

Maternal & Child Health Needs Assessment Report
2009

Prepared by:

Dana Hughes, MPH
Christian Arment, MPA
Caren Bacon, MPH
Diana Costa, MPA
Emily Johnson, MA
Aaron Rapp

Institute of Public Policy
Harry S Truman School of Public Affairs
University of Missouri



**Maternal & Child Health Needs Assessment Report
2009
Table of Contents**

Executive Summary	1
Introduction	11
Methodology	12
Provider Focus Group Results	14
Rural Provider Analysis.....	14
Urban Provider Analysis.....	18
Consumer Focus Group Results	22
Jefferson City Focus Group Analysis.....	23
Cape Girardeau Focus Group Analysis.....	28
Poplar Bluff Group Analysis.....	33
St. Louis (Group 1) Focus Group Analysis.....	36
St. Louis (Group 2) Focus Group Analysis.....	38
Branson Focus Group Analysis.....	42
Springfield Focus Group Analysis.....	46
Kansas City Focus Group Analysis.....	48
Kirksville Focus Group Analysis.....	53
Moberly Focus Group Analysis.....	59
Columbia Focus Group Analysis.....	64
Sedalia (Hispanic) Focus Group Analysis.....	67
Survey Results	70
Recommendations	77
Lessons Learned and Summary	80

Executive Summary

Introduction

The following section provides a brief section by section summary of the maternal and child health needs assessment findings. This summary will guide the reader through the main findings from each section of the report. Additional detail to support each statement can be found in the corresponding section of the report.

Provider Focus Group Summary

Rural Provider Analysis

Patients have difficulties accessing the medical system efficiently

Patients are using the emergency department unnecessarily because they do not have insurance. They wait until issues become severe, or because they cannot find a doctor who will accept Medicaid for their particular health concern. They are then more medically complicated to treat.

More and more patients are uninsured and underinsured, especially when they get pregnant. They are not receiving health care before getting pregnant or early in the pregnancy.

Migrant and Spanish speaking patients face special challenges and need special services. They have language, cultural, and immigration status issues that require special expertise on the part of the health care system. Specially trained staff members to assist migrant and Spanish speaking consumers are needed at the local level.

A child receiving correct immunizations on schedule is difficult. Parents are not educated about the child's immunization needs. They do not have continuity of care which makes tracking immunizations very difficult. Many children will be vaccinated multiple times because parents do not have proof of immunizations, and the MOHSAIC system has been difficult to use to solve this problem. Improvements in the MOHSAIC system and its usability can help to solve this problem.

Children with special health care needs face access issues in rural areas (especially on Medicaid). The specialists are not as available as necessary, and some specialists do not accept Medicaid which further hinders access for children with special health care needs.

Finding providers who take Medicaid is difficult for all consumers. Due to the current reimbursement structure there is a shortage of providers who accept Medicaid or new patients with Medicaid. This creates an access barrier for many consumers who use Medicaid.

The structure of health care limits the services that can be provided in rural areas. Rural areas could be more creative with the resources that are available, however policies like scope of practice, reimbursement from CMS and others limit the ways in which existing resources can be utilized. Rural areas need more flexibility in how they offer adequate health care.

Family

Parents need more education about health and health care. Parents are not informed about immunizations, nutrition, chronic disease, asthma, and other health issues facing themselves and their children.

Teenage pregnancy is a problem in rural areas. Due to cultural norms regarding teen pregnancy and a conservative climate surrounding sexuality education there is a significant teen pregnancy problem in rural areas. Teen parents are particularly in need of more education regarding their health and the health of their children.

Transportation/Geographical Access

Specialists for children with special health care needs are difficult to find in rural areas (especially with Medicaid). Due to this limited accessibility, transportation to specialists in more urban areas is a barrier to receiving the necessary health care.

Travel to specialists is difficult (for everyone). Consumers who need specialists often have more pressing health concerns. If consumers have limited ability to pay it makes the travel problem more difficult. Many needing care from health care specialists must travel long distances to more urban areas for care. This is just another barrier to receiving appropriate care in a timely manner.

Community

Integrating public health into the schools would improve child health in rural areas. Given the limited resources and the lack of accessibility, public health measures in the schools could improve public health for children and families. This could take the form of more education or direct preventive care such as dental sealants or vaccinations.

School nurses are working well with health care professionals in some situations. They are working with health care providers to provide some of the education and services in the schools. While this is a strength of rural areas, more of this work should be done.

Education

There are health education services currently available including local health departments, WIC and the educators at local hospitals. However, additional health education services are needed to address patient education for consumers with chronic diseases, obesity prevention, nutrition education (malnourishment and obesity prevention), asthma managements, substance use/abuse, tobacco prevention, adolescent sexuality and other issues.

Changes in the Past Five Years

During the past five years the providers observed that patients are more demanding of services without being fully informed. Additionally, payers are more involved in health care than they used to be. In addition to being subject to many outside influences, there are more chronic health problems that could be prevented or need to be managed by lifestyle changes.

Perfect Health Care System

The provider focus group participants would like to re-establish the value of the relationship between the patient and the physician. One strategy for accomplishing this would be to reduce payer input into health care. They would also like to use media for patient education and put public health nurses back into schools.

Urban Provider Analysis

Medical/Provider Relationships

Continuity of care needs to be improved. Patients do not return for follow-up appointments and they do not comply with prescriptions. Additionally, they do not always return to the same provider. Many issues arise from the lack of continuity.

Uninsured and underinsured patients have difficulty navigating the Medicaid system. They are not familiar with the rules. They do not fully understand what is covered and when. It is also difficult for providers to keep up with changes in Medicaid policies.

Cultural competence of care is becoming more and more important as providers see more people from different backgrounds with different degrees of health literacy.

Prenatal care in subsequent pregnancies is often lacking since the patients feel that they do not need to have prenatal care after the first pregnancy. This is reinforced when they then have healthy children in second and third pregnancies without prenatal care.

Immunizations present many challenges related to tracking them for children. Schools, providers, and parents need a mechanism that assists with tracking immunizations. MOHSAIC is not currently working in practice, but is a good idea in theory. Making MOHSAIC more user-friendly is necessary.

Specialty care is difficult even in urban areas. Access to specialists is still limited by being in the appropriate payer network, especially Medicaid. Additionally, long wait-times are common in urban areas.

Use of the emergency room for primary care is common. This is especially true among immigrants who are less likely to be insured due to income, eligibility for Medicaid, and fears regarding their immigration status.

Transportation and Geographic Access

Getting to appointments is difficult for some. While consumers have access to public transportation and Medicaid will cover transportation costs there are still barriers. Adolescents are often unfamiliar with how to use public transit, or consumers may not have the money for the trip to the appointment. They are also often unfamiliar with how to use the Medicaid transportation.

Transportation to urgent appointments is difficult to arrange through the Medicaid transportation service.

Health care in schools would increase access for adolescents. Just as in the rural areas, providers felt that taking health care to schools would increase access for much of the population who is currently in the greatest need.

Outreach could increase access by educating community members about health, available services, and social service programs. Providing direct services in the community, rather than in a health center, could greatly increase access.

Education Services

New parents need education. Many parents, especially adolescent parents, do not fully understand all that is needed to maintain their health and the health of their child. Services to enhance parent knowledge and skills regarding immunizations, navigating the health care system, and preventive health are much needed.

More adolescent sexuality education is needed. Teenage pregnancy prevention is needed. Teenage pregnancy continues to be a significant problem seen by health care providers. Additionally, education

regarding the prevention of STDs and other issues related to adolescent sexuality is needed in the community and schools.

Greatest Unmet Need

Urban providers commented that access to health care including prevention services, family planning services, and access to technology like x-ray and mammography for low-income patients was among the greatest unmet health care needs.

Other unmet needs identified included lack of access to healthy food and opportunities to exercise, obesity prevention programs, malnutrition prevention, mental health services and the involvement of men in children's health care and pregnancy prevention.

Changes in Past Five Years

The two greatest changes urban providers saw were both related to paying for health care. They say increased out-of-pocket expenses for patients and increased bureaucracy in health care.

Consumer Focus Group Summary

Medical/Provider Relationships

Hours of availability of some services are too limited. Consumers who are working are not be able to access services offered at limited times.

Providers who accept Medicaid consumers are difficult to find in many areas. Additionally, providers who do accept Medicaid patients may not be accepting new Medicaid patients.

There is often confusion about who accepts specific plans for specific services. Consumers reported being very unclear about which facilities they could access for specific types of health care with specific insurance/Medicaid providers.

Quality of the consumer experience can be variable in terms of customer service and quality of health care professionals. Consumers felt that at some of the health care providers designed to increase access for low-income people that the staff were not courteous or of acceptable quality. Additionally, many consumers reported getting inadequate or incorrect care that was discovered later by a different clinician.

Preventive services are often covered by insurance/Medicaid, but they may be difficult to access due to limited hours and working parents needing to take time away from work. Many local health departments were given high marks for affordable immunizations and good accessibility. However, some consumers report forgoing preventive care in order to save money, especially when they are uninsured.

Long wait times for appointments make health care less accessible, especially for working adults.

Even with Medicaid coverage some consumers find that they still have no/limited providers available. Many participants reported they still have to go to the emergency department to receive care.

Some areas, especially rural areas, have a health care provider shortage that is felt by the consumers.

Language and cultural barriers make accessing health care difficult for some consumers. This includes not seeking care because of uncertainty of accommodations for language interpretation and receiving inadequate care due to language and cultural barriers.

Family

Obtaining immunizations for children can be difficult since they are not always offered at the original health care provider's facility. Parents report needing to take a day away from work to go to their doctor and an additional day from work to get immunizations at the health department.

Many consumers are facing special health care challenges for themselves and their families. Some examples include diabetes, allergies, bi-polar disorder, and brain surgery. These additional special health care needs exacerbate difficulties parents and children may be facing when obtaining health care.

Families facing special health care needs spend more time on managing insurance and care. Due to the complexity of the issues, more time and energy is required on the part of the parents or caregivers.

Health Education/Informational Resources

A variety of sources were cited regarding where individuals receive health education and information including:

- Work
- School

HeadStart
Internet
Clinic
Division of Family Services
Word of mouth
Community organizations
Local public health agencies
WIC
Health fairs
Rural health clinics
School nurses
Nurse hotlines
Parents as Teachers
Lactation consultants
Mommy and Me classes
Birthing classes
Breastfeeding classes

Available education/information resources are often outdated and electronic information is difficult to use. Print materials become outdated quickly in a changing health care environment and consumers report difficulties accessing and utilizing existing electronic or web-based information. An efficient and simple web page with important information about services that is up-to-date was cited as a resource that would be helpful.

A barrier to some community services is that some organizations run out of funding very quickly at the beginning of each month. Particularly utility assistance runs out very quickly. Lack of funding for these types of social services has a ripple effect on consumer health.

School nurses were reviewed very favorably. The only complaint regarding school nurses was their limited capacity due to limited hours at individual schools. Most consumers felt that if there were more school nurses with more time at each school that they could provide even better and more extensive services.

Transportation/Geographical Access

Transportation services are available via Medicaid and other social service programs. Getting Medicaid transportation arranged is difficult for many consumers. Additionally, some consumers reported not being picked up by the Medicaid transportation in rural areas and consequently missing important health care appointments.

Some services require more travel. Particularly specialists and dental services require consumers to travel a long distance to any provider or to providers who accept their insurance/Medicaid. Many consumers around the state are traveling to Columbia, St. Louis or Kansas City for certain types of specialty health care.

In rural areas consumers are typically traveling farther, and that travel requires more time away from work and more difficulty in reaching the needed health care services.

Some specialty or preventive service providers do travel to rural areas occasionally. Consumers were very appreciative of those outreach services.

Financial

Having insurance or Medicaid increases access, but does not guarantee that consumers will be able to access needed health care.

Medicaid is difficult for adults to obtain if they are not pregnant. Many consumers reported that they cannot afford insurance, but they do not qualify for Medicaid. There is a significant gap between qualifying for Medicaid and being able to afford insurance as an adult. Some consumers reported a need for support to keep people working by helping them afford health insurance while transitioning from Medicaid to private insurance.

Medicaid is easier to obtain for kids, but is still confusing to navigate the system at times. For adults and kids it is also common for Medicaid to be “taken away” without consumers knowing why.

Some consumers with special health care needs found the formularies for Medicaid too restrictive. They must endure trying formulary medications before the recommended medications (that are not on the Medicaid formulary) can be covered.

Individuals who have private insurance still find it to be inadequate coverage and need additional assistance with health care expenses.

Out-of-pocket expenses such as co-payments or health care services that are not covered are burdensome for consumers. Support in covering these additional costs is needed. Some services like dental, eyeglasses, mental health, over-the-counter medications diabetic supplies, vitamins, and prescriptions require significant out-of-pocket expenses.

Many consumers find that they cannot have their first choice for health care because of restrictions from insurance/Medicaid. In order to be covered by their particular Medicaid plan they must choose different facilities for their care. Some consumers felt they sacrificed quality of care to go to a facility that accepted their Medicaid.

Reimbursement and finances drive health care decisions made by patients and clinicians. Consumers felt that clinicians were concerned about money and made decisions about what type of health care to deliver based on what would be covered by the payer.

Navigating insurance and Medicaid is difficult and time consuming. Many consumers reported they spent a long time on the phone with payers getting health care expenses approved in order to receive the care that was needed. Sometimes they were never able to figure out the issue and ended up paying out-of-pocket for some expenses they thought should be covered.

Consumers report large co-payments being required before services will be delivered. These large out-of-pocket costs are a barrier to access.

Medicaid's lack of coverage for specific services was sighted as a barrier to those services. Breast pumps and circumcision were two examples cited as services that were not covered therefore changing the health care decisions of the consumers.

Pre-existing conditions were cited as significant barriers to receiving health care coverage due to higher premiums.

Community

WIC is a very well received service. Consumers who had experience with them were almost universally positive. However, WIC is limited to a relatively narrow population. Similar services for other populations (older children, women when not pregnant, men) would be welcome.

Some community organization services help to fill the gaps. Planned Parenthood was an example given in some locations that uses a sliding scale and extended hours. Sliding scale services were a common request from consumers. They do not necessarily want a hand-out as much as affordable health care for their families.

Headstart is a very well-received and well-utilized resource. Many consumers reported satisfaction with the services (childcare and other) provided by their Headstart program.

More extended hours or special clinics for maternal and child health needs are needed in order to increase access, especially for working parents. Occasional weekend hours would help consumers receive preventive care without missing work.

If participants could design a perfect system it would include...

- Access to needed health care
- Increase quality of care
- Easy transportation to appointments
- Extended hours past regular working hours for working families
- Adequate funding to help people who need care
- Free health care
- Better health care for mothers
- Coverage for natural herbs/medicines/treatments

Participants saw the most unmet health needs in their communities to be:

- Dental health
- Mental health
- Vision/eye care
- Prescription coverage
- Accessible health care in rural areas

Participants saw the most significant changes in the past five years to be:

- Reduced services
- Reduced hours by providers
- Fewer funded/free services
- Insurance accepted in fewer places
- Providers who will not accept Medicaid
- Quality of care has decreased
- Stricter formularies
- More out-of-pocket expenses
- Doctors come and go in rural areas of Missouri

Hispanic Consumer Focus Group Summary

Medical/Provider Relationships

There was a perception among Hispanic consumer participants that it was important to know the provider or interpreter in order to be seen more quickly for their health care.

Migrants have difficulty moving from one state to another with Medicaid coverage. When they move from one state to the other some services transfer and others do not. This caused additional confusion and large bills for some.

Focus group participants reported numerous incidents of poor quality of care from bedside manner to misdiagnosis. They also reported poor customer service.

Participants reported being told they would be charged for WIC services and choosing to forgo the services as a result.

Health Education/Informational Resources

A variety of sources were cited regarding health education and information

WIC

A University based program

Financial

Regardless of immigration status, qualifying for Medicaid is very difficult for adults. The maximum income is very low. Consumers feel that there is a gap between Medicaid qualification and being able to afford private insurance. Consumers felt that they should not have to become pregnant or disabled to receive health care coverage.

Kids are easier to cover via Medicaid, but parents have a very difficult time receiving health care coverage.

Out-of-pocket expenses such as co-payment or specific services are not covered. These large up-front co-payments are a deterrent to consumers receiving needed health care.

Consumers report receiving unexpected bills for health care after the fact. The bills are often expensive and they are unable to pay.

Community

Interpretation services are valuable, but then the interpreters know about the patient's health status. Many feel there is a lack of confidentiality with the interpreter. Additionally, participants felt that there was discrimination at some of the community facilities. Some community members report going to a specific Hispanic clinic to get around some of these concerns.

Participants saw the most unmet health need in their community to be a lack of dental care.

Survey Response Summary

General medical care (76%), dental care (81%), childhood immunizations (63%) and pap smears (62%) are the health issues that respondents most need now or have needed in the last year.

Respondents receive health care at private providers more than at any other type of facility. Community clinics and local health departments are the next more popular type of facility depending on the type of service they are seeking.

Respondents are most uncertain about where to receive dental care (21% do not know where to receive dental care) and breast cancer screening (16% do not know where to receive).

Respondents use the emergency room most often for general medical care for colds, flu, fevers, coughs, injuries, allergies, etc. among services about which we asked (11%).

Respondents would be most likely to seek general health information from their doctor (77%). Other popular responses included the local health department (45%), friends (42%) and relatives (37%).

Twenty percent of those responding had a child with a disability or special health care needs.

Only 48% of those responding had insurance/Medicaid/other health care coverage for all members of their family. However, 91% of respondents had at least some of their family members covered.

Of those respondents who do not have health care coverage 29% do not have coverage because they cannot afford it and 29% do not qualify for coverage.

Introduction

The Missouri Department of Health and Senior Services contracted with the Institute of Public Policy at the University of Missouri in the summer of 2009 to conduct an assessment of maternal and child health needs in Missouri. This assessment was designed to highlight needs of Missouri residents for use in the state's Title V application. This assessment involved the following activities.

1. Eleven focus groups throughout Missouri with women of child bearing age, pregnant women, mothers of infants, and caretakers of children. Each participant at these 11 focus groups also completed a survey regarding their health needs and the health needs of their families.
2. Focus groups were held with health care providers (one urban and one rural) to solicit information regarding their perceptions of maternal and child health needs in the areas they serve.
3. One focus group was held in Spanish to learn about specific problems/successes Hispanic/Latino populations may identify regarding maternal and child health. Each participant at this focus group also completed a survey regarding their health needs and the health needs of their families. Facilitation and surveys were conducted in Spanish.

Through these activities throughout the state of Missouri the assessment team has identified themes regarding services that work well for residents and areas where additional services may be needed or enhancement of services may be beneficial. This report outlines the methodology in further detail as well as findings from the surveys and focus groups in the following sections.

Methodology: A detailed explanation of location, timing, recruitment, and lessons learned.

Provider Focus Group Responses: The results from each of two (one urban and one rural) focus groups with providers is presented by group.

Consumer Focus Group Responses: The results from 11 consumer focus groups (10 English, 1 Spanish) are presented. The results from each focus group is presented separately.

Survey Results: A summary of the results from participant surveys is presented.

Summary: A summary of the assessment and lessons learned about the process are presented.

The assessment team has greatly enjoyed our activities throughout the state. We have been very impressed with the willingness of local organizations and offices to assist us with the recruitment of participants. These types of focus groups are not possible if people do not show up. We would have been unable to recruit so many fantastic informants if not for the assistance of those people working in each community. We cannot say thank you enough. Additionally, we learned so much about the experiences of people in Missouri. The participant input is so valuable to this process, and we are indebted to those who attended our focus groups for helping us shed light on the experiences of those in their communities. This valuable information will allow the Department of Health and Senior Services to inform a process of maternal and child health planning.

Methodology

To assess the diverse maternal and child health needs throughout the state of Missouri 13 focus groups were scheduled during July, August, September and October of 2009. The focus group locations were chosen to be a mixture of urban and rural. Additionally, three of the focus groups were designed to recruit specific populations including Hispanic consumers, rural providers and urban providers. The town/city, type of group, location of group, date conducted and number of participants can be found in Table 1. By diversifying the region and the type of host location a wide variety of perspectives were obtained.

