



A Crisis of Care

The community's perspective on health care in St. Louis City

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[Introduction]

“We made a home visit on a family in north St. Louis...because they had missed preventive care. And when the home health worker went into the home, she found the mother was there with many children. The mother was suffering from postpartum depression. The baby was on a [respirator] and the house was rat infested. They had no electricity for the baby, so they were stealing electricity from the neighbor to be able to support the baby’s life support. Obviously they were in health crisis in more than one [way]...but she didn’t know where to begin. There were so many layers to peel away from this family that to get to their health care...and they definitely had health care needs.”

The health care industry in this nation is well known for its benefits but also its problems. While this is also true locally, St. Louis City has often been nationally recognized when it comes to health care resources. The City is home to two medical schools and several nationally recognized hospitals. The City also provides care to residents through 20 different sites associated with Federally Qualified Health Centers, ConnectCare, or private health centers or physicians.

Yet, even with such excellent resources, the City of St. Louis has problems that place it below national norms on many health indicators. Rates of heart disease, stroke and cancer, the nation’s leading causes of death, are higher in St. Louis than in the rest of the state and the nation as a whole. In addition to the chronic conditions, St. Louis has a higher death rate from infectious diseases, such as pneumonia and influenza, than the nation. AIDS is the tenth leading cause of death in St. Louis but is not on the national list of the ten leading causes of death. [See table in Appendix.]

What follows is a report on the impressions of St. Louis City residents as to why health care delivery continues to fail them. In the report, we “peel away the layers” of health care access and quality and demonstrate health care’s troubled infrastructure and its interrelatedness to the fundamental aspects of life in the City. Residents’ views are highlighted through a fictional account of one family’s attempts to access care. This story is documented with the actual experiences of City residents expressed in their own words through a series of focus groups conducted by the Saint Louis University School of Public Health and a telephone survey performed by HarrisInteractive (HI) of New York. Information about these methods is provided at the conclusion of the report. [See Appendix.]

HI Survey Results: *St. Louis residents are more likely than U.S. residents overall to report fair or poor health and to have higher rates of asthma, diabetes, heart disease, and high blood pressure.*



Sylvia Evans is a single mother on a limited income. Right now, her seven year-old daughter Nicole is having an asthma attack. These have been more common lately and it frightens her when her daughter is unable to breathe. This one came on when she started chasing her little brother Jimmy after he pulled her hair. Sylvia stays poised, ready to call 911 if it gets too bad. Medicaid pays for most things, but actually getting her care can still be a difficult process. She runs her fingers through Nicole's hair in an effort to calm her and help her catch her breath. Her inhaler hasn't been as helpful lately. She hopes Nicole's asthma isn't getting worse.

POVERTY

The greatest barrier that St. Louisians perceived as preventing individuals and families from receiving care is poverty. St. Louis residents understood that poverty resulted most immediately in the inability to pay for care and insurance. But they also indicated that it is a more encompassing circumstance that affects one's opportunities for education, housing, and employment as well as health services. One individual aptly described living in poverty as living in crisis.

"You know, that's one of the things you just go without. It's like either you buy bread or you buy milk. Or, you know, you pay the light bill or you send little Timmy to the doctor."

HI Survey Result: *The poor (those below the federal poverty level) consistently indicated that they experienced barriers to care more frequently than the near-poor or those with more resources. These barriers included a failure to receive needed primary or specialty care, the need to postpone care due to its cost, lapses or cutbacks on medication, lack of coverage, difficulties making co-payments when using services, unfair treatment, and disrespect.*

Nicole's breath calms. She says that she is fine. Her coughing fit says otherwise. Sylvia decides a doctor is necessary after all. And so the debate begins: health center or hospital emergency room? It is 10 A.M. on a Thursday and both will already have begun to fill up. An ambulance is faster than a bus, but now that the attack is over it might mean a fight with Medicaid over who pays. The health center will be a long wait. The ER will be a long wait. Nicole's doctor is at the health center. But who knows if he will be at their site today, or if he is even available. The ER could mean a new medicine for Nicole and faster service. Time is of the essence. Sylvia decides to compromise. She'll take the bus to the ER.

LONG WAITS AND CAPACITY

One of the biggest issues identified by residents of the City is waiting to get health care. They describe long wait times as a two-fold problem: waiting to get an appointment with a health care provider, and waiting to receive care in a health center or emergency room after arrival. Participants recognized that the health centers were limited in the amount of services they could provide because of limited budgets and personnel. They believed, however, that the timeliness of service could be improved. Emergency rooms were perceived as having shorter wait times to receive service, but longer wait times were also described.

"You know, it's months down the line to get an appointment into the hospital for the referral, you know."

