens. Participants also spoke again of the need for Medicaid Expansion in Missouri. They talked about how women needed to be able to manage their complex health conditions, especially mental health before they got pregnant. Many expressed the need for resources that helped them manage their health including education, finances, health insurance, mental health and support systems.

Awareness and education about family planning options that best meet the needs of the individual was an issue about which participants felt strongly. Women are not always given accurate information about birth control options and side effects. Also many were uninformed or misinformed about the impact of birth spacing on women and infants’ health.

## **Healthy Life Style**

Healthy lifestyles are the community conditions that support healthy choices and behaviors over the course of a life-time. During the discussion of this priority area, participants raised concerns over the lack of supports for behavioral health services as well as services for

alcohol and drug use. These supports were discussed as being critical to cope with parental stress including trauma and toxic stress. Many shared personal experience with substance use as an unhealthy coping mechanism. Again, participants voiced the need for a navigator for women and families who can connect them to resources and services in these areas.

Participants agreed that good nutrition and exercise were important to maintain a healthy lifestyle. However, the environment where they lived was not conducive to accessing either one of these things. Food deserts and unsafe neighborhoods contributed to this problem. When there is no grocery store in the neighborhood and a high amount of violence in the area it is near impossible for residents to lead a healthy lifestyle. Participants also complained about the cost of healthy foods and the lack of transportation options for them to get to an affordable, grocery store with produce and fresh foods.

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*“Without healthy mothers/parents, babies won’t receive the care they need.”*

*–Listening Session Participant*

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## Physical/Social Environment

This priority area encompasses the circumstances in which people are born, live, grow up and age, as well as the systems put in place to provide social supports, education and full development. In this area participants agreed that increased access and education about community based parenting resources and supports was needed. One concern was that parents were not aware of home visiting services that provided parent education. They also indicated the need for strengthening family connections and positive parenting practices. Parents need strategies on how to deal with the stressors in their lives in order to develop positive relationships and parenting practices. Participants voiced that re-engaging fathers was important and also talked about the need for peer and social support, or home visitation services as a way to help moms relieve their stress and get the parental assistance they need.

Partner violence was raised by participants as an issue that was escalating in the community that was not being addressed or talked about. Moms described that women often fear that they will lose their children if they report violence in the home and therefore stay silent. Many are unaware how this silence impacts their child’s health and development.

## Cross-Cutting Themes

Listening sessions identified cross-cutting themes that impact all five priority areas. When examining the data and community feedback to address infant deaths, behavioral health, access to health care, home visitation, racial disparity, social and economic conditions, and transportation were consistent themes found across all priority areas.

Behavioral health surveyed as a top priority for participants across all areas. Access to timely high quality mental health services and resources, trauma informed care, and reducing stigma were all part of this theme. Increasing access to high quality health care was another theme throughout the priorities discussed in the sessions. This included education, outreach and navigation of services. Home visitation services was an additional theme that would help assist in accessing health care and navigate services but also would provide education and other supports needed for families to thrive. Transportation was cited as a major barrier to meeting health care needs of moms and babies and accessing foods and nutrition to lead to a healthy lifestyle.

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*“We must first be healthy, physically and emotionally before we can have healthy babies”*

*-Listening Session Participant*

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Racial inequity and the economic stressors of poverty related to unjust distribution of resources and opportunity was a key cross-cutting theme. The lack of safe neighborhoods, adequate housing, grocery stores, living wage jobs, and quality education were discussed by participants as a way to help relieve the stress of raising a family and address basic community needs. Many felt discriminated against by health care providers because they were young, black and often felt their voices as parents were not heard.

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*“It feels like the world is not giving us a chance.”*

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## Conclusion

Conducting the *FLOURISH* St. Louis community listening sessions affirmed the challenges that families face in the 5 priority areas identified by the *FLOURISH* Cabinet. There are a great deal of opportunities to improve systems and address cross-cutting themes that stifle families’ growth and progress toward well-being.

Overall, the community listening sessions shed light on issues impacting infant mortality. 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 the St. Louis region a place where all babies celebrate a happy and healthy first birthday. Most notable we encountered some who took part in the first and second round of sessions and were eager to use their voices and lived experiences to improve the community so all can flourish.



## FLOURISH St. Louis: Community Input Survey

Thank you for participating in the *FLOURISH* STL Community Listening Session for improving the Health of Babies, Women and Families. Your input will be used to help make important decisions about where to target efforts that will have the greatest and most immediate impact for reducing infant deaths in the St. Louis region.

Building on what we have heard from the community and learned from the data, *FLOURISH St. Louis* has identified five initial priority areas to help reduce the number of babies dying in St. Louis.