Table 1: Focus Group Descriptions

Town/City	Location	Type of Focus Group	Date Conducted	Number of Participants
Jefferson City	HeadStart Cole County East	Consumer	June 18	8
Columbia	Lutheran Family & Children's Services	Consumer	July 15	18
Cape Girardeau	Cape Girardeau County Health	Consumer	August 10	10
Poplar Bluff	Butler County Health Center	Consumer	August 11	11
Sikeston	Southeast Missouri Health Network	Provider	August 12	9
St. Louis	Grace Hill Settlement House HeadStart Program	Consumer	August 6	37
St. Louis	Grace Hill Neighborhood Health Centers	Provider	August 14	26
Branson	Taney County Health Department	Consumer	August 25	8
Springfield	Jordan Valley Community Health Care Center	Consumer	September 15	9
Kansas City	UMKC Women's Center	Consumer	September 29	8
Moberly	Randolph County Health Department	Consumer	October 8	12
Kirksville	Kirksville Gardens	Consumer	October 15	14
Sedalia	Amigos de Christo Lutheran Church	Hispanic Consumer	October 22	13

Recruitment

The method of participant recruitment varied by location. Staff at each host location worked with the needs assessment team to post flyers and monitor sign-up sheets in the community. Focus group locations were chosen based on accessibility to the target population and the willingness of a facility to partner with the assessment team.

In some locations existing groups like support groups or facility staff allowed the investigators to attend a scheduled gathering. Other times staff posted flyers in multiple locations and allowed interested

participants to sign-up by calling or visiting a specific individual. In many instances, the staff at the host location worked hard to recruit participants by talking with them when they visited their facilities for appointments or meetings. Those times where a local advocate recruited individuals or when we were allowed to visit an existing group for the focus group were the most successful in terms of recruitment. To increase retention, all potential participants who signed up before the focus group were given a reminder phone call one to two business days before the focus group.

The goal for each focus group was to recruit 20 participants with a minimum of 10 participants each time. Participants were recruited from the following groups: Women of child bearing age, adolescents/teens, parents and family members of children without special health care needs, and parents and family members of children with special health care needs.

Each participant in the consumer focus groups was given a \$25 gift certificate as an incentive. The gift certificates were given to grocery stores, restaurants, and Wal-Mart. The incentives varied by location depending on availability of vendors and the needs of the Department of Health and Senior Services. Participants in the provider focus groups were provided a catered meal rather than a gift certificate as incentive.

At each focus group participants signed in, participated in the discussion, completed a survey and then gift certificates were distributed. The survey was designed to give participants the opportunity to provide additional feedback on maternal and child health that may not have been discussed during the focus group.

After each focus group participants were given a gift certificate before leaving the location. Additionally, each participant was mailed a personalized thank you note for his/her participation.

After conducting the focus groups all discussions were transcribed and analyzed by staff analysts for themes that surfaced during the discussion. Each focus group was analyzed individually to capture differences in the items discussed. The survey data was more quantitative in nature. It was entered into a database and analyzed for trends among focus group participants.

Lessons Learned

Participant recruitment was most successful when organization staff people in the community from which we were recruiting assisted in getting individuals to participate. Posting flyers without the personal contact was not as successful as when someone was talking to potential participants face-to-face. Given the importance of these local organizations and staff to recruiting participants, it may be worthwhile to provide an incentive such as a contribution to their organization or an additional gift certificate to them for their participation. These local advocates were more willing to help when the incentive for participants was a grocery store gift certificate or a Wal-Mart gift certificate, rather than the restaurant gift certificates. The value of local individuals assisting with recruitment cannot be overstated.

Provider Focus Group Findings

Two of the 13 focus groups were conducted with health care providers in order to obtain their perspectives on the maternal and child health needs they see among their patients. The rural focus group was held in southeast Missouri via telehealth and the urban focus group was held in St. Louis, MO.

Below is a summary of themes identified from each of the two provider focus groups with specific examples and quotes to exemplify many of the themes.

Rural Provider Analysis

Difficulties Accessing Medical System Efficiently

Using the Emergency Department Unnecessarily is a Common Problem

“Some of the people here in this area if their child gets sick a lot of times will go through the emergency room.”

Consumers are Uninsured and Underinsured, Especially When they Get Pregnant

“A lot of them are without insurance and they will come in here to verify if they're pregnant and then we set them up to go to the health department for their Medicaid coverage and set them up with the OBGYN.”

Migrant and Spanish Speaking Patients Face Challenges and Need Special Programs

“I've had some Hispanics, migrant, and many times we'll diagnose their pregnancy and I'll send them through our, to our Canada office for a migrant worker and she helps set them up on insurance coverage.”

Children Receiving Correct Immunizations on Schedule is Difficult

“The one main issue I see is that children aren't getting their immunizations on schedule like they should. Cause I think it's the parent that's not well educated and to the point to know that it's critical to get their immunizations on a schedule. I had a young baby that was a year old yesterday that had had the initial set in the hospital which was done, Hepatitis B and nothing else. So we did what we could to start catching them up and get some education but somewhere the ball's getting dropped. You know these babies should be getting their, their immunizations.”

“It's been very difficult. We've had a lot of five years olds come in for their shots (because of school) and it's, it's like I hate to traumatize a five year old when a two month old won't remember their initial shots.”

“Or they bounce around to providers, from here, there, everywhere and it doesn't get put in MOHSAIC. They go everywhere so then no one's able to follow up with them and make sure they're happening.”

“And they don't bring their shot records so we don't have verification of what they've had.”

“It's (tracking immunizations) awful (with migrants in particular).”

Children with Special Health Care Needs Face Access Issues in Rural Areas (Especially on Medicaid)

“I think for us it's always about just getting that new referral.”

“Something that we worked on just recently was a really awkward thing, a child needed a referral. We eventually found someone who would do it and now we can't find the child.”

“That would be extra hard on the migrant population.”

Finding Providers who Take Medicaid is Difficult for Patients

“One issue I did have, you know, this wasn't my last practice in the middle of the state, but I had a young girl with a fractured arm. It was her second fracture. I tried to refer her back to the same orthopedist that had taken care of the first fracture and he refused to see her because she was Medicaid.”

The Structure of Health Care Limits the Services that can be Provided in Rural Areas (Providers would like to be more creative with existing resources, but are limited by policy)

“We need a different model. We're just not getting there. You know, with the nurse practitioners they work really hard with the serious laws. They cannot for example do much but ADHD which is one of the biggest issues that they have here and that gets back to education.”

“We need to get out to the people, to have our centers that people come to us. I think we've proven it doesn't work.”

Rural Health Care Infrastructure is Limited which Limits Health Care that can be Delivered

“So what that was in was that you had then a consolidation of maternal services through certain areas, the university, the bigger groups, where Medicaid was accepted. Your reimbursement from Medicaid back in the 80s was pathetic so you couldn't afford your malpractice insurance and in fact after working for 13 years in one of the areas in rural Missouri, you know, I could no longer afford to practice there anymore.”

“Well, that's, you know I'm not gonna say whether that's good or bad. If they have nurse practitioners do it, they're gonna have to have adequate support so that they can be properly supervised and counseled on the cases because in so many times the nurse practitioners, I mean has to do things that really may, they're not really that well trained or comfortable in how to do it, you know, and to give those kind of discussions.”

Family

Parents Need More Education about Health and Health Care

“I think that another thing is once the baby is or the child is grown maybe after one year or maybe one and a half year they are lost.”

Teenage Pregnancy is a Problem in Rural Areas

“And as far as child health, we had a lot of teenage mothers at this area and if there was some service of care for the child, you know, after they come home from the hospitals without food. 'Cause I think a lot of times they lack the skills because of their age or maybe their home environment to care for the child properly and know what immunizations they need or what they need to watch for, even what kind of, type of nurturing they need.”

Transportation/Geographical Access

Specialists for Children with Special Health Care Needs Are Difficult to find in Rural Areas (especially with Medicaid)

“I think finding providers that will actually accept them with Medicaid or whatever. And they usually have to go up to St. Louis.”

“Travel is difficult.”

Travel to Specialists is Difficult (for everyone)

“And if they have to travel to maybe, you know, some other place, the providers, the specialists in this area, you know, don’t take the Medicaid then they have travel. So yeah, and somewhat we do have that problem.”

“Well, they don't have reliable transportation. They don't have the gas money.”

“Medicaid offers transportation for them if they get an advanced notice. But they've also been stood up by Medicaid transport, too. They have an appointment and they can't get there so they're a no-show and then they refuse to see them again.”

“The other issue with the transportation is I've had them call me back and say I have to call and explain why they have to go such a distance.”

Community

Integrating Public Health into the Schools Would Improve Child Health in Rural Areas

“The best public health we did in our country goes back in the 40s and 50s when we had the public health nurses go into the schools, administer the immunizations.”

School Nurses Are Working Well with Health Care Professionals

“Our school nurses are great here.”

“They're very, very good and they have an asthma program for the kids and they worked with the university. And they do as much education as possible.”

“I've had, you know, several of, of the children that I get in the clinic a lot of times, they'll say my, the school nurse sent me.”

Education

Currently There are Available Health Education Services

“We have a health department.”

“The WIC program does a good job on education.”

“And the hospitals, they have educators, too, with diabetes and different programs, but then it's getting those people to go to those programs and that's almost, you can about forget that.”

There are Additional Health Education Needs

“You see people, these are people who's, maybe had a kind of disease for a lot of years and they don't know anything. No clue about how to take care of that, themselves or what's important because they haven't had that education so yes, we could use a full-time health educator. We could use a full-time social worker.”

“They just aren't, they're not interested in it. It would be great to capture them while they are here.”

“Well, and we have such a, a obesity problem in the pediatric population. It's just phenomenal.”

“That age group of 15 or 16 getting them to the physician's office is very hard unless they are sick or for some reason they are behind their shots they are coming, but in the school if they have more education regarding (nutrition and teen pregnancy that would be helpful).”

“I have kids with rickets.”

Most Unmet Needs In Rural Areas are Educational

Nutrition (malnutrition and obesity)

“Lack of knowledge about the effect of drugs on, during their pregnancies.”

“Cigarettes are huge.”

“Alcohol in teenagers.”

Illegal and prescription drug use

Impact of nutrition, drug use, and alcohol use during pregnancy

Adolescent sexuality (STD prevention, teenage pregnancy prevention and teenage mother prenatal care)

“Well, I mean you're talking about teenage, teenage pregnancy, they're both, both the maternal and the child health would still apply to them and so it's a problem.”

“Someone made the suggestion about this parental education, about that could be useful very generally.”

Changes in the Past Five Years

Patients are More Demanding

“The patients I think have become more demanding. More demanding, more empowered but not in a good way.”

Payers are More Involved in Health Care

“Well and I think you know, too, with Medicare and Medicaid, I mean they're all trying to dictate on what we do, what decisions we make, what medicines we can write, you know, for our patients.”

“I mean terrible. I prescribed Fluxoral for a patient and that's a cheap drug, right? It's not on their formulary.”

“The formularies keep changing. And they're not, they're not universal. You have 14 different formularies.”

More Uninsured Patients

“And another thing they're, people are a lot, there's a lot more uninsured than there were five years ago.”

“And so people choose to come to see a physician even here when they are so sick they can hardly hold their head up. You see them one time, you don't see them again. And then when you do see them that one time they want you to, they want you to take care of ten different issues.”

“And I'm not sure that issue's gonna go, you know, better around here with all the factories in town laying off.”

More Chronic Health Problems

“A lot of the chronic diseases we're seeing, even in kids, you know. You've got your asthma kids. You've got, you know, the, the obesity problem is phenomenal.”

A Perfect Health Care System Would Include:

Re-establish the value of the relationship between the patient and the physician

Reduce payer input into health care

Use media for patient education

Put public health nurses back into schools

Urban Provider Analysis

Medical/Provider Relationships

Continuity of Care is Currently Lacking and Difficult to Ensure

Patients do not return for follow-up appointments

Patients do not comply with prescriptions

“But it seems like the starting on the birth control is great, like that willingness to start and do that part, and then the continuing of the birth control seems to be an issue, at least when I was doing my teenage girls. “

Uninsured and Underinsured Patients Limit the Healthcare that Consumers Seek

“Generally speaking, one of the major barriers to care is not having medical care prior to becoming pregnant and then fears of not having insurance, even though we do have programs in place that streamline them through the temporary Medicaid process. I think those are the biggest concerns and barriers that our patient population face.

Patients have difficulty navigating the Medicaid system

Cultural Competence of Care is Important to Improve Maternal & Child Health

“We do serve a lot of Latino patients as well. So sometimes in the population that we work with, there are cultural things and they come up as well. That can kind of raise certain concerns throughout the process as well.”

Hispanic patients tend to view teenage pregnancy differently than other patients.

Prenatal Care in Subsequent Pregnancies is Often Lacking

“Frequently we're not seeing patients for prenatal care and they'll be like, ‘Well, I didn't think it was important to get prenatal care. I've already done this before.’”

Immunizations are Difficult to Track

“I’m glad you brought that up because Missouri MOHSAIC has never really panned out for us. Most of us, I believe, did the applications. I don’t think we ever got our number or PIN to be able to get into the site itself.”

School nurses spend most of their time tracking immunizations

Specialty Care is Difficult Even in Urban Areas

“Like just the other day I saw somebody with neurofibromatosis. They can’t get him in anywhere because there are no specialists who accept Medicaid.”

Consumers Inappropriately use the Emergency Room for Primary Care (especially immigrants)

Transportation and Geographic Access

Getting to Appointments is Difficult for Some

“I think transportation is an issue, too. There’s teenagers that don’t drive cars. They’re too young to drive and sometimes it’s hard for them to get here.”

“I don’t think that they – they may not know how to use it (public transportation).”

“Well I think every issue brought up so far has nothing to do with the medical. If they get in to see the doctor I think everything is taken care. The doctor’s going to know about nutrition. They’re going to know about bleeding. They’re going to know about weight, going to know everything. All the issues expressed here have nothing to do with the medical services. It’s all getting to the medical services.”

Transportation to Urgent Appointments is Difficult to Arrange through Medicaid

Health Care in Schools would Increase Access for Adolescents

“It makes me wonder also how far school-based health clinics actually go. I’m wondering what services you’re able to get in school because transportation can be an issue. And it’s, I think, important to be able to capture the patient where they are, and if they’re going to go to school, if we could put that service there, full service there you would capture some folks that you wouldn’t get otherwise.”

Linkages Between Health Care and Schools Could Improve Health Care

“Well all I’m saying is, for instance, this is a problem and why can’t they get funding to get nurses for the schools to come here to talk to pediatricians to say, ‘What are you doing? What should be done? How can we create a better bridge between that school and this institution?’ That is always a problem. You can’t have the pediatricians riding off to schools. They don’t have that kind of time. But if there were some way to have that organization contact this organization there might be a bridge. We don’t have those kinds of meetings with the schools.”

Outreach Could Increase Access

“You know there’s a immunization van that goes around for children. Why can’t there be a birth control/STD van that goes around?”

Education Services

New Parents Need Education

“I mean I think that there are a lot of broken families. I think that’s a big issue, and limited support that a lot of our parents have, sometimes limited education from the parents’ standpoint. So I think that provides a barrier and some potential issues with how to raise a child, what should be expected, what questions I should be asking. I feel like a lot of the teenage mothers come in and they’re not very vocal with voicing concerns or proactively taking control over providing care for their newborn.”

“We have exactly the same problem. We have the exact same problems as the small towns, and the problem is that you have to educate the uneducated parents. We see it over and over again here those kids are in the cycle and that’s what’s happening. So we’ve got to grab those parents somehow, those young parents, and educate those young parents, ‘cause we can’t change their position, but they can change their kids’ position.”

“My question is whether the daycares are taught to know and to ask the parent, ‘Has this child been in to see a doctor? Are you up to date on everything that you’re supposed to be doing?’ And that’s where the emphasis would be to get them to the doctor, because the problem is getting them there.”

Teenage Pregnancy Prevention is Needed

Teenagers don’t understand what they are getting into with parenthood

There is a cycle of teenage parenthood that needs to be disrupted

“So it’s a broader issue. It’s not just about maternal health, a child’s health, but it’s about people and their broader needs really to education and self-esteem.”

“I think education should be in the school. I think they should hear it on public radio. Everywhere that they are they need this positive reinforcement, because them coming to the clinic and us speaking with them, that’s just not enough.”

“It needs to be on the TV. It needs to be on the Internet. The United States is so conservative about birth control and educating kids. They just prefer to pretend that it does not happen. We’ve got such conservative politicians saying, ‘Oh, we can’t preach birth control because that’s gonna make them do it.’ They’re doing it anyway. Okay, they’re doing it anyway so let them know what’s out there. Protect them against the STDs.”

Adolescents do not Understand STDs

“And you know what I would think, what really amazes me about that is every time you get chlamydia, who did you get it from? Your dedicated boyfriend.”

Greatest Unmet Need

Access to health care

Inadequate prevention services

Inadequate family planning services

Lack of access to healthy food and opportunities to exercise

Obesity prevention

Malnutrition prevention

Mental health

Involving men in children's health care and pregnancy prevention more

Access to technology like x-ray and mammography for low-income patients

Changes in Past Five Years

Increased out-of-pocket expenses for patients

Increased bureaucracy in health care

Consumer Focus Group Findings

Summary

The remaining 11 of the 13 focus groups were conducted with health care consumers in order to obtain their perspectives on the maternal and child health needs they see in their own experiences. These focus groups were held around the state to obtain a diversity of respondents. Details about locations can be found in Table 1. Details from each focus group can be found in this section. Each sub-section below highlights findings from each focus group. Within each focus group the themes that were identified for that focus group are highlighted in bold. Quotations that exemplify each of those themes can be found below each highlighted theme of the discussion. Themes are also organized by discussion topic from the focus group including:

- Medical/Provider Relationships**
- Family**
- Health Education/Informational Resources**
- Financial**
- Transportation/Geographical Access**
- Community**

Consumer focus groups unveiled a tremendous amount of information that can be analyzed from a variety of angles. Focus groups were analyzed to determine if urban consumers describe different experiences than do rural consumers. Additionally, evidence of regional differences throughout the state was examined. The study team was surprised not to find such differences. While the responses were not exactly the same, the issues at the root of those responses often were the same. For example, transportation was one area where we might expect to find that those in urban areas have fewer problems than do their rural counterparts. However, the team did not find this to be true. Rural consumers have to travel longer distances at times, but their urban counterparts cannot afford the transportation options available to them, and they were just as likely to have difficulty finding providers who are willing to accept their insurance/Medicaid plan in their local area. Both groups were having difficulty finding providers and then getting to those providers once found. Both groups had participants who have relied on Medicaid provided transportation, but found the same problems including the required advance scheduling and the sometimes unreliability of this transportation service.

Access to health care providers was another area where we thought we might find regional differences. For example, those who are closer to areas with large hospitals might have better access to health care providers. However, this was not necessarily true. Consumers in areas where there are more healthcare providers (St. Louis, Kansas City, or Columbia) were still having great difficulty accessing providers who accept their insurance/Medicaid. Particularly, those who were using Medicaid had significant difficulties finding health care providers regardless of the geographic location. The one exception was for specialty care. Those in more rural areas were traveling to St. Louis, Kansas City or Columbia to see specialists who were not available in their rural area.

There were identifiable differences in select focus groups. For example, in Cape Girardeau the local public health agency puts together an annual publication that helps consumers navigate which providers offer services to people with which Medicaid payer. Focus group participants who had access to this guide expressed significantly fewer frustrations with the confusing nature of the system. They all expressed a common understanding of the healthcare system. While they still lacked some specialty services, they all understood what was available to them.

Other agencies have assisted their clients in filling similar gaps. Parents who had children at Grace Hill HeadStart reported assistance getting to appointments and figuring out the health care system. Participants who had previously or were currently participating in WIC had received additional advice

about navigating the healthcare system. Participants at Lutheran Children and Family Services in Columbia felt that the diapers, formula, and advice they received from LCFS were a significant help. These consumers who were connected with specific agencies were able to identify significant value these organizations had added to their health care experience. However, these differences emerged as somewhat isolated rather than systematic. If people were not connected to one of these agencies they expressed more frustration. However, these agencies who are assisting with maternal and child health needs were not more or less likely to appear in a particular region or in urban or rural areas.

Below is a summary of themes identified from each of the 11 consumer focus groups with specific examples and quotes to exemplify many of the themes.

Jefferson City Focus Group Analysis

Medical/Provider Relationships

Hours of Availability are too Limited

“Well we have a health department here in a community center, but community centers are only open so many days. The health department is only open – what – 8 to 4 or something like that. So if you have an emergency after 4:00 then we just need to go to the emergency room whether we have health insurance or not.”

Providers Who Accept Medicaid Plan are Difficult to Find

“They stop accepting Health Care USA--- they won't accept MC Plus no more. You gotta go here now because this doctor won't do it no more. It's an on going cycle. You flip flop between providers.”

“Then you run into the problem with a lot of them will say, ‘Well we accept it, but we're not accepting any new patients.’ That's the next one because they've had so many people that made the switch that you can't get in because they've got too many.”

Confusion About Who Accepts Specific Plans for Specific Services Limits Accessibility

“Well when I asked them (the hospital) they didn't accept Health Care USA for [my prenatal care].”