"I have one woman that had a child in a sickle cell crisis and she had had her appointment for the dentist for that same day, and it was a choice. And I told her, 'If you don't go now, that's it. You'll never get it again. I mean, this is miraculous that you even have an appointment.' Go to the dentist or your child? She says, she put up with the pain so far, 'I've got a sickle cell crisis; I've got to get her in.' So she lost out that day. And we went on for months and never were able to get another."

"...so I went down to [the ER] and it was, like, twelve o'clock in the day. It was nine o'clock that night before we got service. I mean, I laid back in that room and just laid there. And I have insurance."

Residents felt that one reason for delays was that the number of professionals and other workers in the system was inadequate to meet community needs. This was especially true of dentists and mental health professionals but also physicians, nurses, and other providers. Residents suspected that low salaries and demanding working conditions were reasons for these shortages.

HI Survey Result: *Medicaid recipients, the uninsured, and adults living in poor or near-poor households tend to use a health center for care while others with employer-sponsored insurance and greater income usually go to doctor's offices for care. St. Louis has a higher level of emergency room use than does the nation as a whole, for both the insured and uninsured.*

FRAGMENTED CARE

In addition, residents noted that services did exist for many, if not all, of the health care problems in the community. A problem with the current system, however, is the complexity and fragmentation of services and the fact that little effort is made to connect people with existing services. Similarly, residents felt that more effort was spent on enrolling residents in Medicaid than showing them how to use the health care system. Focus group participants felt that services were more effective when they reached out to individuals in neighborhoods and established relationships with them.

"...of course that's one of the big issues we've always had in this town – we know there are consumers that need the service out there. Where are they? As I've said about the pregnant teens, you name the group, there are services for them, but there never seems to be utilization that's even close to expected."

"Because I know that from working in communities, I'm there for long periods of time. So if there are things that happen, there is potential because I am there and the people that I'm with are there to actually begin to talk about that and, you know, relationships develop over time."

HI Survey Result: *Compared to the nation as a whole, St. Louis residents are slightly more likely to report that they **did not** get needed medical care. This was especially true of the uninsured, low-income adults, and African American adults.*

CONTINUITY OF CARE

A result of the fragmentation, complexity, and frequent use of the ER for primary care was that many individuals expressed concern over the lack of continuity of care. They seek care at neighborhood health centers. They are treated. If they need additional care, they may be referred to ConnectCare or another specialty setting. They now enter another system in which they are unknown and about which they lack an understanding. The familiar medical faces of their health center often disappear from the treatment process and the path back to their health center is unclear. Participants recognized, however, that some St. Louis citizens frequently changed their place of residence, making it difficult for them to establish lasting relationships with providers and create continuity of care.

"Most of the health care I've had before I became an adult was in the City hospitals... Someone in this City had your medical history so that when you came in they didn't come in blind to see you."

"And then you've got to go to one doctor for this and one doctor for that. It's there, but it's not there because it's not reachable for the people who need it."

"One of the...other situations is just the transient nature of St. Louis residents and the difficulty...establishing relationships..."

HI Survey Result: *Uninsured residents of St. Louis are less likely than their U.S. counterparts to have a place they usually go when they are sick or need medical advice while insured residents are similar to their national counterparts.*

Residents also felt that the lack of a consistent physician reduced their ability to receive high quality care. For example, one participant noted an instance in which a child who was being treated for a chronic ear infection had received the

same course of antibiotics over several weeks because she had not seen the same physician twice. When possible, residents indicated they would pay to continue with the same physician, but this was not always possible.

"And a lot of people are forced to do that [change their doctor]...If there is any one single complaint I hear, that's the one I hear the most."

Of course, the bus isn't really the bus. It's the buses. It takes two to get to the hospital. Sylvia and her two children get off the first bus and see that they have just missed the second. This means that it will take another 20 minutes to a half-hour to get where they are going. Sylvia begins to wish she had just called the ambulance. Travel alone can be a half-day affair.

TRANSPORTATION

Availability of transportation affects health and access to health services. Although transportation for Medicaid and Medicare is improving, City residents view this as a more complex issue than simply getting an individual to and from an appointment. For example, health centers are frequently only open during the day rather than evenings and Saturdays. Taking time off from work means losing income, and with frequent absences, the potential of losing one's job. In addition, children and elderly individuals who cannot be left alone must be brought along, or family,

friends, or neighbors must be found to care for them. Finally, public transportation is viewed as lacking flexibility with little evening service available if a health center is open.

"And a lot of us, a lot of people don't have choices, and a lot of days I can fix it myself. I don't have bus fare. So if I don't even have bus fare to even get to the doctor, I sure couldn't pay the co-payment."