1. **Prenatal Care** - The care a woman receives during pregnancy.
  - Increasing availability to high quality prenatal care
  - Encouraging/supporting mothers' use of prenatal care services
  - Supports for child care and transportation
  - Availability of insurance, physicians
  - Knowledge of prenatal care service
2. **Infant Health**
  - Increasing availability to health care/well-child visits for young children
  - Improving infant health through safe sleep practices (ensuring the baby does not sleep on its stomach or with others; babies sleep in safe places)
  - Increasing access to well-child care and/or home visiting for children under 5 (either to check on infant health or to increase parents' understanding of infant health and development)
  - Promoting supports for healthy physical and social environments (Safe and nurturing families and neighborhoods, free from maltreatment and other social adversities)
  - Promoting breastfeeding
3. **Preconception Care/Sexual Health** – Steps women/youth can take to stay healthy prior to and between pregnancy that promotes good health and birth of a healthy baby/  
Teens receive age-appropriate, medically accurate information on a broad set of topics related to pregnancy, sex and their bodies.
  - Improving women's/teens' access to birth control
  - Increasing access to teen pregnancy and prevention education
  - Increasing youth development opportunities and other options that encourage teens to postpone pregnancies
  - Promoting improved birth spacing (length of time between births)
  - Improving the health of women prior to pregnancy (managing health risks such as diabetes, hypertension, heart disease, infections)
4. **Physical/Social Environment**

- Improving support for pregnant and new mothers (and their babies) from fathers, their extended families, friends, and other mothers
- Engaging fathers support during and after pregnancy
- Supporting mothers and fathers in their abilities to bond with their babies and supporting good parenting practices
- Ensuring all families are screened for partner violence

**5. Healthy Lifestyle** - Ensure there are resources in the community which promote healthy activities and mental health supports

- Improving nutrition and availability to healthy foods
- Increasing resources in community that promote exercise and healthy eating
- Supports for decreasing tobacco, alcohol, and drug use
- Increasing coping skills for dealing with multiple kinds of stress
- Providing responsive behavioral health (mental health) supports

Please rate the following areas you think will have an ***immediate impact*** for reducing infant deaths.

Focus Area	1-NOT a Priority	2-Medium-level Priority	3-TOP Priority	I don't know/ No opinion
Prenatal Care				
Infant Health				
Preconception Care/Sexual Health				
Physical/Social Environment				
Healthy Lifestyle				

Please rate the following areas you think will have the ***greatest impact*** for reducing infant deaths.

Focus Area	1-NOT a Priority	2-Medium-level Priority	3-TOP Priority	I don't know/ No opinion
Prenatal Care				
Infant Health				
Preconception Care/Sexual Health				
Physical/Social Environment				
Healthy Lifestyles				

Please tell us what you think are most important issues within each priority area.

<b>PRENATAL CARE</b>	<b>1-Not at all important</b>	<b>2-Not very important</b>	<b>3-Somewhat important</b>	<b>4-Very important</b>	<b>I don't know</b>
Quality of information/education provided during prenatal visits					
Transportation					
Availability of health insurance and physicians					
Support for child care					
Increasing availability of prenatal classes					
Knowledge of prenatal care service					

What else would you recommend to help improve this priority area?

<b>INFANT HEALTH</b>	<b>1-Not at all important</b>	<b>2-Not very important</b>	<b>3-Somewhat important</b>	<b>4-Very important</b>	<b>I don't know</b>
Increasing the use of safe sleep practices					
Increasing availability to health care/well-child visits for young children					
Increasing health care home visiting services					
Increasing parent education/child development home visiting services					
Promoting supports for safe/nurturing families and neighborhoods					
Promoting breastfeeding					

What else would you recommend to help improve this priority area?

<b>PRECONCEPTION CARE/SEXUAL HEALTH</b>	<b>1-Not at all important</b>	<b>2-Not very important</b>	<b>3-Somewhat important</b>	<b>4-Very important</b>	<b>I don't know</b>
Improving the availability of birth control for women/teenagers					
Increasing availability to teen pregnancy and prevention education					
Increasing youth development opportunities and options that encourage teens to postpone pregnancies					
Promoting improved birth spacing (length of time between births)					
Improving the health of women prior to pregnancy (managing health risks such as diabetes, hypertension, heart disease)					

What else would you recommend to help improve this priority area?

<b>PHYSICAL/SOCIAL ENVIRONMENT</b>	<b>1-Not at all important</b>	<b>2-Not very important</b>	<b>3-Somewhat important</b>	<b>4-Very important</b>	<b>I don't know</b>
Improving support for pregnant and new mothers from fathers, extended families, friends, and other mothers					
Increasing fathers support during pregnancy					
Supporting mothers and fathers in their ability to bond with their babies					
Supporting mothers and fathers in using good parenting practices					
Ensuring all families are screened for partner violence					

What else would you recommend to help improve this priority area?

<b>HEALTHY LIFESTYLES</b>	<b>1-Not at all important</b>	<b>2-Not very important</b>	<b>3-Somewhat important</b>	<b>4-Very important</b>	<b>I don't know</b>
Improving nutrition and availability of healthy foods					
Increasing resources in community that promote exercise and healthy eating					
Supports for decreasing tobacco, alcohol, and drug use					
Increasing coping skills for dealing with multiple kinds of stress					
Increasing behavioral health (mental health) supports					

What else would you recommend to help improve this priority area?

**Final Question**

When examining the data and community feedback to address infant deaths, behavioral health, education, access, racial disparity and childcare were consistent themes found across all priority areas.

How can these challenges be addressed or fixed?

How can the system be improved to address these challenges?

Who has the system left out and how can it be changed so it serves all people with what they need?

**Please provide information about you:**

<b>Age</b>	<b>Gender</b>
<b>Racial/Ethnic Background</b>	<b>Zipcode</b>

*Thank you for your feedback!*