Discussion covered specific services that were covered at specific times for different participants. There was general confusion about what is covered by which plan.

Quality of Care is a Concern for Consumers Using Medicaid

“Well my son, he had a problem or whatever and none of the doctors down here caught it. I'm havin' to go to Columbia to have him – he ended up havin' surgery up in Columbia and then they ended up messin' up so now I'm goin' to St. Louis.”

“I probably heard that one other time before. It's just some of the doctors are not very compassionate. They're just standard physicians, okay. Let me check you out. Nothin's wrong. If there's nothin' obvious to 'em without them followin' up or doing any other tests and scan – whatever they do and then nothin' doesn't get detected and problems develop more later.

“Like she said, you have to keep goin' back, keep goin' back and they still tell you the same things over and over again. Then that's when they'll send you to another specialist somewhere yonder that will probably either figure it out or if they don't, like she said, you have to skip and jump [from place to place].”

“Free clinics also. Those are the most non-compassionate physicians ever to live.”

Basic Preventive Services are Covered by Medicaid and Local Public Health Agencies

“I think most of them will cover the basic preventative services. That’s about it. Your dental, your vision, maybe womanly care. That’s about it. And immunizations; stuff like that. They don’t expand beyond the basic needs.”

“I haven’t complained about it. At least they have and make sure that the preventive services are free because that’s just a basic need that every person needs, including children. So that seems to be okay.

Family

Obtaining Immunizations for Children is Difficult for Working Parents Due to Scheduling

“That’s one thing that drives me nuts though about immunizations. I don’t know if anybody else has run into that, but like last three doctors that my kids have gone to, their doctor’s office doesn’t do immunizations. So you gotta go to the doctor’s office and get your physical. Then you gotta go to the health department to get your immunizations.

“So then you gotta take two days to go and do whatever it is. I really thought that they would still continue to do that and I’ve run into three different offices where they would not do the immunizations.”

Consumers are Facing Special Health Care Challenges for Themselves and Their Families

Diabetes, allergies, bi-polar disorder, brain surgery were listed as concerns for participants

Families Facing Special Health Care Needs Spend More Time on Managing Insurance & Care

“Like here lately I’ve had a run into doing a whole lot of authorizations and stuff for out of network type stuff or whatever. And a lot of specialty doctors, like they weren’t available with that insurance and stuff or couldn’t give him the care that he needed. So had to go elsewhere, but they were pretty lenient as far as like getting out of network approvals and that sort of thing. So it wasn’t nearly as bad as I thought it was going to be.”

Health Education/Informational Resources

A variety of sources were cited regarding health information that is available to consumers

- Work
- School
- Head Start
- Internet
- Clinic
- Division of Family Services
- Word of mouth
- Community organizations

Available Education/Information Resources are Often Outdated and Electronic Information is Difficult to Use

“The one problem that I know we run into as far as just educational resources even here on site is the fact that a lot of the times the information we get may be outdated shortly because there are so many things that are changing constantly and those educational resources aren’t sharing the information with everybody they just disseminated information to. So we may give something to a parent and say, ‘Okay, this is something that you might be able to use.’ Then they take it and

this number doesn't even work. You get really frustrated at the system, like we're part of the system. We're trying to disseminate that information and share with the public and what we get isn't even right. So that makes it really tough."

"So much information and access to the technology."

A barrier to education is that some organizations run out of funding very quickly at the beginning of each month so people have to wait. Particularly utility assistance runs out very quickly. Lack of funding for these types of social services has a ripple effect.

"There's been an increase of health issues increase because lack of food, lack of utilities, no transportation 'cause they can't get to 'em in the first place. So stuff develops, problems develop. So we right back to square one. It's just a circle."

Transportation/Geographical Access

Transportation Services are Available Through Medicaid

"They have services to where if you don't have transportation you can get."

Some Services Require More Travel to Providers who Accept Medicaid

"There's a lot of dentists that don't accept any type of Medicaid –there's only a slight few. Then you got to reach into Columbia –They had it here, but they cut it off. Small Smiles take Health Care USA and I think they've signed on with one of the other of the two. Then there's the office up in Columbia, but now I have to go to Columbia and that's a inconvenience. That's the difference. You got a 30 mile drive. Just for a check-up."

Specialty Services Require the Most Travel to places like Columbia, St. Louis, and Kansas City

Financial

Having Insurance or Medicaid Increases Access

"If you have health insurance or don't have it (that's a barrier)"

Medicaid is difficult for adults to obtain if not pregnant—People cannot afford insurance, but they do not qualify for Medicaid

"You can get on Medicaid if you're pregnant. That's the standard. And that lasts for about a year. And then you've got –When it's cut off. That's it."

"The most a family of four can make to qualify for those problems 'cause like my husband just got recently diagnosed with diabetes. He didn't have health insurance because we cannot afford it plain and simple. Cannot afford it. Recently diagnosed with diabetes. So he went and he applied. You can only make like \$300.00 a month for the whole family of four people to qualify. That's impossible."

Medicaid is easier to obtain for kids, but is still confusing at times

"But they changed the way that it works I think from after they're five though the guidelines are different what qualifies for the income because my daughter just turned six and it changed. Like she may go into a premium category and my son may remain with no premium just based upon age once they first five and enroll in the regular schools."

Out-of-Pocket Expenses Such as Co-Payment or Services not Covered

"the other alternative is we do have an urgent care. They're open till 7, but they expect co-pay at the time that you're there. It's not like the emergency room where they might be able to do

something for you and then you can just go. They expect \$50.00 or more just for walkin' in the door. So that makes it tough, too."

"Your insurance doesn't cover – I mean depending on if you work or you don't work. In my case, my insurance will pay for something, but depends if I'm meeting my deductible, how much my co-pay will be. If I don't have the money right then and there to go see the doctor or specialist or whoever it may be."

"[The County Health Department] used to be free and then they said that the state pulled their funds. So now it's like a whole lot of chargin' for simple yearly check-ups."

"With like Medicaid they have it to where if you make so much money you are in a certain bracket to where you have to pay so much money a month, but it still doesn't cover everything."

"Dental; I won't go at all"

"I've honestly had times when we've gone and we've gone to the doctor and we go to pick up the prescription and we've got to wait maybe three, four, five days just to save the money to go pick up the prescription. That makes it tough."

"Like my son after his surgery they gave him pain medicine. Well they wouldn't accept it so we had to wait a couple days before that otherwise we had to pay almost \$100.00 out-of-pocket just for his pain medication. They had to have prior authorization from the doctor or from the insurance company that they were going to pay. I'm like, 'My son just had major surgery. You think I want to skimp on some pain medicine. I don't think so.'"

"I went to take my daughter to the doctor and she was just telling the doctor she just have a little acne problem. So she wrote a prescription. I didn't think anything of it. Then I went to pharmacy and he was like, 'What insurance do you have? Do you have another insurance?' I was like, 'No.' Then he was like it wouldn't cover it. I'm like, 'Why?' It cost \$200.00. I have to pay \$200.00 just for acne medicine for her face. I just tell him that's okay, thank you."

"Eyeglasses, too, is another one that they don't cover. Eye appointment, prescription, the exams."

"Also a lot of lab work insurance doesn't cover."

"Mental health is worse than regular health care; a lot worse. Then you worry about the quality of care and that's the problem that I got into is the quality of care that nobody's taking this so am I just settling for what's less simply because of what I'm eligible to get. That's tough. I've got a daughter that's got bipolar disorder and she's got several other different clinically diagnosed – she's been in-patient hospitalized over the past few years. Medicaid finally says, 'Sorry. You're going to have to come out of pocket.' How am I supposed to do that?"

Could Not Have First Choice for Health Care Because of Insurance/Medicaid

"When I found out I was pregnant with him. All the other kids were born at St. Mary's. So I want him to be born at St. Mary's too, but by the time I got pregnant with him everything had switched around. I had to go to Capital Region."

"I had to switch over to Missouri Care."

“You might have a dentist in Columbia that takes Missouri Care, but the rest of the providers that you normally see take Health Care USA. So then you’ve got to make a choice because they aren’t on the same network and that’s managing all your care. That’s your dental, that’s your vision, that’s your medical, but the providers you want to see may not all fall under the same insurance company. So then you’ve got to pick and choose. Is it because I want this doctor or is it because I want this dentist that I’m going to choose my insurance company?”

Reimbursement and Finances Drive Health Care Decisions Made by Patients and Clinicians

“And a lot of it is about money. They’re not really concerned about the patient.”

“Or they don’t provide the services because they don’t think that the insurance is going to cover it one way or the other so they won’t want to do it because they don’t know if they’re going to get their dollar.”

“Even my pediatrician. They told me that I needed to call my insurance and see if the vision and hearing would be covered under the well check. Like it was my responsibility to do that.”

“Otherwise he would have just kept on waiting and waiting. Next thing you know my kids could have been deaf or something. It’s just him probably not wanting to recommend it to the ENT or whatever because maybe I got the special insurance and that’s why it took so long for them to do something about it.”

Navigating Insurance and Medicaid is Difficult and Time Consuming

“Then like with the insurance companies you have to sit on the phone for I don’t know how long for this person and this person and this person. “

Community

Community Organization Services Help to Fill Gaps in Healthcare

“Planned Parenthood probably the only organization that probably offers the basic preventative services for free. They still have a pay scale. They still take all your info, even if you work or you don’t work they count all that stuff in; unearned, earned, whatever the case may be and they base it on how much you make and they’ll put you against their pay scale. It’ll determine whether or not you’ll pay anything at that point in time.”

Extended Hours or Special Clinics for Maternal and Child Health Needs Are Needed

“How can you tell a low income mother to take off work all day long to go and get this done? Like why can’t there be somebody in the evening that can do something like that. Even a physical. They all need a physical before they can go to school –Gotta take time off for that.”

“Even if they set up like a certain day like one weekend or whatever where they actually had somebody that people who fall into this category and don’t have the time can actually go in on the weekend and actually get the stuff done that they need done – just even periodically the stuff that you know has to come out before they start school “

“Doctors offices or pediatricians who do accept our insurance or Medicaid, Health Care USA, if they can designate one day out the month to stay open later to meet those parents that work until five.”

If Participants Could Design a Perfect System it Would Include...

Access to needed health care
Quality of care
Easy transportation to appointments
Extended hours past regular working hours for working families
Adequate funding to help people who need care

What is the single most unmet health need in your opinion?

Dental health
Mental health
Vision/Eye care

What are the most significant changes you've seen in the past five years?

Reduced services
Reduced hours by providers
Fewer funded/free services
Insurance accepted in fewer places
Providers won't accept Medicaid
Quality of care has decreased

Cape Girardeau Focus Group Analysis

Medical/Provider Relationships

Providers Who Accept Medicaid Plan

“Or even for the kids. If they get orthodontic problems then you have to go to St. Louis, and they only want to see them until they're 12. I've got a kid whose teeth are all messed and he's ten, and if he waits two more years he's gonna have some major issues.”

“So it seems like dental care, both availability in town and for adults seems like an issue for you all.”

“It's always hard to find doctors that accept Medicaid.”

“Unless you've already been a patient with them, most of the time they will take Medicaid for their patients. And of course any of your specialists, you always have to go through your primary doctor, which is fine. No specialist is gonna take your child without a referral.”

“And you do get discriminated a lot when they know you've got Medicaid.”

“Yeah. Just 'cause you get Medicaid don't mean you're not providing, that you're not hard working and out there. I've got four kids. So we can make okay money; it's just we have a large family. So you do get discriminated a lot.”

“And even if you have a co-pay or something like that, he probably – I was referred to him by the emergency room doctor at Southeast. She told me, she said, “Well if you have Medicaid they'll probably pay for it, but even if they don't he'll work out a payment plan for you.”

Quality of Care

“For example, with the dental. We went to a dentist in Jackson, and my son's teeth were terrible and we didn't know why. There was no explanation. And instead of referring us to somebody to get the work done, 'cause he needed – all his teeth needed to be fixed. This dentist just said, we'll just do fluoride treatments once a month.” Well I said, ‘Forget it.’”

“I just went and called a pediatric dentist. This is what I told the pediatric dentist. I said, “I’ll pay cash if I have to, but my son needs his teeth taken care of.” Well they ended up, believe it or not, took the Medicaid, and then he had to be put to sleep to get his teeth fixed. But I just felt like just because we have Medicaid with this other dentist he wasn’t going – he wouldn’t spend the time.”

Limited Care

“Because my husband, we didn’t have any insurance, ‘cause nobody would even cover him because he had cancer five years ago, so then last year he didn’t want to go to the doctor and he almost died. His appendix had ruptured and it had been two weeks before he got medical treatment. He was dying and we didn’t know it. And people are dying because of that, ‘cause they don’t have insurance and they can’t pay for it.”

“And I’m on Medicaid, but I’m trying to figure out. Don’t they have programs for homecare nurses that come in and help you as far as – you know.”

“Well Medicare or Medicaid will pay for skilled nursing care in the home, but it’s usually on an intermittent type of thing. It’s not somebody that’s gonna come and stay with you all the time. There has to be what they call a skilled nursing need. The best way probably is to talk with your doctor, to get him or her to make a referral to home health. But homemaker services, Mary, do you know?”

“But with Medicaid there’s just a waiting list for in-home services, even from – that seems to be a real problem.”

“The ortho is the only thing we have problems with, but otherwise we have fine at Cross Trails or the pediatric.”

“And we have several dentists. I think we have a list back there in WIC. We have several dentists I think that do take Medicaid, don’t we?”

Limitations because of preexisting conditions

“We don’t mind paying for insurance, but good grief, they want \$700, \$800 just for my husband and I just because of his past history. That ain’t fair.”

Preventive Services

River City Health Clinic: “Actually it is because – I mean this is my personal business, but when I go to the doctor and be seen I only have to pay like 20 bucks, and I don’t think that’s bad compared to \$100, \$200, \$300 that I could have to be paying. So I think that’s pretty reasonable and they go off of your income and stuff like that. So it’s pretty reasonable.”

Medicaid Discrimination

“I was just gonna say something real quick, when she was talking about discrimination. When Madison was born I worked all the way till I was eight and a half months pregnant to keep insurance, and I had her at St. Johns. I don’t use that. I usually go to University of Missouri and St. Luke’s, but St. John’s Mercy Hospital. I had her there and the pediatrician wouldn’t even see her. He was like, “I don’t even want to see her,” and he was extremely rude and everything.”

“I had my insurance and I worked eight and a half months pregnant and he denied her. So yeah, I know exactly what she means by discrimination.”

“And I feel like – especially as a child, I mean I broke down in tears because as a child, how can you not accept a child, Medicaid, insurance, whatever? But I just wanted to say that I totally know what she means. It’s sad.”

Family

Obtaining Immunizations for Children

“Well I come here for vaccinations, but she goes to Regional Primary.”

Facing Special Health Care Challenges for Themselves and Their Families

“So I mean you have one here, but that treatment isn’t probably here is what you’re saying. Cause they told me today that I need to go try to find out about Barnes Hospital. I went to St. Francis. I went to Southeast and it was the same thing. ‘

Health Education/Informational Resources

A variety of sources were cited regarding health education and information

“To the clinic downstairs”

“To the Rural Health Clinic”

Transportation/Geographical Access

Transportation Services Availability

“We were just touching on that Medicaid does provide for medical transportation, but no one from our experience with our clinic downstairs for kids who have to go to Children’s or Barnes it’s a real effort for our staff to try to get transportation arranged for clients through Medicaid.”

“We do have BART, which is a system. I don’t know if Medicaid pays for BART though. I don’t think they do. I don’t know.”

“It’s a real effort to try to get Medicaid transportation arranged first of all.”

“You’re right. It does list that. It’s listed as a transportation. This is a card that we developed of resources in the community and it does list Sadie, you’re right, as a transportation, and Workforce Investment Board. I don’t know what that is.”

“And the Medicaid process for getting it arranged is not always the easiest thing.”

Some Services Require More Travel

“Yeah. They actually come here from St. Louis about once a month. So it’s convenient.”

Specialty Services Require the Most Travel to places like Columbia, St. Louis, and Kansas City

“Barnes Hospital is connected to those schools up there. So a lot of time they’re treatment they do up there is more advanced than what we are down here, and some of the doctors down here have never heard of it before because they’re kind of still trying it up there at the school. So it’s easier for them to get it up there, where we have never heard of it down here, and that might be what it is too.”

“They’ll be able to have more, be able to get those medicines more than we can down here because of their schooling and trialing and stuff, so that might be why.”

“But either way, transportation and going kind of far is a barrier for some kind of specialty care, at least it seems like.”

“Yes. Service to the specialty clinics would be very difficult. It could be a big barrier. We used to have one van service. I think they’re bankrupt now, aren’t they?”

“Yes, but transportation to St. Louis would be very difficult, a big barrier for specialty care.”

Financial

Medicaid is difficult for adults to obtain if not pregnant—People cannot afford insurance, but they do not qualify for Medicaid

“Me personally, I did want to say I do feel like Cape Girardeau, as in Medicaid, I don’t feel like there is enough for adults as in doctor-wise, because I mean yeah, like with my knee and then my tooth or whatever – I breastfed for eight months and it took a whole lot out of me. And I didn’t really take my prenatal vitamins maybe like I should have, and now my little tooth right here is having some issues and they’re saying, “You got to go to St. Louis,” and stuff just for Medicaid. I mean its like – I don’t know. I just feel like maybe we could as a community get some more Medicaid doctors that do accept Medicaid here in Cape for adults also.”

“I can’t get any kind of healthcare or Medicaid or anything because supposedly I have a job now and I’m working, and I can’t make more than \$234.00 a month in order to get medical insurance. So I have to pay when I go to the hospital and to the doctor and for all my medicine and everything. I just kind of felt like it wasn’t right, because I don’t know what’s going on with other people and what they have, you know, going on with their selves, but I see so many other people and mothers with Medicaid who work and the same predicament that I’m in, and I just don’t understand why. I’m just one of those people that can’t receive it.”

“So it kind of keeps me from going to the doctor when I need to or the hospital, because I don’t want to have a lot of bills. That’s just something I never understood with this system around here.”

“Now that I’m working I can’t have Medicaid. But I mean they want you to work. They want you to have a job, but –But then you don’t make enough to afford insurance either.”

“He was dying and we didn’t know it. And people are dying because of that, ‘cause they don’t have insurance and they can’t pay for it.”

“Yeah, do you not work? I know. It doesn’t make any sense. I mean it’s hard, ‘cause even when I started working, like how she was saying, you just don’t make enough and then they cut everything off and it’s like – you know.”

Medicaid is easier to obtain for kids, but is still confusing at times

“Usually with the Medicaid, I know once you have a kid it’s easy. They usually just give it to you after you have a kid, but as in insurance, you know, the same routine. When you’re working at a job, three months or six months till your insurance kicks in.”

“I noticed with her medicine I don’t have to pay co-payments. I don’t know how it is with your daughter, but they give you – her medicine is always free.”

“She (daughter) has full coverage Medicaid. They pay for everything.”

“Yeah. I will say this. With Medicaid with the kids, I don't know how it is with the older kids, but with the babies or whatever I feel like they're good on Medicaid with the babies, yes, 'cause the medicine –“

“Yeah, they even pay for infant Tylenol.”

“And if you ever had the nebulizer or any of that it's always paid for. I will say that.”

“And I always have to say Dr. Louis, he got our daughter in, in about four days, but it was because she had broken a tooth. She was 14 at the time and he was like, “Well we can't have this.” I mean they got her right in. But at the same time, while I was there I was able to set up an appointment for a week later for our other daughter, without a problem getting her in either. And he is rough. He is.”

Out-of-Pocket Expenses Such as Co-Payment or Services not Covered

“I'm a Type 2 diabetic and I went to Walgreen's to get glucose tablets. I didn't know Medicaid didn't cover that. Why don't they cover that? I mean they cover the kit to torture yourself with, the medicine. They don't cover the glucose. Why don't they do that? I mean that's –“

“I mean I'm just now finding out I'm diabetic and she wrote a prescription out for it. They gave me the medicine for my high blood pressure, but they didn't give me the medicine for my glucose, that stuff, and I'm like, “Huh?”

“I have a prescription written out for a knee brace and she said Medicaid would cover it and they didn't.”

“One example, I know a girl right now. She's pregnant. She's 15. She needs the iron. She can't afford it. Medicaid won't pay for it. Her mom does not help her at all. Her family doesn't help her at all. I mean she's basically doing stuff by herself at 15. I mean she's got friends that help and her boyfriend is in the picture, so he tries to help her, but he's only 17.”

“I mean the iron for me was not a problem. I can afford that. It's only \$5.00. But I mean if you don't have the \$5.00. And that's something – I mean I really needed it and I'm 40 years old. I needed it bad. I had my first baby when I was 17 and I needed it bad then. I mean it was just something I have to take when I'm pregnant. I mean this girl, I just – you know, \$5.00 seems like 100 when you're broke.”