"And then you've got doctors in there, they're not going to work every Saturday. It will be every other Saturday. Nine times out of 10, you're going to have to either leave work

early or work it out with your job. And if you leave work early, they dock us a half a day. It don't make any sense. Basically, you're in a no-win situation. So you can't take off of work because you can't.... You take off too many times, they'll write you up. Yeah...you're either wrote up, suspended, or you're fired."

Sylvia leans her head against the bus window and sighs. She wishes she better understood Nicole's asthma. Maybe then she wouldn't be going to the doctor at every little cough. Her family had never really trusted doctors and hospitals and she guessed that she didn't either. Maybe if the doctors would better explain her condition, she would better understand. Maybe if she had a better job she could actually afford insurance and have more time with doctors who would help her to understand. Sylvia doesn't have a better job. ER and health center doctors do not seem to have time, but she wishes that they did.

ATTITUDES AND BELIEFS ABOUT CARE

Focus group members spoke frequently about their profound lack of trust in the health care system. Black families in particular were able to cite incidents in local hospitals as sources of distrust. Many individuals were also aware of the Tuskegee experiments. Because of the pain and fear caused by these incidents, they are hard to forget, and stories are passed down from generation to generation.

"You had to go there and they would experiment on black people, especially when there's just you, no family or nothing."

"You know, because I felt more like a specimen rather than a patient, you know. They [doctors and residents] had discussed a note, I know it was a learning session, but if they had discussed some of the stuff with me or to me I would have felt better."

"...you hear these stories all the time while you're young and then when you get sick, of course you're not going to a hospital."

EDUCATION AND HEALTH LITERACY

St. Louisans cited lack of education and knowledge of health and medicine as one of the difficulties involved in taking care of their health concerns. This includes a lack of knowledge about proper preventive care, the causes or consequences of health problems, or what services exist for lower income residents. Individuals expressed how hard it is for many to understand written materials, such as health care bills or explanations of services. Individuals like Sylvia need help and support to better understand how to use the system.

"You know, most people are at a loss as to where do I go from here? Who can I call? Who can I depend on? Who can I call on?"

"I think part of it may be...a lot of it has to do, I know for a fact, with education, of knowing what resources are available. I think sometimes African American families are not made aware of various resources that's available in health care free of charge or for a nominal fee.

"I want to speak on that, too. Now that's another thing. See, a lot of times lower income people, we're not as educated on, uh, the different causes of our health."

The bus gets near the hospital. A short walk, and Sylvia and her children are there. Nicole stopped huffing on the bus, but the walk stirs things up again. When Sylvia reports that the incident started several hours ago, the ER nurse questions why they didn't get here sooner. Don't they know that Medicaid provides transportation? Sylvia knows this. She knows a lot of the ins and outs of Medicaid. But she also knows that Medicaid isn't a limo service. You have to set up an appointment in advance to get transportation.

QUALITY OF INTERPERSONAL INTERACTIONS

City consumers of care often feel that health care providers do not respect them. The belief is that health care is about the bottom line and that finances drive decision-making. Participants cited several situations in which they felt like they had been treated poorly by a doctor, nurse, or support staff. Disrespect was displayed by rudeness, indifference, preferential treatment, failure to listen, and the priority given to administrative over medical concerns.

"[The doctor] was just talking around me, you know. And when I went to pose a question to him...He was just really nasty, just like 'Don't you know? You his mama.'"

"Well, one, when I enter the place, they didn't even acknowledge me for me. For two, I'm

standing at the desk, I sign my name in, when two more other people come in – I'm still standing here – they [the receptionists] didn't even sign in. They talked over me talking to them as if I wasn't even there...I followed all the procedures that you posted up here. They didn't do any of that; I'm nonexistent. So I do know that that does take place whether you're in the clinic or whether you're paying your money out of your pocket, you know. That happens."

"Well, I saw, uh, doctors treat patients differently. The rich patients, they come in, 'Oh, how are you?' They're so excited; they'll take their time. They walk through the wards, mm mm mm, okay, they're gone. I mean, they don't tell you anything. They give you no respect. They might say 'good morning' and they might not. They'll just read your chart and write something down and they're gone, you know. And I think they could come in and

give you the same, 'Good morning. How are you? How was your night?' You know? And they don't do that. They're all in a hurry, especially at the research hospitals and the training hospitals."