“So these sort of the over-the-counter things aren't covered.”

“Even when I did have Medicaid I still had to pay a co-pay on my medicine. It was \$5.00, \$7.00, \$2.00. I still had to pay some kind of co-pay even when I did have it.”

Community

Community Organization Services

“I think WIC has some pretty good information over there. They have a lot of little spots where you can go and pick up information on just about anything for your child, eating, all that good stuff. I think they have a good selection over there of information that you can go get if you ever need it.”

“We have a very generous civic group here, the Kiwanis, and they help support what we call our Happy Kids programs here, and they donate to the Health Department each year, and we utilize those funds then to have moms and babies and pregnant women get services. “

If Participants Could Design a Perfect System it Would Include...

“I think they should have a better program for mothers, because it’s pretty good for the kids, but I think they should have some kind of better program for the mothers because – I mean just some things you can’t do because you don’t have Medicaid or the right type of health insurance that you need to have, ‘cause sometimes a lot of people go unhealthy and become really sick because they can’t go the doctor when they need to. I just think that mothers should have a little bit better of a plan than what they have going on.”

“I know there’s men in here, but even with the gynecologist thing, there needs to be more coverage by Medicare, because there’s a lot of things that can go on and be undiscovered and then you’re sick. Ovarian cancer does run in my family a lot and a lot of them don’t take Medicaid.”

“Exactly. And they need vision, too.”

“I would think first and foremost it would have to be something based on a person’s ability to pay. I mean not exclude Medicaid certainly, but give them the same coverage and rights as people who are paying, or for private insurance for that matter.”

“Just because you’re on Medicaid you can’t have the same access to healthcare as somebody who can afford \$400.00 a month for family health coverage.”

Poplar Bluff Group Analysis

Medical/Provider Relationships

Preventive Services

“I think it’s a good thing that they [Health Dept.] provide shots and things for underprivileged children without no cost. So they can go to school and stuff”

“And the health department is awesome for like support with breast feeding and things like that. I cheer them on. I’m an advocate for that.”

No preventive dental or vision

“At every drug store, I think you can do your blood pressure.”

“Even if you don’t have Medicaid, the WIC Office is very good in that department.[HIV testing]”

Time Issues

“And I made a doctor’s appointment, and of course, I couldn’t get in there for like a month.”

Family

Families Facing Special Health Care Needs Spend More Time on Managing Insurance & Care

“Well, my son had the same problem. And it ended up, it took year to finally figure it out. Well, not years, a couple of years. He had a hole in his ear drum. And when he would talk it wouldn’t come out right and he would say, he said, there’s a girl in my not class, he left the CL out. I said,

“Brandon, when mommy hears you talk, you’re saying you have a girl in your.” And he says, “Oh,” see he didn’t understand. He couldn’t hear that part of it. So he did have a hole in his ear drum.”

Health Education/Informational Resources

A variety of sources were cited regarding health education and information

“Their doctor. Clinic doctor or ER if I have to. My daughter has a pediatrician and I have a clinic and I like I said, I had to find a doctor out of town to take me...”

Chiropractor
Natural health medicines
Research at home
School fair
WIC department

“It’s a good thing to have Amy, she always goes with me to the doctor, a health advocate, just to make sure that I’m saying the right things. I’m not forgetting to tell him something. You know, because she knows all my problems.”

“I want to know what my cholesterol and my triglycerides, I want to know all that. Because mine are very high, almost 800 cholesterol and I had to ask him to check me for that to begin with. I wouldn’t know today.”

Transportation/Geographical Access

Some Services Require More Travel

“He gets my doctor in St. Louis and then I have to drive to St. Louis, I don’t know how many times, so the gas money and transportation”

Significant travel for a specialist.

“There’s the bus that takes you to St. Louis, St. Louis or Cape. But you got to let them know ahead of time.”

“I have a friend she has to have a mastectomy in three weeks and now she went earlier, but she had nobody to take her to the doctors. But she didn’t tell me or I would have took her, but some people don’t have the vehicle. She’s elderly. She, you know, finances.”

“I think this goes back to transportation.”

“And the gas money”

Financial

Out-of-Pocket Expenses Such as Co-Payment or Services not Covered

“Medicaid is not paying as, it doesn’t pay for as much as it used too. Like you go to the hospital. I had \$600 bill and I had to pay half of it.”

“You can’t hardly find a dentist, I mean, these are like main things that like Medicaid, I mean, you have to fight a great big battle in order to get your children’s teeth take care of. Not to mention yourself as an adult, and adults suffer lots of dental problems and the dental problems have a lot to do with our actual physical health.”

“I feel that they should do something for the people that have major eye issues like glaucoma, early stages, because my boyfriend has early stages of glaucoma and they told him if he does not go to the doctor like he’s supposed to, he could wake up and it’d just be gone, but he can’t afford to see anyone without any insurance.”

Medicaid is difficult for adults to obtain if not pregnant—People cannot afford insurance, but they do not qualify for Medicaid

“Because, Medicaid will send you are approved for Medicaid, but then they don’t tell you that you are only approved for certain types of services and that’s might be why you are, you know, they way that we don’t take Medicaid here. ‘Cause I work, so I don’t qualify. My kids have Medicaid, but I don’t qualify for insurance so I don’t have any, so if I get sick, I just don’t go to the doctor.”

“But I do have family planning Medicaid and that only covers birth control and medical visits, you know, it has to be about the women’s body, but like if you get sick, really sick, you won’t get any coverage.”

“... just because you are working, that’s when you should be lifted up and pushed up, at least they should have like a year or two span that says, hey, if you’re working, we’re going to keep you on and give you these benefits so that you can make it to the point that you can support yourself and get that insurance that you really do need and not cut you out.”

“Because, you start work and then they cutting you out then it becomes a disability and then you can’t work to the point where you can become self sustaining and actually get off of the system. I’m like right there in the middle is where I’m at. So it’s very, very difficult.”

“You can have like four kids and they’ll send you \$200 a month, but the minute that you go and get a job to try to better yourself, they take it away.”

“I second that.”

“And even with a job it’s hard to get insurance.”

“We want something that’s going to work to cause everybody to be successful so that we don’t have to be dependent on the system all the time.”

“They really do what to work and they really want to do what’s best. But when they’re looking at it, like she’s going to work, is it better for her to go to work or is it better for her to stay on assistance.”

Could Not Have First Choice for Health Care Because of Insurance/Medicaid

“I know people without Medicaid, the only place they are allowed to be seen is ER. Urgent care will even turn them down and I don’t think that’s right.”

“I finally found a doctor in Sikeston that’s got me x-rays last month, MRI this month and then he’s gonna get me set up with the doctor in St. Louis because no other orthopedic doctors will take Medicaid.”

“They turned her away three times before her gallbladder was getting ready to explode.”

“And having health insurance is one thing and calling it Medicaid, that’s one thing, but then to have an invitation, these people from social service think that that’s a free invitation that they can come into your home and tell you how are you going to treat, or take care of your children or your family. That’s wrong.”

“You only get one pair of glasses every two years.”

Community

If Participants Could Design a Perfect Healthcare System it Would Include...

“Well, a perfect healthcare would do with being, having the means to be able to be covered, but not having the invasiveness of being scared of having that coverage. A lot of the things that we talked about was being scared of actually getting the coverage and then the lack of the coverage when you do, you know, when it is there. Just because we need the help doesn’t mean we want to sign our lives away.”

“I would like to see doctors do more testing and spend more time on just that patient instead of trying to worry about hurry up and get this one done so I can go on to the next one.”

“You know, our own privacy, our own rights to make our own decisions about what’s best for us.”

St. Louis (Group 1) Focus Group Analysis

Medical/Provider Relationships

Hours of availability

“But when you make an appointment it’ll be months later because like this particular time my daughter I need an allergies test. She’s not getting in till January. That’s how full they are.”

“And then I don’t like the fact that these clinics you make an appointment for like your check or whatever it may be and they schedule an appointment almost six months down the line.”

Providers Who Accept Medicaid Plan

Preventive Services

“My daughter, they see their school nurses for it and they let me know when they need shots and all that kind of stuff.”

Family

Obtaining Immunizations for Children

Available at clinics and at school

Facing Special Health Care Challenges for Themselves and Their Families

Health Education/Informational Resources

A variety of sources were cited regarding health education and information

“Nurse hotline”

“My daughter, they see their school nurses for it and they let me know when they need shots and all that kind of stuff.”

“I would take her to the nurse practitioner. Like I had tonsillitis or something like that. But they have nurse practitioners at those Walgreens.”

Transportation/Geographical Access

Transportation Services are Available

“You know, I could walk to it but still though I missed a whole lot of appointments because I was tired and I had no way to get up there. And I was getting surgery on my foot and stuff, and I can’t carry.”

Some Services Require More Travel and have Costs

“There’s plenty of times I didn’t go to my doctor’s appointments because I didn’t have no money to get there.”

“You go to Barnes and you have to pay to park. You go to the doctor, “I ain’t got no money.” You know what I’m saying? How can I pay to park? It’s ridiculous.”

“When people live in the small towns have to get helicopter-ed in this could save those tremendous hours and hours, days really. Because I’ve been and I felt like I was waiting for like two days, you know

Specialty Services Require the Most Travel to places like Columbia, St. Louis, and Kansas City

“I don’t use Grace Hill, but I – me and my children go to the clinics in the St. Louis area.”

Financial

Medicaid is difficult for adults to obtain if not pregnant—People cannot afford insurance, but they do not qualify for Medicaid

“Right. I like – I’m a diabetic, and I don’t get – they – I’ve been going through trying to get on Medicaid and all this stuff because I don’t have no income coming. I can’t – and you’ve got to pay to see the doctor, and you’ve gotta pay for your medication. I get high blood pressure pills. I get diabetic insulin. And then like insurance and stuff I can’t afford to get it ‘cause I don’t have no job and I have no money.”

“You have to pay for Medicare benefits. I mean, I went from having Medicare and no income to getting barely income and having to pay on that. Plus I have to pay for a drug plan. Plus I have to pay for a prescription. You know what I’m saying? Medicare is really – it’s a serious issue. I have \$8.00.”

“But we’re not trying to make excuses saying that – for people to say they just want to get stuff free. No, because I think every able-bodied human want a good-paying job and have insurance. And I work and have insurance, but it’s not a good insurance policy.”

Medicaid is easier to obtain for kids, but is still confusing at times

“I don’t agree why they changed it like that, but I can understand on both sides. But at the same time there are some people that need it for not just for the children. Even though it’s good that the children do have fully covered Medicaid. So that’s a good thing that they need to keep it for the children, even though they took adults off.”

“So I’ve had Healthcare USA the whole time. But they don’t pay for a lot of things unless you’re a child.”

“Unfortunately some of us don’t have income, are not working. They only will see your children and they’re full.”

Out-of-Pocket Expenses Such as Co-Payment or Services not Covered

“And they are under Medicaid, and then they also have some type of insurance from their father’s income. But as far as for me the Medicaid system has changed a whole lot because we don’t have dental anymore.”

“I know research can show how many times people go to emergency rooms because of teeth. And then when you want to get a toothache taken care of they say you have to pay so much money. But most of us we’re on Medicaid and we can’t even afford to pay.”

Could Not Have First Choice for Health Care Because of Insurance/Medicaid

“Exactly. It used to be we could see a dentist, but now we just have – just basically actually the only thing that’s on Medicaid is for your GYN accommodations. And to me that’s not because you don’t have a lot of parents that have children at all, but they can only get the GYN. They’re willing to give you birth control and GYN checkups, but they still – you still need antibiotics for colds. You still have cold, cough, sore throat. You see what I’m saying? You still need a medical doctor. That stuff costs money to have. Now we have to go and get private insurance for dental and vision, and your upper things just like a cold or infection. We have to pay for that now because that’s not on Medicaid anymore.”

“...your well-woman. Medicaid is supposed to pay for well-woman. They’re supposed to pay for that, but sometimes when you go in they be like Medicaid ain’t covering and we ____ you have to pay.”

“Some places don’t accept Medicaid. They’ll turn you away if they don’t accept your Medicaid”

“I’m trying to get me some dental now. But I ain’t got no Medicaid because I ain’t got no Medicaid. But I can’t pay for it ‘cause I don’t get no income.”

Navigating Insurance and Medicaid is Difficult and Time Consuming

“Then like with the insurance companies you have to sit on the phone for I don’t know how long for this person and this person and this person. “

St. Louis (Group 2) Focus Group Analysis

Medical/Provider Relationships

Language and Cultural Barriers

“Yeah, we have us a language barrier many families they don’t go to see provider. They don’t how they would speak for their health.”

“Language would be a big barrier.”

“Cultural barriers.”

Providers Who Accept Medicaid Plan

“And with so much going on and stuff, a lot of the specialists and stuff do not want to take Medicaid. They won’t even take anything that has to do with Medicaid. They don’t even want you walking in the door. They don’t want to take it because they having so many problems of getting paid or only getting paid a certain amount. So it’s like we refuse to get Medicaid at all.”

Confusion About Who Accepts Specific Plans for Specific Services

“Because like with my son having autism a main problem is to a certain specialist he needs because of his autism, and the insurance wouldn’t cover it. So it’s, like, okay, in order to see the specialist you need \$200.00, \$300.00 for this test and the doctor recommended it, but they’re like we’re not covering it. Or you think they’re covering it and then you’re getting a bill later on saying you owe. I’m like I don’t have \$300.00. If I had \$300.00 why would I be on Medicaid.”

“And another problem is, too, is once you’re over 18 they don’t cover dental. Even though you qualify for Medicaid but it’s like your teeth has – they don’t care about your teeth.”

“See that’s the problem my mother has because she’s disabled and she had the Medicare and Medicaid and she’s paying for it and they still won’t cover dental. So she’s like I’m paying for insurance, but I still can’t get any dental.”

Medicaid Discrimination

“Right. ‘Cause with him having so much stuff most of the more expensive insurance don’t like taking on autistic because he’s constantly – he has like 10 or 12 doctor appointments.”

Family

Obtaining Immunizations for Children

“I don’t know that’s right. No, that’s not right because he’s 4 years old. He’s still getting ready to go to school. He needs to get those shots and those shots and different things are expensive. That’s – there should be something that could be done about that.”

“With that, yeah. That’s my only experience with it. And I take my son to a pediatrician. And actually I’m kind of like quarreling with them because he needs a second chickenpox shot I just found out. And back in June I called four times they didn’t have it.”

“Yeah, his pediatrician’s office. So he’s gone for the rest of the summer. He’ll be back on Tuesday. I called today and said do you have your shot yet? They still don’t have it. And my son is going to middle school. He starts next Thursday and still no shot.”

School Nurses

“Basically just like if the doctor orders blood pressures or certain medicines they have to be given.”

“They basically just carry out whatever the doctor orders. And like if something happens to the child at school they make sure they’re safe or bandaged or whatever. They keep them safe. But then also just do what the doctor ordered.”

“One thing about that, some schools the nurse is not always – they’re not there five days a week. You might get two days.”

“I think basically what they’ve been doing is the teachers and stuff have been doing it. Because the nurse, like the nurse is not here today or the nurse is only here on Tuesday and Friday.”

“But the major problem with that is like, okay, if you’re working or something and something happens to your children, instead of the nurse being able to take care of it you have to leave

because there's no nurse there. They're like we don't have a nurse here. You have to come right away."

Health Education/Informational Resources

A variety of sources were cited regarding health education and information

Friends

Word of mouth

"And also in the doctor's office they have a lot of magazines on certain things we can get or if you want more information and get a free brochure you can go, you know, like about diabetes and stuff like that. They have them in the doctor's offices."

Transportation/Geographical Access

Transportation Services Availability

Grace Hill:

"They real good about it when your kids are going to the Head Start and stuff. They'll make sure like if you don't have a dentist they'll take you. They'll provide transportation for you."

"Mm-hmm. And they make sure that these shots or due or this dentist and like eye exams. It's people that come to the building and they'll do a free eye exam or refer your child for further services. They're real good about helping. And if you don't have a car they'll take you. Those are services you get because your kids are in Head Start."

"I haven't really ran into barriers because as far as transportation with the Healthcare USA if you call – you know you have an appointment you call five days ahead and you set up that transportation and they'll come pick you up."

"Uh-huh. It might be EMT or something like that. They'll come pick you up from home and take you to your doctor's appointment and then come back and pick you up."

"All of the providers. I think all of them have transportation."

"I think most of them want to know like at least three days ahead to arrange it, but if it's something urgent then they need to know at least 24 hours."

"Sometimes you might have to sit and wait a while for the transportation but there you got it."

Some Services Require More Travel

"Because most of the time if you deal with a hospital like with my son, all of the specialists and everything are go to the first floor or second floor or whatever. But it's like more with the clinics that's when you have to travel because they're going to say, well, I need to refer you to here or refer you to here or refer to wherever, so you might be traveling all over. You might run into some people that won't take it. You might got to go here and go here. But most of the time with the hospital everything was under one roof."

Financial

Medicaid is difficult for adults to obtain if not pregnant—People cannot afford insurance, but they do not qualify for Medicaid

"One problem is I know they're real strict about, they'll give you the Medicaid but they're easy to take it away from you. So if you go over this certain income, not including your expenses or what

can be going on then you still can, but they said, okay, you make over this amount you cannot get it even though you still can't afford insurance."

"They'll give it to you real easy but as soon as you go over the amount that they said you're allowed to make they'll take it away, not including your expenses. And you can't afford to pay for insurance. And then it's like once they cut you off you've got to go through all that process again just to get back on."

"I'm not even eligible through the state to get Medicaid because I have no small children. Or without disability."

Out-of-Pocket Expenses Such as Co-Payment or Services not Covered

"For my children, co-pays everywhere we go, \$25.00, \$30.00."

"I have to pay \$100.00 to talk about the results."

"My mom, she got asthma really bad, so she take steroids and she got to take Albuteral, but she don't have no insurance."

"Because the way they ordered it's like special tests. No, they ordered to try to see exactly where the autism one and what caused it. And if they don't feel it's necessary they won't cover it. And then you know with that it means a certain problem, like he has a problem paying attention, so they had him on ADHD medicine."

"But it's like you have to go through these other three medicines that can harm him or fail him or he might be allergic to before they'll pay this one medicine the doctor said, "I know for sure this is going to work." But if you don't try all all these other three or four. Then they still might not cover it then. It's more the doctor calling and waiting to see if they cover it after the doctor call. So sometimes they still won't cover it."

Could Not Have First Choice for Health Care Because of Insurance/Medicaid

"Yeah, like a lot of stuff with my son they won't take because it's Medicaid because they said Medicaid only paid them a certain amount, and their services cost more than that."

"And you're sick you can no longer go to the doctor where he's going now. He's not going to take Medicaid. I didn't know that."

Reimbursement and Finances Drive Health Care Decisions Made by Patients and Clinicians

"And then they was saying – a lot of doctors were saying they weren't having, too, a lot of problems of certain time they get their money, and they want their money at a certain time. So a lot of them are just – like if they're already established people they're people that you knew they won't take you."

Community

Community Organization Services

Our Lady of Perpetual Health

"I did. I had my niece here. I'm from New York. I had my niece here for a school year while my sister got herself together, and she needed a shot for school and didn't have a pediatrician. Like I needed it right away, so I took her to the health clinic and got her shot. And it was free."

If Participants Could Design a Perfect System it Would Include...

- Dental
- No co-pays
- Healthcare for all children
- Healthcare for everybody
- Customer service

“What I would do to improve the healthcare system would be have coverage for natural medicines, herbs, supplements and alternative therapies.”

“As long as the medicine is prescribed by a doctor they should cover it.”

“And be more adjusting to the patient needs.”

What are the most significant changes you’ve seen in the past five years?

“Now it’s actually part of it the beginning. You could be – if you were disabled and you automatically – even though, right. They still won’t give it to you.”

“They’re more stricter with the medicines because it used to be if the doctor prescribed it __you need it. Now it’s like even though the doctor prescribed it we’re not going to pay for that.”

Branson Focus Group Analysis

Medical/Provider Relationships

Care Options

“It seems living in Branson that there is not a shortage of, there is a shortage of options for pediatricians in the area if you don’t want to drive to Springfield.”

“We avoid the emergency room at all cost.”

“My son was premature, and before I left the hospital – I had him 9½ weeks early - before I left the hospital, I was told that he had to have a pediatrician, was not allowed to see anybody but a pediatrician. Well have fun finding a pediatrician anywhere within the time of you getting out of the NIC Unit.

Quality of Care

[With regard to Nurse Practitioner] “With my first son I did, and I attribute that to a lot of misdiagnosed ear infections, and my son should have had tubes sooner, which caused – I don’t feel like that was adequate. So I now only want to see a medical doctor because of that.”

“So basically I had to just take whatever I had. And I went to him and – well you’d never see the doctor, you just see nurse practitioners, PA’s, stuff like that – and working at a pharmacy, I work at a pharmacy, and they would tell me to do stuff that I knew was wrong..”

“I mean we all go to the same doctor, but it’s very hard to get in, and you can tell that he is rushed when you’re in there, and that’s really frustrating to me, ‘cause I’m paying the office visit whether he takes all the time or none of the time. So, I’m having to go back before, over the same issue because it didn’t get correctly taken care of the first time.”

Medical Services Used:

“Where I work, I’m pretty fortunate, because we have our own health clinic.”

“Both of my sons have had chronic ear infections, so we have used Urgent Care a few times on the weekends.”

Preventive Services

“I don’t [use preventative services], because I don’t have insurance. So, but my children get what they need.”

“I don’t have any dental.”

Family

Facing Special Health Care Challenges for Themselves and Their Families

Vasectomy complication, tachycardia

“So now my husband has a pre-existing condition that’s still being treated, and now we’re having to pay for it without insurance.”

“Prune Belly Syndrome... He’s had like five surgeries since he’s born. So he sees the urologist, and he has kidney damage, and so he eats, he sees a nephrologist, and then he had club feet, so he sees an orthopedist. He sees a number of doctors. But anyway, he’s going to need a kidney transplant ... racked up \$250,000.00 before he’s 18 years old, we’re going to reach our maximum lifetime.”

Families Facing Special Health Care Needs Spend More Time on Managing Insurance & Care

Health Education/Informational Resources

A variety of sources were cited regarding health education and information

Transportation/Geographical Access

Some Services Require More Travel

“We travel to St. Louis too for my son’s specialist, ‘cause he has something that a very, very few kids have, and so nobody in Springfield would touch him.”

“and something told me I wanted a NIC Unit, which I ended up needing. But I went to Springfield for it, but it was just a pain, ‘cause you know, you got to go once a month for your appointments. You got to go for your labs, you know. So I had to go to Springfield all that, for all that, and it was just really a pain.”

Significant travel for a specialist

“Our location” [is a barrier to services]

Time Issues

“You got to get them there. You got to get back. I mean you miss a full day of work, and if you’re working, there’s not a lot of jobs as it is.”

Financial

Out-of-Pocket Expenses Such as Co-Payment or Services not Covered

“Well our pediatrician won’t give shots anymore, because he can’t, he’s on his own. He’s not with the hospital that’s here, so he’s, and he won’t give shots to children anymore, because he can’t get reimbursed for them through the insurance company. So he makes everybody come to the Health Department now.”

“I would say when I had my second son, I went to teaching part time, and I lost my insurance, and so we paid out of pocket so I could have Blue Cross and Blue Shield, and it was over \$400.00 a month, and now, and that was for maternity. So it was good, but that was just for me, not including my sons or my husband.”

“I had a surgery while I was on maternity leave, and my insurance only covered ten percent of the surgery, and the surgery was \$10,000.00. So right off the bat, so even with insurance - I had some complications – it was astronomical, well not astronomical, but it was very expensive what it cost me to have”

“Now, you know, but the problem for us lately has been making payments, coming to some kind of agreement with clinics for making payments, because we, when my son was born we had thousands of dollars, and we just put it on a credit card. We learned that doesn’t work.”

“my son’s 2½ - and to this point he has over a quarter of a million dollars worth that our insurance has covered, and we’ve paid probably you know ten grand. So, I’ll take ten grand over \$250,000.00 any day.”

“That is exactly what I was going to build on with what she said. When I went in for, I was five months pregnant, had to have my gallbladder removed. So I go in to preregister for the surgery, and that’s when I learned the surgery’s \$10,000.00. They wouldn’t let me go any further. They said okay, your insurance covers this much, and this is how much you’ll owe, and you’re going to owe \$1,000.00 today.”

Medicaid is difficult for adults to obtain if not pregnant—People cannot afford insurance, but they do not qualify for Medicaid

“I mean we’d end up getting pregnant and we have health insurance, but we don’t have maternity coverage, and we couldn’t be added on, I couldn’t be added onto my husband’s plan until July. And so I tried to get Medicaid twice, denied twice, because we own our own business.”

“We, my children qualify, be we never qualified. You have to make like \$400.00 a month.”

“And it was, you know we were right at the level where we make too much money to get these programs, but we make too less to pay our bill”

Could Not Have First Choice for Health Care Because of Insurance/Medicaid

“She’s a high risk pregnancy and has a lot of problems, and had no job, and had not planned to have a baby. She was, got denied.”

“I cannot even imagine in my mind how many boys right now that are going around not circumcised because Medicaid does not cover it. And there was something else, and I can’t remember from visiting her in the room, that I just kind of felt bad for, because I don’t know that she was getting the same treatment in that room.”

“But Medicaid wouldn’t pay for her pump in the hospital, so therefore she didn’t breastfeed.”

Reimbursement and Finances Drive Health Care Decisions Made by Patients and Clinicians

“I have two health insurance programs right now. I have the Cox program that is with my kids that costs me \$91, or \$191.00 a month for me and my three kids. I didn't drop that program because the school program is \$350.00, and I want to be able to drop that as soon as I have this child. So now, not only am I paying for Cox health insurance through the school, I'm paying for Cox health insurance from my kids so that we can keep the same copay, because if I was to drop myself and then add myself back on, guess what happened to my copay and my, my monthly payment - \$221.00. So they're getting double payment from me and made me sign a waiver saying that I wouldn't charge the other insurance, that I'm paying for.”

Community

Health information services used by community members for childbirth

Parents as Teachers' program
I don't think we have enough down here.
I had trouble even getting into like child birth classes
Lactation consultant
Mommy and Me classes
Birthing class
Breastfeeding class
Videos
Bear Program

Health information services used by community members for older children

“My son gets speech, physical and occupational therapy, and we get it through First Steps”

“Our daycare sends home a lot of information about the development and learning”

“Parents as Teachers”

If Participants Could Design a Perfect Healthcare System it Would Include...

“Free and not crowded.”

“More doctors available.”

“It's a completely free hospital. So you walk in, everything is free, it's all donations. We have a ton of doctors in the area that are willing to go. We have podiatrists, we have ear, nose, and throat. We have Doctor Givens, dentists. I mean everything is going to be there. So it's just getting everything together for that.”

“But I mean that's what we need is an in between, or if you're having a bad month.”

Overall noticed changes in Healthcare in the past 5 years

“The cost for office visits [increased].”

“Used to be \$71.00, and he's only gone up to \$91.00.”

“I think the most shocking for me was finding out with the facilities that do not want to work with you on payment if you can't pay.”

Springfield Focus Group Analysis

Medical/Provider Relationships

Difficulty getting a doctor, including specialists, to accept a Medicaid patient:

“Unfortunately, the list, even though there are like really long and extensive of the doctors that are available to go to, trying to get into one that will accept a Medicaid patient is almost impossible.”

“He has to see the specialist so that’s a big concern of mine and I’d like to see more providers being added to that list...”

“I know if you have – both my daughters have, their dads are supposed to pay their medical insurance.”

Involvement of health provider

“So I think the actual care itself if it were a little more involved, maybe that would be great. And I’m not just talking about the emergency room but I’m saying that’s kind of a place to start.”

Weaving through the system is complicated

“waiting lists”

“It’s a really long, drawn out process”

“Why do you have to go track all that stuff down to apply for Medicaid? They have that information accessible to them. I mean, or they should have that accessible to them.”

Health Education/Informational Services

Sources of Information

“There’s no website. There’s no, you know, you can call to get information about this, you know, medical situation or where you could get this information from. There’s no, like, one centralized place and you have to go.”

“Head start which is a government funded program.”

“I know all of our churches are pretty much all together, the Public Council of Churches so if you need food – pretty much anything other than medical care in Springfield you can find it. You can find housing, you can – I mean, if you don’t have any food there’s the Victory Mission, there’s – The Council of Churches they’ll help with coats and everything but when you’re an adult and you, you know, you’re sick you’re just.”

“That’s why I always try to grab those community blogs that they have like at McDonalds and at Walmarts so if they let you know...”

“They do a parents and teachers program here that’s really great and they do, not only screenings but they do pre – it’s like preschool activities to get them ready for kindergarten. So it’s like pre-kindergarten activities that sort of, you know, get them ___ and stuff like that which is really great”

“The Internet.”

“Yeah, I’d call the nurse”

Transportation & Geographical Access

Difficulty finding specialists in close proximity

“Whenever I have to go to the psychiatrist, since I had cancer, I had to drive all the way to Baltimore. That was the only option that I had. You know, there was no other option. There is none in Springfield. I was on waiting lists for eight, nine months.”

“I mean, we have a bus system but it doesn’t really go – it doesn’t run great routes and if you take the bus and you try to get somewhere usually you end up having to walk more than a mile or two to get where you’re going and if you’re doing that to take your child to a doctor, it’s just impossible.”

“Well, to get on Medicaid to get dental care as an adult in this city is impossible. You have to travel somewhere else and the last time I went to a dentist I can’t even remember what the town was but it was three-hour drive to go to the dentist which is insane.”

“Well, to get on Medicaid to get dental care as an adult in this city is impossible. You have to travel somewhere else and the last time I went to a dentist I can’t even remember what the town was but it was three-hour drive to go to the dentist which is insane”

Financial /Medicaid

Out-of-Pocket Expenses Such as Co-Payment or Services not Covered

“as for myself it’s all out of pocket so I don’t go more than I have to.”

“Yeah, I was gonna say limited on dentists who accept Medicaid – is very low.”

“I mean, I’m lucky enough that my father helps me or I would have never – even pap smears...”
“It’s so expensive even with my private insurance you still gotta pay a big co-pay and then you gotta come back if they have to do dental work so still you gotta come up with so much money. I’ve got insurance and I don’t even go to the doctor. I don’t even go to the dentist. The only time you gonna see me, like you say if I’m dying and I’m really sick I will use my insurance ‘cause I can’t even afford to pay my co-pay. Everything is so expensive...”

“We’ve got a \$20.00 a month – she has eczema, okay, but if you can buy over the counter then you can’t, you know what I mean but like she would be in the same situation if her child had eczema, that’s \$20.00 a month that’s just between lotion and soap, And that’s it. Lotion and soap and that’s \$20.00 a month,”

“It’s so expensive even with my private insurance you still gotta pay a big co-pay and then you gotta come back if they have to do dental work so still you gotta come up with so much money. I’ve got insurance and I don’t even go to the doctor. I don’t even go to the dentist. The only time you gonna see me, like you say if I’m dying and I’m really sick I will use my insurance ‘cause I can’t even afford to pay my co-pay. Everything is so expensive. I got three kids in college, work full-time, and it doesn’t pay that much money and, you know, if wasn’t for Jordan Valley that I’m able to bring my kids here to get some services I don’t know what I’d do ‘cause even when they were little I didn’t qualify for Medicaid because of the money my daughter have in the state. So I used to take my children when they were little there used to be a baby well clinic. They were done at a church so I used to take them up there because I never did qualify to get my children on Medicaid because of the settlement money was put in the state.”

“Yeah. And I, I mean, even people who do have insurance the premiums, you pay so much out of your check every time and then you still are having pay co-pays or out of pocket or if you need, you know, so it’s just so frustrating...”

It’s difficult to qualify for Medicaid if a woman is working, but the job may not provide insurance or pay enough to cover insurance or fees

“so I mean, if you get welfare then you can get Medicaid but other than that as a working woman you can’t get Medicaid...”

“if you can’t work you’re pretty much [in trouble] because how are you supposed to pay your bills on \$230.00? If you want to go to the doctor, forget that noise. You can’t even afford to pay your rent”

Difficulty getting preferred coverage when services are not covered or too expensive

“I would say either dental for children or adult – working adult care period. I mean, if we could just even get, you know, two visits a year, you know, we’ll pay for two visits a year and then after – or even pay, you know, I know some parents that pay \$60.00 a month for their children to be on Medicaid. Even if we had that option, you know, I’d pay \$100.00 a month if I could have it. You know, that’s still less than a doctor’s visit.”

Community

In a perfect world...

“put out in the school newsletter or you know what I mean so just to let parents know this resource is there.”

Kansas City Focus Group Analysis

Medical/Provider Relationships

Barriers to getting services

“My aunt has Type 2 diabetes, and my aunt – my aunt and uncle – my uncle runs his own business, and he consults with firms, like MasterCard and AT&T, but since he’s not an employee, he has to find his own insurance. And I think they had to shop for six months to find an insurance that would cover for her because she had diabetes. I think they’re paying \$1,500 a month, just to cover her.”

“The doctors that won’t – we have friends that do more of the alternatives, and some of them are selectively vaccinating, you know, just doing some things and not others, and some of them are delaying vaccines until their kids are older, or not doing it at all. And there are pediatricians – a number of them in the area – that are refusing to see their children that says, you can’t – what?”

Preexisting Conditions

“My biggest nightmare right now is ‘cause we have Cobra, is just losing our Cobra, because we have so many various pre-existing conditions in our family, we can’t – we have to lose our house before we lose our health insurance, and that’s like something that keeps us up at night, because it has to be paid, no matter what. And so that would be the one healthcare change, if they could say, “No more pre-existing conditions,” that would solve so much.”

Difficulties with Providers who Accept Medicaid Plan and those Providers Availability

“I had some issues when I first got on Missouri HealthNet. When they send you all of your information, they tell you that you have to pick a general practitioner, which I’ve tried that several times, but they tell you, if you’re a cash patient that most doctors won’t even take you.

And so then being on Missouri HealthNet, I'm like, "Oh, great! I'll have a general practitioner." I called 15 offices, and out of the 15 offices in my packet that said that I could pick from, two-thirds of them were closing down to become traditional offices and only accept insurance, and the other third said they weren't accepting new patients."

"It's almost impossible for me to find a GP that I can follow. The only thing I can do is act as if everything that comes up is an emergency, and I can go to the Swope Health Services for their prompt care, or something like that. But it's kind of crazy that you can't even find a regular doctor."

"It's even worse when you try to do dental, because we had HealthNet like five years ago, and there was nobody that my husband and I could see – nobody! I called every single person in Kansas City, you have nobody in Kansas City with dental for an adult."

Confusion about Who accepts Specific Plans and what Specific Services are covered

"My husband was throwing-up for 36 hours, his lips are turning blue, I'm on the computer looking up his insurance policy trying to figure out where I can take him. And I'm sure I wasted two hours doing that while he's miserable, and that's ridiculous. I shouldn't have to do that in an emergency, but, you know, I need to know that it's going to be paid for. "

"That's what we went through with my husband, was when he got sick, I'm like, well, maybe it'll just go away, because if we can just wait an extra four days we can go see the surgeon and get it taken care of, and we know it's affordable. But it's arguing with the insurance company afterwards, because, my plan says that you cover this, but then somehow you're finding a reason that you don't? Or something like that. And so it's arguing with them about how much we have paid in for the year, or not. He's got a high deductible HSA, and so it's been a long struggle writing letters to the insurance company, and to the hospital, and to the physician saying, you know, this should be covered, or this shouldn't be covered, or something like that. It's just a lot of work. "

"And they tried to cut me off for my orthodontist, because I guess I hit 21, and then I was in school. So my dad threw a fit. It was like, braces are very expensive!"

Limited care and Variety of care

"We would like to do a lot more of the non-traditional stuff, and are stymied by the lack of options from our health insurance plan to do that, just because we have several children, and so it adds up to do them for everybody. I can usually hit one person and put a lot of out-of-pocket expenses into that one person for a while for something acute, but then once that's been settlement then it's kind of onto the next person."

"Our midwife that we had for our last three births, that was all out-of-pocket because it was not covered by our health insurance."

"I want to do a natural birth, and so we've already decided that it's just going to have to be out-of-pocket, because it's almost impossible to find a place to have a natural birth that is in a hospital, and so it's pretty frustrating to have healthcare that works. I'm not on a crappy insurance plan, I'm on a really good – MO HealthNet, and it still doesn't work."

“When we came from India we were told that in the insurance plan that the UMKC offered, your dental services and your eye services would not be included. So we were told to have an eye check-up, and fix your teeth, before you come here.”

“I have a little bit of trouble with coverage for my woman stuff, not because of insurance, but because my midwife doesn't do that type of stuff, and the MD's are unwilling to work with me because I work with a midwife.”

“I honestly don't know that much about my – this probably isn't good – just because like I'm still under my parents', just because I'm a student. But I know like when I got here last year, it was my freshman year and like I had a cavity, or whatever, so I had to go to the dentist, and she ended up doing like a lot more work than the cavity. And all I remember is like my parents ended up having to pay like \$2,000 for all the dental work she did, and we have like good dental insurance.”

“We have food sensitivities – we work with an allergist, and so we have gluten intolerance in our family, along with a number of other things, and those foods are crazy expensive. We cannot buy anything in a regular grocery store, and so our food budget rivals our mortgage. I mean, it's just insane how much we have to spend on food in order to feed people, and, you know, make everything from scratch because it's at least cheaper that way, comparatively speaking. And then things like we don't have orthodontia coverage, so we're getting ready to start shelling out for that. Eyes glasses are not covered. Our exams were covered under this insurance claim, which was unusual for us, but glasses and contacts aren't.”

“I think vision, just because it's not pertinent. Dental care, like, you're going to go see the dentist if your teeth hurt. You're going to the doctor if your body hurts. I don't think people think that vision is really like that necessary, and a lot of insurance plans don't cover it. Or like she said, they'll cover the exam, but they won't cover the glasses. So, I need them. Actually, I do need glasses. I have astigmatism in my eyes, but I don't know, I'm not covered under my parents' vision here, 'cause it's just between them two, and they didn't think their children would need glasses, so they didn't cover it. So me and my brothers kind of, okay, and I went to the eye exam and they was like, “You need glasses.” I said, “Well, I'm not covered,” and I didn't want to pay no \$300 for some glasses. So I just refused to go and get 'em.”

“I agree with the eye care. Like I had good health insurance about four years ago, 'cause I was working for a Japanese firm, and let me tell you, Japanese firms know how to give health insurance. But I had an all inclusive plan that covered dental, and my eyes, I could get glasses, and contacts, and everything. And so I got all of those things as soon as I got covered, and then I quit that job, and then the plant closed, or whatever, and all of a sudden I didn't have anything, and I just went without. And then I broke my glasses, and lucky me, my husband's father works with an eye doctor, and so he just found some frames that fit my lenses, so I didn't have to pay for them. But I don't know, I mean, I can't go to the store and pay \$100 for frame 'cause I broke 'em. So that's been a huge hassle, and I'm just lucky right now.”

Preventive Services

“A lot of our healthcare has to be preventative. We do a lot of herbs, a lot of medicinal teas, things like that.”

“My husband and I invest most of our healthcare money into preventative care. My husband has high blood pressure, and so the pills that his doctor gave him were making him more lethargic,

which was making the blood pressure worse, 'cause he can't exercise. So we decided to treat that naturally with teas and herbs, and supplements, which is a lot more expensive than the pills, but that maintains it better. But other than that, I mean, you can't find anyone who's going to cover preventative care.”

“Planned Parenthood has kind of been a great resource for me, for well-women, mostly because I go through them for a lot of my birth control, which I haven't been getting because I'm pregnant again. They just make it a requirement that every year when I come back to fill, they do a well-woman exam, and that's been real easy and affordable. So I like going there a lot.”

“Yeah, just preventative healthcare. The reason I go to St. Louis – I go quarterly to visit – I have family there, I'm from St. Louis. But we go quarterly just to see our homeopathic doctor just for preventative care and maintenance, 'cause we can't find someone in the area who is not just a GP, but who understands that we're into preventative medicine and homeopathy, and that we're interested in staying healthy, and not just seeing someone to not be sick.”

Family

Issues Involving Immunization of Children

“I've known several families that have been denied healthcare because they won't vaccinate their children.”

“The doctors that won't – we have friends that do more of the alternatives, and some of them are selectively vaccinating, you know, just doing some things and not others, and some of them are delaying vaccines until their kids are older, or not doing it at all. And there are pediatricians – a number of them in the area – that are refusing to see their children that says, you can't – what?”

Facing Special Health care Challenges for Themselves and Their Families

“We have a primary care physician we see for check-ups, but I take the kids for check-ups. Apparently, I had not gone in a while, because I needed antibiotics last week, and he would not prescribe it over the phone because had not seen him long enough. So, the kids go regularly, and then we also utilize primarily Children's Mercy for things that our family doctor is not qualified to deal with. I have some with some health issues, and another one that has OT, and a daughter that has like lazy eye, those types of things, we primarily utilize the Children's Mercy for that”

Health Education/ Informational Services

A Variety of Sources were cited regarding Health Education and Information

“We have been given an emergency help line number. “

“Our first stop is WebMD”

“I have a homeopathic doctor in St. Louis that's a friend of the family, and so any time something comes up we usually give him a call, and he lets us know what kind of vitamins and supplements, or medicinal teas that we can take, or there's a couple of acupuncture points that he can help with I have a couple of friends that are really good sources for that type of thing. A retired midwife, and a friend that just reads everything in this world. So I'm looking for something non-allopathic, they're a really good source.”

“If I need the answer right away I usually will call the nurse line.”

“If it's like a long-term thing, that I want to research all my options, then I go to the Internet and Google it, and just read everything I can find.”

“If it's just like a cold, or something, I would probably call, or I have a book that has a nice combination of allopathic and complementary medicine stuff, and look it up.”

Transportation & Geographical Access

Some Services Require more travel

“We don't have public transportation outside of metro, but we have to travel 35 minutes to our family doctor to find somebody that was respectful of our choices, as far as they actually respected our right to make choices – we should say – as far as our healthcare, 'cause we live out in eastern Jackson County, and we're traveling all the way to Olivette, and that's a pain.”

Specialty Services Require the Most Travel to places like Columbia, St. Louis and Kansas City

“Yeah, just preventative healthcare. The reason I go to St. Louis – I go quarterly to visit – I have family there, I'm from St. Louis. But we go quarterly just to see our homeopathic doctor just for preventative care and maintenance, 'cause we can't find someone in the area who is not just a GP, but who understands that we're into preventative medicine and homeopathy, and that we're interested in staying healthy, and not just seeing someone to not be sick.”

Financial

The Cost of Insurance/ the Costs Insurance does not Cover is Great:

“My husband and I are both artists, so traditional healthcare doesn't really work for us because it's just unaffordable. So the way that we've done it is when one of us knows that there is an issue coming up, we have a high deductible plan that we'll join for a few months and take care of it, and then just let that lapse. We also – the Swope Health Services, has been a really great resource for us, just because they give great care.”

“My daughter with the eye thing, we really, really, really want to do vision therapy for her. Children's Mercy is saying they want to do surgery; vision therapy's not covered by our insurance. It's \$600 to even have the evaluation, and then \$100 a session afterwards, and my husband's been out of work since April – we're in October right now. There's just no way that we can do something like that. And so I would love to have an option.”

“I'm having my first baby, and I'm just lucky that Missouri HealthNet is a comprehensive plan; otherwise, I don't know what we would do for healthcare. We just finished having a surgery for my husband, which was a nightmare, and we had him covered because we knew that was coming up, but even with insurance it's almost unaffordable. And so it's just kind of crazy for us that the only way that we could get reasonable insurance is to work 60 hours a week for a company, and hope that that company has a half decent health insurance policy.”

“A lot of my friends who are doing that right now, even their health insurance policy doesn't even cover half of what they need. And so it's just crazy to me right now.”

“Insurance said there's a limit to how much they can pay you, and you've passed that limit. And my parents are not in the financial situation to pay for everything now.”

“You can't find anyone who's going to cover preventative care.”

“It's either invest in healthcare, or invest in good food, and we're just choosing that it's better for fight it beforehand than worry about cancer or something more serious later. “

“The deductibles generally aren't too bad as long as you stay in network, but the co-pays for the doctor are fine, it's when like last week when I was so sick, I had to go to urgent care, and that's when you're paying \$50, or \$100. I mean, that's real money. And that's difficult when you're trying to decide, you know, it's Friday night and your kid's sick, and can we afford \$100, or can we hang on for 48 hours and make it till Monday morning, and get into the regular doctor.”

“My husband has seasonal allergies, and he likes his – yeah, he does several prescriptions, and we're probably paying \$100 a month in just co-pay, yeah, to do that.”

Community

Community Programs

“I have a friend who lives in the area, and he'll go to the free health clinic occasionally when he gets sick. I started taking him over to the Swope Health Services, because their facility is so great, and the people there are nice, and they have a sliding scale. But other than that, I mean, he just goes to work sick.”

“When I went on MO HealthNet, they offered me WIC, and the problem I had with WIC is that not just that they haven't changed their program in 30 years, which they are changing in October, but it is absolutely insane to me that with all the research that they've done on milk and how dangerous it is, and how much it's been linked to cancer, and the feminization of little boy babies, and all sorts of things, that they're still giving out 60 gallons a month to women. And it's crazy that they're still giving out hormone-laden cheese, and I just wish that they had more options where they could give you a check and say, "This is how much you get to spend on eggs. You can buy the organic ones if it falls into this." If they could just give you checks that have an amount on it, and say, "This is for eggs, or this is for milk," and you could get an organic or a soy option, and not have to get the cheap store brand, I can't even use the program because I can't eat any of that, it's so unhealthy.”

“We looked into WIC like five years ago, and that was our experience, that nothing worth – I mean, the amount of juice we got, I mean, I don't give my children juice. If they do it's like this big treat, and they're like, "Wow, juice!" you know. And we were getting ridiculous amounts of juice. And there was, yeah, nothing worth eating on WIC.”

Kirkville Focus Group Analysis

Medical/Provider Relationships

Providers Who Accept Medicaid Plan

“What insurance and what insurance you have. That's always one of the first questions, what is your insurance? And if it's Medicaid, conveniently, I know, they don't have openings. “We're not accepting new patients.”

“On that point, too, I've been trying to get to a urologist here in town and they don't take my insurance. I'm going to have to go to Columbia just to get a urologist that will accept the insurance that I have.”

“And there's only one place, I think, that I know of in town, on Crown Drive, that even has a sliding program. And so that would be a smaller bill, but I think it's still a lot and they want it all at once.”

“I tried to get my son in just to – for them to check, and they’re like, “Well, he’s not so old, like five or something, like school-age, or if you don’t think there’s something wrong with their teeth, then we’re not gonna look at them.”

Confusion about Who Accepts Specific Plans for Specific Services

“They don’t accept your insurance or you don’t have insurance, they don’t take payments.”

“They want the payment in full right then and there. Especially the hospital.”

“My daughter was in an accident three years ago, and actually got hit and ran over. And there was five insurance companies that could pay. First her health insurance, the insurance of the driver, the insurance of the car, the insurance of the people that own the property, the – you know. Five insurance companies that could have paid, and all of them denied her claims. And when we had about \$50,000.00 worth of medical bills, we got a lawyer to talk and communicate with her own health insurance to make them pay her bills first.”

Quality of Care

“Probably in better hands if you go to Columbia.”

“Yeah, they sent my husband home with the flu when he actually had food poisoning and went into kidney failure, because they diagnosed it as he just pee-peed, and I’m like – then why did you do an emergency EKG?”

“My little nephew was having seizures and then we took him into the ER here and then sent him home, said nothing was wrong with him, so we drove him straight down to Columbia, and they had diagnosed him with seizures on Christmas.”

“I know a doctor that will not refer patients to this hospital because of all the unnecessary testing and charges or misdiagnosis that they do that they have refused to deal with the __, which is pretty sad.”

“Yeah. My friend – she’s on her second pregnancy. The first one she had a miscarriage, and she was about 11 weeks along, and she started bleeding so she went to the emergency room. And right now they don’t really have a doctor in the emergency room, they just have people in there pretending to be doctors, I guess.”

“He refused to do anything – any kind of test to see if she was having the miscarriage, just told her to go home and her baby was dead and to get over it. And she went to the doctor the next day and the baby was fine.”

“I actually had an incident at the hospital with my oldest daughter that we were in the hospital here every weekend for six weeks. And they couldn’t diagnose what was wrong with her. And I actually had a nurse that worked on that floor that finally said, she took me outside, and she’s like, “I gotta talk to you.” And she says, “I’m just telling you now that we don’t know what’s wrong with your baby, but nobody wants to tell you that.” And so she said, “As soon as I leave, you didn’t hear this from me,” but she said, “You need to request to go to Columbia.” I went to Columbia, they did tests and then figured out right away what it was. She had kidney reflex and she had to do surgery on her in Columbia.”

“I’ve never been a patient at this hospital, but having been to Mayo’s and seeing what the patient care was like there, it’s all-encompassing. We – they just don’t treat the illness, they treat everything, your mind, body, everything, and the family, too.”

Limitations because of preexisting conditions

“Well, it’s like my insurance company dropped me ‘cause I didn’t tell them I had a cyst on my ovaries. And it’s like, are you serious? What female doesn’t? I mean did you ask that day, “Do you have a follicle today?” You know?”

Preventive Services

“I don’t – some of us for being younger, we don’t think about preventive services, unless you’re, you know, birth control’s about the only preventive.”

“I think our OB/GYN, I’m really pleased with their office, ‘cause I just delivered a baby three months ago, and they’re – that was like the best doctor’s office I’ve been to as far as being on top of things. Usually have to remind them or you have to call for this or call for that, and I never had any problems like that.”

“I go to Columbia for a mammogram. They do it here, but – I hear it’s hard to get in here, but my first one was done in Columbia, so I keep going back ‘cause they’ve got the baseline pictures.”

Family

School Nurse Help with Child Health Care

“Usually your child has a temperature, headache, or upset stomach.”

“Yeah. And you know, she’s really good. That’s pretty sad when you’re on a first-name basis with the school nurse, but she’s pretty good. She changes bandages, stitches and things like that. The kids will go in for that or administer meds.”

“And I yeah. I have a daughter with ADHD and she administers the meds during the day.”

Facing Special Health Care Challenges for Themselves and Their Families

“My son has asthma. So, we’re crossing our fingers for this winter.”

“My son is allergic to everything.”

Health Education/Informational Resources

A variety of sources were cited regarding health education and information

“Parents at Teachers, Children’s day, Health Department and WIC Department, The Lion’s Club, Life Line Pregnancy Center.”

“People do come in once in a while and they will just do like a check-over of the kids’ teeth in that center.”

“Life Line, there’s a crisis pregnancy center here in town, and they’ve got a huge variety of – it’s a video education and paperwork and stuff that goes with that for prenatal and parent education type stuff. You watch a video and then you earn points. I got a new car seat with my points. I mean it helps for people out there that need the education on – you know on teen pregnancy.”

“And they do a lot of healthy nutrition and whatever, all kinds of health-related education.”

Transportation/Geographical Access

Some Services Require More Travel

“So, that’s been – the doctor that go to here in town, he’s a really good doctor, but – yeah. He’s traveled to Columbia and back several times for specialists and I’ve been happier here in town with him.”

“We travel to go to the dentist just because I prefer a pediatric dentist and we don’t have one here, like an actual pediatric dentist. So we travel to Columbia for dental appointments. And I know there’s a lot of dentists that will refer them to Columbia if it’s an oral surgery, ‘cause they don’t have the facilities here to do that.”

“My son just had a hernia, and we had to go to St. Louis for that.”

“Well, I went to the ER this week with my son, and they didn’t even know we had an ENT in town. He was gonna refer me to St. Louis to an ENT ‘cause he didn’t know we had an ENT in town.”

“The appointments I travel for, I kind of choose to do that. Like some of them are available here, but I choose to travel. I just arrange my schedule so I can travel.”

“Pediatrics, specialists – I mean we don’t have – we had a pediatric group in this area. And I know that’s who they want my child to see is a pediatric specialist, so I have to travel to see those pediatric specialists.”

“We’ve been referred to Columbia several times. Like there’s the pediatric nephrologists and a few different pediatric specialty doctors there.”

Traveling to places like Columbia, St. Louis, and Kansas City is better

“I know prices in Columbia are a whole lot cheaper than it is here.”

“Like for an ultrasound here at the hospital is \$950.00. And my doctor’s office in Columbia is \$100.00. It’s like I’d rather travel an hour and a half out of the way to go spent \$100.00 rather than, you know, have to spend a year paying it off here.”

“Colonoscopies are cheaper at the endoscopy clinic in Columbia, like \$1,800.00 versus \$3,000.00 here at the hospital. Of course, you still have the medical – the doctor bills on top of that, but if you’re at the hospital, you’re going to have all that anyway.”

Financial

Medicaid is difficult for adults to obtain if not pregnant—People cannot afford insurance, but they do not qualify for Medicaid

“For Medicaid, it’s hard. My son’s dad broke his ankle and for three months and had a doctor’s note saying that he couldn’t work ‘cause he couldn’t walk, and they didn’t give him Medicaid because it wasn’t permanently disabled.”

“I think it’s pretty easy to get insurance, but you just can’t afford it.”

“Now, it was very easy when we went into apply for Medicaid for pregnant women.”

“And they make you go get papers like how much it would cost you, and even after you go show them and tell them there’s no way, you guys can barely pay the bills now, they still wanna refuse you at times.”

“For prenatal, yes. But I mean it’s almost impossible to get on it if you’re an adult and you’re not pregnant.”

Medicaid is easier to obtain for kids, but is still confusing at times

“You can get it for children, but as far as for adults.”

“That was fast and easy and no problems whatsoever. But, I do know applying for children even, our families encountered some problems along the way.”

“I had problems at the very beginning trying to get my kids in to the dental clinic ‘cause you had to call that one day a month Now, unless I had a referral from Head Start. Now, if you had a referral from Head Start, you got in just perfect.”

Out-of-Pocket Expenses Such as Co-Payment or Services not Covered

“I guess what we need is we – there’s a lot of discounted things, but there’s nothing for, like eye care, there’s no eye care that’s discounted. There’s no dental. I guess we do have the dental clinic that does take the sliding scale, but as far as eye exams and things, and right now like even some of the doctor offices, only \$25.00, but some of our families don’t even have an extra \$25.00.”

“They want their kids circumcised, but then they can’t ‘cause they can’t afford it. That to me I think would be a health issue. That’s why they dropped it from Medicaid is because they said it wasn’t medically necessary.”

“My doctor was out of town when I broke – my son was born, so he didn’t get circumcised at the hospital. We had to go back to the hospital to do it because she didn’t do it in her office, so I had to pay for the room on the fifth floor to do it in and the circumcision, so it was \$700.00 for a circumcision.”

“I know in some insurances they say that they’ll pay for it, but then they don’t. That’s what happened with mine. Like, I was supposed to be able to have an annual, and came back and I wound up paying for the whole entire bill. They say that they’ll cover it, but then they don’t, and they can do it because what are you gonna do? I mean, who has the money really, nowadays, to go hire a lawyer? You know, \$50,000.00 is a lot more than that, but to go hire a lawyer and turn around sue and insurance company, like you’re really gonna win.”

Community

Community Organization Services

Formula and Food, Testing, Hemoglobin, HIV testing

“The health department also does, like, STD testing and pap exams and that kind of thing.”

“There’s a women’s clinic and then there’s a dental clinic.”

The OB/GYN

Mental health section

“But there again, like I said, with Head Start, it’s real easy. I can always make a phone call, say we’re Head Start and – so those services for us are just a little different.”

“Well, lots of services, of course the comprehensive childcare that we have. Plus, we do physicals and dentals and mental health evals on children. We get them services for IAPs if they have disability of any kind.”

“One thing good with the Head Start program is if they don’t actually do that service under Head Start, like they would make referrals to First Steps, which sometimes would do occupational therapy and speech therapy and stuff like that with kids that need it.”

“I think some of the community, there’s just not enough ____ available, so you’re rushed in and out. So maybe if we have more services available, it’d feel kind of like they cared instead of just rush in and out, because we don’t always get that feeling.”

Extended Hours or Special clinics for Maternal and Child Health Needs are Needed

“We have one neurologist here in town, and I think he moved. “

If Participants Could Design a Perfect System it Would Include...

Cheap and affordable

Quality

New Hospital

“You want somebody who’s gonna – the follow up, too, can consistently follow up with you.”

“A different hospital. Not a privately owned hospital. They tend to run on their own agenda, and that’s a lot of the issues I think that they have here, is they’ve got a different agenda.”

“I’d like to see a good ER physician that would actually stay here, because the last one I went in, he didn’t even look at my daughter. He had the nurse look at her, and she had MRSA in her toe, and then I took her – he sent her home, said that she was fine, didn’t look at her though. I mean he stood where the curtain was pulled, on the other side, and peaked at her through that, didn’t even come up and even listen to her or anything.”

“Actually, I wrote a letter to the hospital, because I wasn’t too pleased with him. I’ve heard a lot of people that had problems with a specific doctor there. So, I’d just like to have a decent ER physician.”

What is the single most unmet health need in your opinion?

“A decent ER.”

“The variety. The – we don’t have a choice, we have one place, and it’s not adequate I mean.”

What are the most significant changes you’ve seen in the past five years?

“Went down the drain by far.”

“Well now one thing that I feel that we have been seeing is some new doctors coming into the area.”

“Another thing, too, not to just jump into of – but they are bringing some Columbia doctors are coming here now and seeing patients saving people that drive clear down to Columbia.”

“I’m very impressed with our OB/GYN specialty group that we have in town.”

Moberly Focus Group Analysis

Medical/Provider Relationships

Providers Who Accept Medicaid Plan

“Sometimes it takes days for my son’s prescriptions to get filled, just like her, but his is more of a mental thing. So he’s having breakdowns and being physically aggressive and it’s all because they just don’t want to accept that he has to take this medicine at this time and they’re just put – I’ve had weeks where he’s went without medicine and it’s not good for him to be without medicine, put him back on it, then have to – you know “

“So I mean as far as like personal services I think if you can get the right person it’s really good but like with my Medicaid they cut me off right before my six-week check-up, right before my six-week check-up.”

“Yeah, because they’ll say they’re taking new patients but they’re not taking new Medicaid patients.”

Confusion about Who Accepts Specific Plans for Specific Services

“I know when I was pregnant I had to have an echocardiogram done and I was on Medicaid and to get that echocardiogram – I’m diabetic so my doctor wanted an echocardiogram done. Well, Medicaid really don’t cover that. So I had to go through these numbers and then just call these people and call these people, get it set up. I mean it was just a fiasco trying just to figure out if Medicaid would cover it, you know, because I wasn’t gonna do it if I had to pay it out of pocket because that’s like \$400.”

“I kinda went through the same thing when I had my second son because we had to – when he was born he was fine but had a little bit of jaundice, but they still sent us home with the belly ribbon blanket. Well, miscommunication happened to where we’re having to pay for the blanket instead of the insurance because the hospital did not call and get confirmation from the insurance to pay for it. ”

“And with my two-year-old we just found out with him he’s got a speech and language delay, but before they would diagnose him I had to go through so many different office appointments to get him diagnosed so Medicaid would pay for it. And all the things that we are getting right now for him we’ve had to go through every single step before Medicaid would pay for it. ”

“I was able to get my birth control after I had twins because they ordered it, like, they had called it in and they didn’t have it. So they didn’t have it in stock, so I had to wait but by the time it got there and I couldn’t get it because my insurance wouldn’t cover it anymore. ”

Quality of Care

“I mean that sounds cruel, I mean but they will. They will hire anybody. Graduated last month, let’s go, you know, here we go. It’s by attrition and then they get their feet dirty in the practice and then they find somewhere else that’ll pay them more money, then they’re gone. I mean it’s just a high turn-over rate at the doctor’s office. ”

Preventative Health

“So they overlook real issues and then it creeps up later and it becomes a catastrophe, and so I think preventive – they have more preventive resources.”

School Nurse Help with Child Health Care

“Yes, but I had a middle-schooler last year and the nurse was very rarely ever there, and he was an asthma student, so there was no one there who could administer asthma medication in case of an emergency, so I would have to go pick him up from school. It was bad. ”

“I have a phone call from her on a regular basis”

Facing Special Health Care Challenges for Themselves and Their Families

“I have a daughter that’s at GBE and I have a son that’s at North Park, and both of them are special needs. My son’s got ADHD and bi-polar, so he’s on medication and my daughter has got a rare skin disorder. So just about anything that happens to her during the day, they call me about.”

“My son has cancer and we – it was hard getting a doctor to even look at him here because his pediatrician, he wanted to ignore us and brush us off on his concerns because he was – he’s too busy. He’s got a lot of people in his office and he’s more concerned about getting people in and out than actually taking time to listen to you. So we ended up having to take him to the Emergency Room here in Moberly just because that’s who’s going to listen to us, and then from there he was transferred to Columbia. And so we always have to drive to Columbia several times a month. He has scans and stuff that has to be done and he’s only five months old, so it’s really frustrating to kind of get him in and everything, and then there’s like nobody really knows about cancer and there’s nowhere for a real child with cancer in this town at all which kind of makes it more frustrating. ”

“My daughter’s got PKU, so when she was hospitalized she can’t have protein. So when they put her up there they couldn’t figure out why she wasn’t eating her food. Well, she couldn’t eat what they brought her and you’d tell them what she could have and they’d still write down, “Well, she can’t go home because she didn’t eat.” Well, she can’t have the bread, the hamburger and the french fries, and they were not getting it. So it’s just the hospital itself needs a makeover. ”

Health Education/Informational Resources

There are Some Good Prevention Services in the Community

“WIC does a wonderful job keeping me informed. ”

“Yeah, if it wasn’t for WIC, my poor son. He’d probably have been eating bananas when he was two months old. I mean WIC is amazing for me as a first mom. I mean I had no idea when to start him on milk, you know, just stupid little questions that you don’t even think of, they can help you out so much and I – I mean they’re just wonderful”

Transportation/Geographical Access

Transportation Services are Available

“I call a network on the back of Missouri Care Card and you schedule, you tell them the time, day of your appointment in Columbia or wherever outside of your region and then they’ll come pick me up and take my kid to the doctor, take me and my kid to the doctor and then when it’s time, I’m done, they’ll pick us up again.

“They do a gas mileage. I think it’s like 30 some months and some mileage, and we get \$24.00 just for driving down and back for my son’s appointments and then our cars broke down, so we have to do the transportation as well. We have to – basically like with those cars, I mean we get assessments.”

Some Services Require More Travel

“Yeah, it’s difficult to find specialties.”

Dental services are difficult in Moberly

“I have to go to Kansas City for my daughter just to get dental work done.”

“Yeah, there’s no pediatric dentists near here and there’s like three different ones in Columbia.”

“When my children were young I used the services here of the Health Department for the cleanings and screenings, but then as they got older and they had more complicated teeth issues like crowding or cavities, then I’d take them to Columbia and I’ve been with the same dentist in Columbia since.”

“Traveling to places like Columbia, St. Louis, and Kansas City is better.”

“And so we always have to drive to Columbia several times a month. He has scans and stuff that has to be done and he’s only five months old, so it’s really frustrating to kind of get him in and everything, and then there’s like nobody really knows about cancer and there’s nowhere for a real child with cancer in this town at all which kind of makes it more frustrating.”

“Mostly the kids, when we go to the doctors it comes down to if he gets asthma we might have to go to St. Louis or Kansas City for his appointments. So right now he’s waiting to get into chemo where it’s everything like that, so we have ongoing appointments.”

“My daughter’s dermatologist, if she – if he didn’t come back when he did we was gonna have to go to St. Louis every month.”

“Yeah, we almost had to take our son to Kansas City, I think, or St. Louis for his liver biopsy because the doctor was on vacation. So that’s lots of travel.”

Financial

Medicaid is difficult for adults to obtain if not pregnant—People cannot afford insurance, but they do not qualify for Medicaid.

“Well, me and my husband were both unemployed this summer and we still made too much on unemployment to get healthcare, which I thought that was kind of backward, you know.”

“I don’t have anything. My husband does because he’s disabled but I don’t have anything. I mean I only got it when I was pregnant for about six months afterwards. I’m like, ‘Okay.’”

“I have it through my work. I don’t receive insurance but it is offered at my work and it is almost \$300 a paycheck. I mean it is just an outrageous rate.”

“I know when I was pregnant I tried to get my teeth cleaned through the Medicaid program, and they did that but I have a bunch of – not a bunch, but I had a cavity and I mean it was just a mess trying to get something done about it, and I never did get anything done.”

“Another thing, I’m not sure how that all was working out but I know with my daughters I’ve experienced this here, like they put you on the Medicaid like if you’re pregnant then you get to go to that extent, and then they get you to this point and they drop you out. ”

“And if you ain’t got your birth controls and everything out your hand, you’re all, “Oops, here we come, we got another baby,” because they’re not covering it. So population and babies is flourishing, and that part I thought was very important that we need to get something and apply for that because and then when you go back for your six months check-up or however, then you go back and then we express, ‘Okay, your insurance don’t cover that.’”

“We only had the insurance for like a month after we had a baby, like some women have complications after they have the baby. My friend, like her C-Section, she got really infected and she had a really hard time getting them to extend it to continue to pay for her home healthcare, to come and pack her C-Section and, finally, the last time the lady came she was like, ‘Your husband is just gonna have to learn how to do it because your insurance won’t cover it anymore and I can’t come anymore.’”

“See and it’s also – I had a miscarriage in April and I had med leave from February 15 to April 1 when I had my miscarriage, and then I had six weeks after that. Then I got a letter in the mail saying since I had my miscarriage I got the women’s health plan extended program for a year that would pay for any birth control that I needed, any pap smears or mammograms, if I had any abnormal bleeding from the miscarriage they would pay for it, just anything with women’s health they would pay for for over a year after my miscarriage. ”

“So you keep on going and going but and then your health gets bad and you can’t work anymore. Well, then you qualify for stuff but in order to qualify you can’t work. So you can’t – you’re like stuck in a vicious circle you cannot get out of because you want to work but you can’t work because there’s something wrong with you.”

Medicaid is Easier to Obtain for Kids, but is Still Confusing at Times

“Then for my son, so far, we haven’t had to pay for anything for his cancer treatment. ”

“My son has asthma, and his breathing, they don’t pay for breathing treatments, or breathing machines for children his age or something. There was some stipulation. So I had to use – he’s using a choo-choo train at 14 that was – belonged to one of my younger children. So – yeah. So I called up in Columbia, I think it was Columbia Dental Care and they – I asked them, “What is your age limit of taking children?” They said three. And I explained to them what was going on and they got me right away. They got -- I called, I think, Friday and I have an appointment for the 20th. I mean it was like no issue whatsoever. Now when I get there it might be a different story but I mean I didn’t have any issue getting in.”

Out-of-Pocket Expenses Such as Co-Payment or Services not Covered

“There still co-pays go up, so of course there’s always a co-pay, and then with the dentist they don’t cover near as much dental-wise. ”

“Back to the last question, I do pay because I make so much money I should have to pay for a premium every month of \$21.00, which isn’t bad, you know, but I rarely ever take him to the doctor. We haven’t had to go to the doctor or anything but still I just wanted to add that in there. ”

Community

Community Organization Services

Poison control
Emergency room
Pediatrics

“Wal-mart’s got the plan where you get the birth control for \$4.00.”

“We started going to this place in Macon and they do it based on income. So we started going there, I had a whole bunch of health problems that couldn’t get fixed, and started going there, and they call it a charity program, but they do it based on your taxes and I got 100 percent health. I had a hysterectomy and everything. They finally figured out the whole problem and just fixed it.”

“At the health department I could get my blood pressure checked, you know, just different – just different blood counts. I keep my blood counts down and just they actually do yearlies too, which there’s a co-pay for that also.”

“And like if you have an issue with your child’s development, like they were concerned about my son has cancer, concerned about his development. His big motor skills were kind of delayed. They had actually filled out the paperwork to give an evaluation with the First Steps Program.”

“Plus I have my son enrolled in the Baby Biz Program out here and I love it. I absolutely love it because I’m – like I told you – I’m a first-time mom. I don’t know – I don’t know what they’re supposed to be doing at six months, you know, particularly, and they just come there and they say that he’s on track, he’s doing good with this but he’s delaying in this, you need to start working on this and focus in on this. I mean that’s just wonderful. I absolutely love it.”

“I was gonna say with Time For Tots I was really impressed last month when they brought the flu information.”

“I know a couple other steps that me and my daughters and my grandkids has done is not so much the smaller ones but basically me and my daughter went to change up some things. We started exercising. The Faith and Fitness program that they have from here is excellent, you know, give you a lot of information on good healthy eating, how to change up your eating habits. Since we’ve been walking and stuff blood pressure has gone down, everything is down, my bladder has gone down.”

“And programs get closed down that are actually really helping the community only because they’re like not for profit, like Open Arms was an awesome program.”

If Participants Could Design a Perfect System it Would Include...

“It’s free.”
Flexible with income

What are the most significant changes you’ve seen in the past five years?

“Went downhill”

Columbia Focus Group Analysis

Medical/Provider Relationships

Medicaid is a Very Valuable Resource

“My child kept catching everything that was in daycare, and she was coming back with colds and pneumonia, whooping cough, the RSV. She has severe asthma now all the time. We had to do the at home treatments. But everything, I didn’t really have, Medicaid covered all of it.

Everything I had, no questions about it, no problems. They paid for it all and showed me how, they brought somebody else in and showed me how to use all of the equipment, do the treatment and everything like that for her.”

Navigating Medicaid and other Social Services can be Difficult to Understand

“It’s been pretty easy for me. They cover a whole lot of things, Medicaid I mean I haven’t had any problems. What I would want is more information about it. It seems like you don’t know all the rules, well how long do I have Medicaid? When, they got different divisions. I mean we haven’t been able to figure it out when we went to the emergency room and there was two different kinds of Medicaid or something or other and they had billed it to the wrong one, and I know nothing about insurance.”

“I know when I first got pregnant I got insurance, they put me on Molina Healthcare and that was all the way in California. I mean I couldn’t find a doctor here.”

“After I was pregnant, they tried to take me off insurance, because I wouldn’t put him on child support. So they said that after my three months is up I don’t have any insurance. But I talked to a manager and she said as long as I am under 19, then I’m still going to get it.”

“Yeah, they told me the same thing that, they told me to put my child on child support because we don’t live together.”

“Well my mom has a lot of mental problems with us, and like seizures. And like some of her medicine costs like over \$300.00 and she just got approved for disability. So they took her Medicare away, so now she’s not able to pay for none of her medicine or nothing.”

“I think it’s weird how she has Medicaid and she goes to a doctor at the Boones Clinic or whatever, and she has to get her shots and everything at the Health Center. I mean it’s two totally different places.”

Finding Doctors who Accept Medicaid is Difficult (Especially Specialists)

“So then a lot of doctors aren’t accepting new patients because they have such a big load or whatever.”

“Cause I found, the doctors at the Family Health Center, they were fine, but as far as like her asthma needs and everything, I didn’t feel like taking her there ‘cause I had seen a specialist growing up and everything, and some of the things that had worked for me, they weren’t even recommending a thing. You know what I’m saying? So I wanted her to see a specialist that my whole family had seen, and he wasn’t accepting new patients either. He did finally agree to see her because he knew our whole family and everything, but it was going months and months before he could actually do that. And she would stop breathing at night. It wasn’t urgent enough to take her to the emergency room and be there all night, but it was just scaring me.”

“I know my, pregnant women insurance, it was, I had surgery when I was pregnant. I had to get a stint put in and taken out, and they would try to make me drive all the way to, where’d they make me drive, I think it Callaway County. Yeah, Callaway County to try to get it out. I couldn’t even ride, like it hurt just to ride somewhere. So I mean I had to drive 30 minutes down the highway to get a stint removed, I mean the doctor just did it, just so I wouldn’t have to ride, but I mean it was difficult.”

Dental Care is Difficult to Obtain with Medicaid

“I mean it’s good having it (dental coverage), but what’s the point of having it if nobody will take it.”

It is Difficult to Find Providers Who Accept Specific Private Insurance

“I have private insurance that my employer pays for, but my husband is self-employed, and so he and my son have their own insurance we pay for privately. And we, when we were looking for a pediatrician we found several who wouldn’t take the one that he was signed up for. And then after he was born, we found out insurance wouldn’t cover him for 90 days. So we just got a bill from the pediatrician for quite a bit of money for his preventative care, immunizations and stuff that his insurance won’t cover for that 90 days.”

Transportation/Geographic Access

Dental Services Require the Most Travel

“My clients to go to the dental school in Kansas City.”

Specialty Care Requires Longer Distances

“He had to go all the way to St. Louis to see our network provider, we didn’t know if that was an option to even see a different doctor out of town.”

Health Education/Informational Resources

WIC is a Well-Used and Well-Respected Resource

“I did WIC from there. I don’t know if any other mothers went there. They taught me to make, like healthy stuff for like teens and young people. And when she was born, like they do things, gave me baby food, like rice, oatmeal, stuff like that, her milk.”

“That formula from WIC is wonderful. I don’t know what I had. She has to be on a special formula (hypoallergenic), and I don’t know what I would do without WIC.”

Word of Mouth is a Popular Way to Receive Health Information

Financial

There are Many Out-of-Pocket Costs that are not Covered by Insurance or Medicaid

“When you get your prescriptions, like sometimes they say that they’ll total the prescriptions, and then when you go in you have to pay like a co-pay or more than what you actual thought you were going to pay.”

“Everything’s generic for Medicaid, and one thing, there’s one pain killer that they gave me was generic and I was allergic to it, so Medicaid would not pay for it.”

There is a Gap Between Medicaid Income Requirements and Being Able to Afford Insurance

“I mean my mom had a job, and it was over the table. We can’t afford. That’s a big difference, you paying for insurance. We didn’t qualify for Medicaid but we couldn’t afford private insurance.”

Community

Childcare and Headstart Services are Valuable

“My daughter goes to the Head Start in Bear Creek. And they, the lady talked with me before I had my daughter.”

“The lady that works at her daycare came with me through my whole pregnancy taught me stuff, just got safe with me, and stuff like that.”

“(She talked to me) about my health and her health afterwards, what we wanted during labor, and everything else.”

Some Participants Found Other Services Difficult to Access

“Some parents have tried parents as teachers but have had some issues.”

“Parents as Teachers was difficult because they were non responsive. When they finally did respond it was too late.”

Family Health Center is a Good Resource, but it has Some Issues

“I like the Family Health Center. I just didn’t like the fact that the doctors keep changing. They have students there, so since my daughter has been born, I’ve had like five different doctors. So, consistency would have been helpful. And then to make an appointment, is it’s the hardest she had pneumonia and whooping cough. The Family Health Center didn’t, like she got out in May. They’re just now seeing her now to follow up appointment. I needed for her to go to a different, a specialist, because it just, it just took so long. I would feel she was at home still breathing and wheezing. So it’s just hard to get an appointment there.”

“I feel like the well checks are done by different doctors every month. So I really didn’t do them. You couldn’t compare it was a whole different doctor. But, other than that it’s been pretty cool. Some of the doctors are good my daughter had an allergic reaction to a certain lotion that I was using and they told me about that.”

Other Resources were Popular and Well-Respected

Open Arms
LaLeche

Poor Customer Service is an Issue

Qualities of a Perfect Health Care System

Quality care
Health care before and after pregnancy
Employer insurance coverage for families of employees
Transitional programs for people moving from Medicaid to private insurance
More information about Medicaid and how it works
24-Hour health information phone line
Free health care
Free dental care

What is the Greatest Unmet Need?

- Dental
- Prescription coverage
- Follow up care
- Mental health

Sedalia (Hispanic) Focus Group Analysis Medical/Provider Relationships

Providers Who Accept Medicaid Plan

“What I think is – There’s a difference when they take care of people. She says that some people they do see, you know, faster than others. With Hispanics – and I see where she’s coming from – with Hispanics, if you know the person that’s translating or the caseworker, you get in faster and it’s a lot friendlier.”

“Her husband got upset because he went to apply for Medicaid and he – it looked like they wanted to deny him because he wasn’t a citizen, but she took all the documentation that he was. She says that the lady – She says, “Just because we have colored skin that we haven’t – you know, we’re Hispanics, they wanna cut us off.” She says, “I wanted to apply also to see for myself and my kids, because we’re all residents.”

Confusion about Who Accepts Specific Plans for Specific Services

“And we had to go to the hospital there, and my daughter ended up having to get IVs and fluids and everything else ‘cause she was so dehydrated, but the medical – it was weird. When we came from Minnesota, our medical transferred over for emergency situations. Now, in Missouri, that Medicaid does not transfer over, so right now I have \$25,000.00 in medical bills up in Minnesota because the Medicaid did not cover the emergency care up there.”

Quality of Care

“A lot of people, you know, just won’t anything nice to say about the hospital here. They would rather go to Warrensburg. I actually had an episode. I went to the emergency room with my daughter, and she had fractured her wrist, and five hours’ wait. And there was – the whole room was full, 32 people, and they only have 12 beds. They were all full, so I went to Marshall.”

“She says she had an episode that she got bit by a spider, and she went to the hospital, and they gave her a – I guess some sort of cream or something that it wasn’t for that, too.”

“We’ve had several incidences, and I know part of it is their beside manner is horrible. I’ve had incidences where they glued my son’s eye shut, and one time I had been in and out of there for four months because I had been so sick, and they kept trying to tell me, “Quit coming back for the flu.” And I’m like, “Well, you can’t have the flu for four months.” Come to find out, I finally got a proper doctor who referred me over to a surgeon, and it ended up being my gallbladder.”

“Well, a little bit of that I can relate, because I was real sick, and they have a new policy that they can only treat you for two things, and then you have to make another appointment. So, like, I have been having chest pain and like dizziness in my head, and they counted that as two, so even though I hadn’t slept in four days, had not – zero sleep in four days, which I have a – you know, sleep apnea.”

“It’s took me four years to get on the medications that I should’ve been on four years ago.”

“Yeah, I always make sure I don’t go to Katy Trail. When I went, they say my appointment is for 9:30. They didn’t take me in until 12:00, and even though that I had that paper that say, “If you’ve been waiting more than 15 to 30 minutes, let them know,” they keep on – a they’re real snotty, and I’m the type of person, if you’re snotty .”

“I think that because I had a small hole when I moved out from Boston a year ago, and I’ve been telling them the hole is getting bigger. They waited until my teeth broke in half. My mouth got so swollen. Unless they were able to tell me I had to get it pulled out, and then, like, I’ve been telling you for the past couple weeks my mouth has been swollen.”

“And without – I’ve had two abscessed teeth. The one broke, exposed a nerve. I was at Boswell. My blood pressure was 156 over 98. They sent me home with it like that. I started vomiting blood. My mother ended up driving me all the way to Kansas City, and they said I should’ve never, ever, ever have been released.”

“Well, the day that I went to the emergency room at Boswell, it looked like a third-world country. There was another girl that she got her arm caught between the boat and the dock, and her arm was in a zigzag. She had been there for five hours.”

“When I had kidney stone and I went right after Thanksgiving last year, I was telling her, “I’m about to pass out, pass out.” “Oh, just go ahead and just wait,” and there was like 20 people there, and then I did pass out, ‘cause one of the girls from here, she told the nurse, “Oh, she passed out.” And then, that’s when they was able to attend me and put me in the room ‘cause I started throwing up, too.”

Limited Care

“When I got sick, when I got that episode – the ambulance would take me two and three times a week. She says that they gave me some sort of medication. They were big, white pills, and to the point she was really dizzy and not coherent at all. She said she almost crawled to the kitchen to be able to get stuff to eat when she was hungry. So, she doesn’t think that – in other words, experience.”

“No, no WIC, in Pettis County. She says that they have made the appointment. They said they were gonna charge me \$70.00. That’s why I didn’t go.”

Health Education/Informational Resources

A variety of sources were cited regarding health education and information

WIC

University Program

“There is a mother-and-daughter team that worked for the university, too, that they cover nutrition, and they go visit the families and tell ‘em about it.”

Financial

Having Insurance or Medicaid

“Another thing that’s goin’ on with the insurance companies, legally or illegally or citizens – She says that they only give Medicaid or Medicare to the people that are \$7,000.00. That’s the catch. That’s the limit that they have, you know.”

Medicaid is difficult for adults to obtain if not pregnant—People cannot afford insurance, but they do not qualify for Medicaid

“She says, “I think that, you know – what I think is that they should make some sort of like a bracket or something for those kind of people to get some sort of Medicaid or, you know, kind of insurance.” She is saying that why is it that women that are pregnant get emergency Medicaid and those – I mean, do you have to be – do you have to get pregnant to get, you know –?”

“And it took me four years to get medical help when I became disabled.”

Medicaid is easier to obtain for kids, but is still confusing at times

“What I don’t understand is when I worked, I got Medicaid. I get it now again after I got hurt and injured, but when I was first stopped and I didn’t accept any cash help or anything like that – I was just living off of only the little bit of child support I got. I got cut from my Medicaid when I pulled in almost \$600.00 less a month, and then when my son got disability, they cut me again. And I’m like, “But, disability isn’t supposed to be for you. You’re not supposed to be using that toward your bills to go to the doctor. You’re supposed to be using that for that child.” And there was a big lapse missing, ‘cause I barely pulled in – I was pulling in \$362.00 a month when I first started after everything happened, when I had to quit work and too much to qualify for Medicaid for myself.”

“We even went to a doctor in Columbia, and they didn’t – still wouldn’t give it to him.” He crawls because he’s in such pain, but he doesn’t have – Even with his job, they don’t wanna give him disability. She says that she was – and in the letter that they submit from their work to her, to her husband, it says because of code such and such, and we cannot give you .”

“My Husband can’t get it but our kids are covered.”

Out-of-Pocket Expenses Such as Co-Payment or Services not Covered

“She says that she gets sick very frequently. She says that she is afraid to go to the hospital, because sometimes they say, “We can’t put \$200.00 down,” you know, they won’t take care of it. She said – She said that one time after she went to the hospital that time that – she said that they had to put \$200.00 down. She got another episode that she just blanks out, so the last thing that she saw was the, you know, paramedics people in front of her, and she remembered back to the \$200.00. And the lady said, “Are you okay?”

“Nobody charges me a co-pay but Katy Trail. My caseworker don’t know why Katy Trail charges me a co-pay ‘cause I live on –\$202.00 a month. You know, that covers my lights, gas and running water. She says that when she goes to Katy Trail, they ask her for the \$50.00 up front, and then before she leaves that day, the rest of it will be \$50.00 or \$70.00. That’s what she’s paid to go to Katy Trail.”

“First they tell you you’re paying only \$15.00 for that consultation, but then you receive a bill of 100 plus dollars.”

“And so, you would think that they would help you out, and – She says it’s \$50.00 just to get the pap smear, and it used to be free, which I know that’s true, because even Yolanda had, and they’re all agreeing, they used to get it for free, and their breast exam once a year free. Not anymore, right?”

“No, no WIC, in Pettis County. Uh-huh. She says that they have made the appointment. They said they were gonna charge me \$70.00. That’s why I didn’t go.”

Community

Community Organization Services

“The only thing I don’t like about that, I guess, that facility is the women that translate in that facility saw your business.”

“She’s talking about Katy Trail now, that that facility is geared more towards children, that when it comes to adult medical services – Medical is Medicaid. She says that for the elderly and, you know, the ones that have Medicaid and just low income, they – she sees that there is only the Americans, the Anglos that are being treated, you know. But, she says, “I feel that we don’t get the proper medication and things like that, ‘cause if we have like a sore throat or anything like that, they say, ‘Oh, you’ll be done with it in five days.’” You know, and they’re not getting the right medic. She says, “Then, if you don’t give the right, you know, medication, how do you expect that person to get well? And also, you know, they are waiting for you to get worse so then they could treat you.”

“I actually go to, like, a Hispanic clinic”

What is the single most unmet health need in your opinion?

“Dental is horrible.”

Survey Results

At the end of each focus group participants were given a survey on which they could report additional information that may or may not have been discussed during the course of the focus group. The survey was completed by 143 participants from the focus groups. Below is a summary of the results from the surveys.

Demographics

Gender

Gender	Number (Percentage)
Female	127 (89%)
Male	15 (11%)

Age

Age Category	Number (Percentage)
12-20 years of age	24 (17%)
21-44 years of age	96 (66%)
45+ years of age	24 (17%)

Race

Race	Number (Percentage)
African American	59 (42%)
White	68 (49%)
Asian	2 (1.4%)
Other	10 (7%)

Ethnicity

Ethnicity	Number (Percentage)
Hispanic	17 (12%)
Non-Hispanic	126 (88%)

Language Spoken at Home

Language	Number (Percentage)
English	130 (91%)
Spanish	8 (6%)
Both English and Spanish	3 (2%)

Average Number of Children by Age

Age of Children	Average Number in Participant Household
0-5 years	1.08
6-11 years	0.41
12-20 years	0.38
21+ years	0.16
Total number of children	1.99

Response Summaries

The following section summarizes the survey participant responses to all survey questions.

Number of respondents who report agreement with the statement: My family/I have faced serious health problems within the past year.

Response	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Number (Percentage)	38 (25%)	32 (22%)	36 (25%)	24 (17%)	16 (11%)

Respondents were asked to check whether or not they had needed services in the past year and whether or not they knew where to get those services in their own communities.

	Number (percentage) of Respondents Who Need Now (✓)	Number (percentage) of Respondents Who Have Used in the Past Year (✓)	Number (percentage) of Respondents Who do not need (✓)	Percentage who know where to get this service in his/her community (✓)
Prenatal or pregnancy care	12 (8%)	44 (31%)	65 (45%)	56%
Childbirth facilities, delivery of a baby	12 (8%)	41 (29%)	64 (45%)	63%
General medical care for colds, flu, fevers, coughs, injuries, allergies, etc.	43 (30%)	66 (46%)	14 (10%)	60%
Childhood immunizations	33 (23%)	50 (35%)	27 (19%)	63%
Breast cancer screening	31 (22%)	23 (15%)	59 (41%)	47%
Pap smear (cervical cancer screening)	40 (28%)	49 (34%)	28 (20%)	57%
Vision care, eyeglasses or hearing for children	48 (34%)	31 (22%)	33 (23%)	50%
Dental care	81 (57%)	34 (24%)	10 (7%)	45%
Women Infants Children (WIC)	32 (22%)	35 (24%)	44 (31%)	60%
Food stamps	39 (27%)	32 (22%)	41 (29%)	64%
Temporary Assistance	26 (18%)	18 (13%)	67 (47%)	56%
Family Planning, birth control	25 (17%)	29 (20%)	62 (43%)	58%
Cancer Care	13 (9%)	3 (2%)	96 (67%)	39%
HIV/AIDS care	5 (3%)	4 (3%)	102 (71%)	43%
Testing and care for sexually transmitted diseases (i.e.: Chlamydia, gonorrhea, syphilis, etc.)	9 (6%)	20 (14%)	80 (56%)	50%
Smoking cessation treatment	16 (11%)	5 (3%)	98 (69%)	24%
Specialized health care needs (such as speech therapy)	21 (15%)	10 (7%)	77 (54%)	25%

Respondents were asked how they pay for the following health services.

	Number who use Private Insurance (✓)	Number who use Medicare/Medicaid (✓)	Number who pay Out of pocket (✓)	Number who report needing this service, but cannot afford to pay (✓)	Number who report they do not need (✓)
Prenatal and pregnancy care	16 (11%)	50 (35%)	8 (6%)	3 (2%)	77 (54%)
Childbirth facilities, delivery of babies	14 (10%)	47 (33%)	5 (3%)	4 (3%)	77 (54%)
General medical care for colds, flu, fevers, coughs, injuries, allergies, etc.	36 (25%)	56 (39%)	31 (22%)	25 (17%)	13 (9%)
Childhood immunizations	19 (13%)	71 (50%)	8 (6%)	12 (8%)	34 (24%)
Breast cancer screening	22 (15%)	30 (21%)	10 (7%)	14 (10%)	59 (41%)
Pap smear (cervical cancer screening)	31 (22%)	51 (34%)	19 (13%)	19 (13%)	22 (15%)
Vision care, eyeglasses or hearing for children	21 (15%)	49 (34%)	29 (20%)	22 (15%)	28 (10%)
Dental care	33 (23%)	40 (28%)	30 (21%)	40 (28%)	9 (6%)
Family Planning, birth control	20 (14%)	40 (28%)	14 (10%)	12 (8%)	57 (40%)
Cancer care	8 (6%)	16 (11%)	1 (1%)	7 (5%)	106 (74%)
HIV/AIDS care	5 (3%)	12 (8%)	1 (1%)	6 (4%)	114 (80%)
Testing and care for sexually transmitted diseases	13 (9%)	30 (21%)	10 (7%)	10 (7%)	80 (56%)
Smoking cessation treatment	4 (3%)	6 (4%)	7 (5%)	8 (6%)	111 (78%)
Specialized healthcare needs	19(13%)	28 (20%)	10 (7%)	15 (10%)	68 (48%)

Respondents were asked where they go to get the following health services?

	Number (Percentage) who report Private physician (doctor) (✓)	Number (Percentage) who report Community Clinic (✓)	Number (Percentage) who report Health Department (✓)	Number (Percentage) who report Emergency Room (✓)	Number (Percentage) who report Other (✓)	Number (Percentage) who report they Don't know/ unsure (✓)	Number (Percentage) who report they do not need (✓)
Prenatal and pregnancy care	51 (36%)	14 (10%)	6 (4%)	0 (0%)	3 (2%)	4 (3%)	62 (43%)
Childbirth facilities, delivery of babies	52 (36%)	3 (2%)	2 (1%)	9 (6%)	4 (3%)	4 (3%)	66 (46%)
General medical care for colds, flu, fevers, coughs, injuries, allergies, etc.	70 (49%)	36 (25%)	16 (11%)	16 (11%)	6 (4%)	6 (4%)	9 (6%)
Childhood immunizations	51 (36%)	28 (20%)	29 (20%)	2 (1%)	2 (1%)	6 (4%)	29 (20%)
Breast cancer screening	39 (27%)	20 (14%)	3 (2%)	2 (1%)	2 (1%)	23 (16%)	50 (35%)
Pap smear (cervical cancer screening)	69 (48%)	33 (23%)	11 (8%)	0 (0%)	1 (1%)	13 (9%)	15 (10%)
Vision care, eyeglasses	68 (48%)	22 (15%)	3 (2%)	2 (1%)	11 (8%)	25 (17%)	16 (11%)

or hearing for children							
Dental care	62 (43%)	31 (22%)	5 (3%)	1 (1%)	6 (4%)	30 (21%)	7 (5%)
Family Planning, birth control	42 (29%)	29 (20%)	11 (8%)	0 (0%)	1 (1%)	7 (5%)	54 (38%)
Cancer care	14 (10%)	4 (3%)	3 (2%)	1 (1%)	1 (1%)	12 (8%)	100 (70%)
HIV/AIDS care	10 (7%)	7 (5%)	4 (3%)	1 (1%)	1 (1%)	6 (4%)	109 (76%)
Testing and care for sexually transmitted diseases	21 (15%)	27 (19%)	10 (7%)	0 (0%)	1 (1%)	7 (5%)	76 (53%)
Smoking cessation treatment	6 (4%)	6 (4%)	2 (1%)	0 (0%)	3 (2%)	13 (9%)	107 (75%)
Specialized healthcare needs	24 (17%)	12 (8%)	3 (2%)	5 (3%)	9 (6%)	10 (7%)	80 (56%)

Respondents were asked where they would go in their community to learn general information about the health of their children.

Where respondents would go for health information	Number (Percentage)
Doctor	110 (77%)
Local health department	64 (45%)
Friends	60 (42%)
Relatives	53 (37%)
Nurse or nurse practitioner	51 (36%)
Community based agency	35 (24%)
School nurse	17 (12%)
Other	16 (11%)

Respondents were asked if they had a child with a disability or special health care needs. If they answered yes they were asked to specify what type of special health care need.

Response	Number (Percentage)
Yes	29 (20%)
No	114 (79%)

Types of Special Health Care Needs
speech therapy
ADHD and social disorder
rare skin disorder and ADHD /BiPolar/OCD/Sensory Disorder
neuroblastoma cancer
developmental delays
ADHD/ADD, GAD, Depression
Hemanogioma of face

sickle cell disease
asthma, severe allergies
mental health issues
prune belly syndrome, kidney disease, club feet & urological issues
asthma, allergies
asthma
ADHD
asthma
heart murmur
traumatic brain injury
autism
speech care
seizures
developmentally delayed and has PKU
sensory integration disorder
speech, vision
learning disability
both sons have chronic ear infections, one has severe allergies, both have tubes in ears
severe asthma
developmental delay
ADD

Respondents were asked if their family had health insurance coverage.

Response	Number (Percentage)
Yes, all of my family is covered	69 (48%)
Some members of my family are covered	64 (45%)
Children, but not adults	42 (66%)
Adults, but not children	6 (9%)
Other combination	13 (20%)
No one in my family has health insurance	9 (6%)

If respondents had health insurance, they were asked to report which type of insurance.

Type of Insurance	Number (Percentage)
Private insurance	41 (29%)
Medicaid	82 (57%)
Other health insurance	5 (3%)

If respondents had health insurance, they were asked to report which of the following benefits were covered by their insurance.

	Number (Percentage) who are covered by Private insurance (✓)	Number (Percentage) who are covered by Medicaid (✓)	Number (Percentage) who are covered by Other insurance (✓)	Number (Percentage) who do not know (✓)
Preventive/primary medical care	39 (27%)	60 (42%)	4 (3%)	17 (12%)
Medical care for infectious diseases including prescription drugs for treatment	38 (27%)	58 (41%)	3 (2%)	25 (17%)
Prenatal care	29 (20%)	52 (36%)	2 (1%)	36 (25%)
Family planning, birth control	30 (21%)	49 (34%)	3 (2%)	34 (24%)
Childhood immunizations	26 (18%)	70 (49%)	2 (1%)	22 (15%)
Breast cancer screening	28 (20%)	30 (21%)	3 (2%)	53 (37%)
Vision and hearing screening for children	26 (18%)	56 (39%)	5 (3%)	33 (23%)
Dental services for women and children	30 (21%)	54 (38%)	5 (3%)	36 (25%)
Smoking cessation	10 (7%)	10 (7%)	3 (2%)	83 (58%)
Specialized benefits for children with “special health care needs”	14 (10%)	32 (22%)	1 (1%)	65 (45%)
Mental Health Services	21 (15%)	28 (20%)	2 (1%)	63 (44%)

Respondents who reported not having coverage for all members of their family were asked to report why they do not currently have health insurance/Medicaid.

Response	Number (Percentage)
Cannot afford it	42 (29%)
Don't Need It	1 (1%)
Do not qualify	41 (29%)
Other	6 (4%)

Recommendations

Based on the consumer focus groups, consumer surveys, and provider focus groups the following areas should be addressed in future maternal and child health initiatives.

- 1) The greatest difficulties expressed surround **insufficient coverage by Medicaid**. Providers and consumers alike described difficulties consumers have finding providers who accept their specific plan, lack of specialty care covered by Medicaid, out-of-pocket expenses that are not covered, and the difficulties even being covered by Medicaid if not a child or pregnant. These issues need particular attention, especially an increase in general and specialty providers who accept a variety of Medicaid plans is needed. The gaps in the current system lead many adults and sometimes children to go without healthcare because that care is not covered or it is too difficult to obtain. In addition to not being able to find providers who accept Medicaid, many who do accept a Medicaid plan are not taking new Medicaid patients. Lastly, assisting consumers with out-of-pocket expenses like eyeglasses, large co-payments, dental health, over-the-counter medical supplies and some prescriptions will improve the health of children and families.
- 2) A close second to insufficient Medicaid coverage is the **complexity of Medicaid**. This complexity leads parents to delay care for their children while they are figuring out the system, parents must take multiple days off from work in order to take a child to multiple providers to get the needed health care, providers have difficulty knowing what is on the formulary for a particular patient's payer and some parents are not able to obtain care for children because they cannot figure out a reasonable way to access the needed health care. While increasing the providers who accept Medicaid may be difficult, helping consumers navigate the difficulties of the Medicaid system may be a more feasible area to improve their experience. Consumers felt that current print materials are often out of date and many electronic venues were complex. A simple, website that helps consumers find providers who will accept their Medicaid/insurance plan was a request heard at multiple focus groups. An ombudsperson whose services are widely advertised to assist clients with the process could help clients obtain healthcare more readily.
- 3) **Obtaining and tracking immunizations** were difficulties expressed by participants in provider and consumer focus groups. The consumers felt that immunizations required them to have a second appointment beyond their initial healthcare appointment since they are given at local public health agencies. Providers felt that consumers did not always know which immunizations they needed for their children, and that consumers had difficulties keeping track of immunizations. Providers in both the rural and urban focus groups expressed that it seemed something like the MOHSAIC system should work to help with tracking, but that it had not worked at all. They had not been trained, people were not using it, and it did not assist them in tracking childhood immunizations. Enhancing the training, user-friendliness, and the frequency with which MOHSAIC is used could assist with this problem. Whether enhancing MOHSAIC use or another strategy is used, increasing education about immunizations and enhancing tracking should be undertaken.
- 4) **Enhancing school nurse services** is a potential avenue that should be explored. School nurses received overall favorable reviews from providers and consumers, however the limitations on their time were acknowledged by both groups. Providers felt that closer linkages between schools and health care providers via school nurses could enhance maternal and child health. Immunizations could be given and tracked in schools. Nurses could make referrals to healthcare providers. Other health education programs could enhance maternal and child health by bringing

those prevention services into schools. While urban providers discussed this avenue, the rural providers expressed more excitement for the potential of enhancing the services of school nurses.

- 5) **Health education and policy change are needed to enhance maternal and child health.** Particularly in the areas of nutrition, physical activity, obesity prevention, family planning, STD prevention and teenage pregnancy prevention. Urban and rural providers identified these areas as needs they see among their consumers. Providers felt that this education was vital to enhance maternal and child health. However, providers also expressed an understanding of the need for policy changes that will enhance these social and behavioral determinants of health. Increased access to healthy foods, more comprehensive sex education in schools and more physical activity in the school day are all policy changes discussed by providers that would help to enhance maternal and child health. Additionally, using existing networks to distribute health education information has great potential. Many consumers are obtaining information from doctors, friends, family, and current social service agency staff with whom they already interact. Ensuring that those individuals are educated and know how to educate the consumers can enhance the knowledge of parents.
- 6) **Dental care, mental healthcare, & vision/eye care were described as the most unmet healthcare needs** in the community by consumers. These were the services that they were least likely to be able to obtain, have the most difficulty paying for, and for which they sacrificed the most quality of care. Assisting families in obtaining quality dental, mental and vision/eye care should be among the top priorities.
- 7) **Healthcare should be provided in more outreach settings.** Consumers and providers offered many solutions that fall under the heading of more outreach healthcare. Breast cancer screening vans, STD screening vans, healthcare in schools, use of mass media for health education, and other outreach solutions were cited as ways to improve maternal and child health.
- 8) **Parents of children with special healthcare needs need additional assistance navigating the complex healthcare system.** While all consumers reported difficulties navigating certain aspects of the current healthcare system these issues are exacerbated for parents of children with special healthcare needs. They are interacting with the system more and run into obstacles more frequently. While many parents of children with special healthcare needs had learned much about the system, they also told many of the most frustrating stories of their experiences. Additional support should be offered to these parents.
- 9) **Migrant and Spanish speaking patients face special challenges and need special services.** They have language, cultural, and immigration status issues that require special expertise on the part of the health care system. In particular, migrant consumers face difficulties when they move from one state to another and their healthcare coverage changes. Specially trained staff members to assist migrant and Spanish speaking consumers are needed at the local level to ensure that consumers are receiving all services that are available to them. Fear of government is a barrier to documented and undocumented consumers of health care that should be addressed.
- 10) **Perceptions of quality of care should be addressed.** Consumers in English and Spanish speaking groups expressed that they felt they received lower quality of care when visiting facilities that accept Medicaid or otherwise serve a lower income population. Improving quality of care and patient perceptions of the quality of care should be a priority.

- 11) **Transportation to healthcare appointments could be improved.** Consumers in general felt that it was good to have transportation covered by Medicaid, and they also understood the difficulties that running such a program presents. However, they still found it frustrating to arrange the transportation several days in advance and to sometimes not be picked up by the transportation service. Continuing to improve this service would enhance access to healthcare by Medicaid covered consumers. Additionally, expanding the service so that consumers not covered by Medicaid could utilize it would increase access.
- 12) **Cultural competency of healthcare providers and all facility staff should be addressed.** Language issues, cultural differences, religious backgrounds, and other cultural issues present challenges in the health care environment. Ensuring that providers understand how to address these differences in a sensitive manner is an important step.

Lessons Learned & Summary

Lessons Learned

Recruitment for focus groups was more successful when we were able to either attend an existing group of individuals who meet on a regular basis (support groups, staff meetings, etc.) or when we had a local advocate who helped to recruit participants face-to-face. Given that these contacts make recruitment much easier, future contracts should consider incentive for those contacts in addition to participants.

The incentives used for recruitment were a challenge that we were eventually able to overcome. Incentives must be chosen carefully to meet the requirements of the Department of Health & Senior Services and to be an incentive that helps to recruit participants effectively. Grocery store gift certificates best meet all of the criteria when the store is willing to print needed restrictions on the certificates. The variety of locations made the different grocery stores a challenge, but it is worth the additional work on the contractor's part.

We gathered a significant amount of data via a survey at the focus groups. However, the focus group discussion provided much richer information for the needs assessment. A shorter survey to collect demographic information and to provide the opportunity for participants to write down thoughts that were not discussed is sufficient for this needs assessment. A rich discussion provides much more valuable information than did the survey.

Participants stated at many of the focus groups that they really appreciated the opportunity to talk to other participants and to learn from their experiences. They often shared tips regarding places where they received health care or had negative experiences validated by other participants. In addition to getting the change to talk with each other they appreciated the opportunity to provide feedback to the state.

Summary

This report provides a summary of issues faced by residents of Missouri when attempting to protect and restore their health and the health of their children as they were presented by our participants in our focus groups. We hope that this information will provide important guidance to the Department of Health & Senior Services as they plan for the upcoming grant period. Participants are facing important issues regarding access to services, relationships with providers, transportation, health education, and community services. They shared very compelling stories to support their requests for changes in the current state of service provision. While many of their issues may not be fully addressed in the next grant period we hope that this document provides guidance in helping to begin to address them.