HI Survey Result: *Non-elderly adults in St. Louis City reported significant instances of denial of care or unfair or disrespectful treatment by medical professionals in the past few years. Uninsured adults, those with low incomes, and black adults are especially likely to have encountered these problems.*

ORIGINAL

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Sylvia, Nicole and Jimmy settle into the hard plastic ER chairs. Today it is crowded. It will be a while. There should be a better answer, but Sylvia has yet to find it. And she has looked. She thinks about how lucky she is that at least she is not sick. “Welfare to Work” resulted in her taking a low paying job. She didn’t mind that. But she lost her Medicaid. Her kids are still insured, but she is not. The company that she does janitorial work for doesn’t offer her benefits – at least not any that she can afford. At least the children were allowed to keep their benefits.

INSURANCE COVERAGE

Sylvia’s situation is not unique among many City residents, even those who can afford insurance. The capacity for insurance to provide access to care is related to employment status and income. Jobs with low wages and less stringent educational requirements often do not offer or pay enough for employees to have insurance benefits. Individuals in such circumstances are typical of the uninsured in St. Louis. Those who could afford insurance for their family expressed frustration at not being able to afford care after paying for coverage. Making co-payments and purchasing drugs were viewed as significant problems.

“But a family of four, just think about that. You know what I’m saying? Kids have to go in, go into the doctor’s office very often. You pay \$10 to \$15 for co-payments, you know...”

“My oldest son...he has...a bad problem with allergies...Now, when I did finally get him in the clinic they gave me a prescription. I said, ‘He’s allergic.’ He couldn’t take those penicillin. They gave a prescription that cost \$150...So even through we finally got him to see the doctor who could prescribe the medication, we [still do not have] the \$150.”

HI Survey Result: *The greatest percentage of uninsured residents (15 percent of adults under age 65) are near-poor individuals with incomes between 101 and 200 percent of the federal poverty level. The high cost of health insurance and lack of access to employer-sponsored coverage are the greatest barriers to health insurance among City residents.*

Hence, the issue for many City residents was to find a way to purchase coverage and make the best use of it. For some, the solution was to drop one’s spouse or other family members from the plan to reduce its cost. For others, it was trying to find a physician who would accept their plan but who also had late or

Saturday office hours so that they did not lose income. And for others, it was a tradeoff of the waiting time for care versus the cost of more accessible providers. And finally, many individuals gave up choice of provider or specific benefits to acquire affordable insurance. Having found a solution, however, many residents remained frustrated that it did not always provide needed care.

"If I go down to [the health center], I could pay \$15 and see the doctor, but I have to sit and wait all day, and then my boss says, 'You've got insurance. Why do you go there?' Because I don't have the co-payment of \$15 every time I go. And [the health center] will see me and tell me, 'Okay, you can bring the money back tomorrow when you get paid or something.'"

HI Survey Result: *About one in five St. Louis residents had medical bills that they were unable to pay in the past year. Additionally, a substantial minority of St. Louis residents experienced a financial hardship due to their health care expenses.*

MEDICAID

Participants were keenly aware of the eligibility requirements for Medicaid. They understood that the program was more open to children and felt that this was an important aspect of Medicaid. As with those with private insurance, participants were most concerned about the lack of choice in managed care plans as well as the complexity of the processes of qualifying for Medicaid, getting approvals, and merely seeking care. This was viewed by some as "red tape," intended to keep them from qualifying and getting care. Residents also indicated that it was especially difficult for a person to get reinstated to Medicaid once they have been removed from the program. A few participants indicated that this situation resulted in their withdrawal from Medicaid.

HI Survey Result: *Compared to the U.S. as a whole, St. Louis shows higher rates of Medicaid coverage and lower rates of employer sponsored insurance. African American adults and poor households are much more likely than others to receive Medicaid benefits.*

While lack of choice in care and bureaucratic red tape are viewed as major issues of Medicaid, many felt that the loss of benefits under "Welfare to Work" was an injustice. The welfare system is seen as unsupportive of those trying to transition out of it.

"...they're doing the 'Welfare to Work' program and they encourage the mothers to go out and work. Okay, when you go out and work, you lose your benefits...But you work and you have a little part-time job. That part-time job doesn't give you benefits. So in a sense, it's like you're damned if you do and damned if you don't."

Sylvia had turned to her church for help. A nurse who belonged to the church had told her that she thought that Nicole had asthma and encouraged her to get treatment. It was part of a screening event the church had sponsored. The church had no way to really help her follow up. They wanted to support her, but their funds were limited. The school wasn't able to help much, either. Nicole had to bring her own inhalers to school and the nurse would help administer it if she had a problem. It seemed like the school could be more involved. But Sylvia doesn't really know how.

CHURCH AND SCHOOL

Churches and schools were identified as important institutions for providing support to those in need. Participants felt that churches could provide assistance to individuals in using the health care system, provide limited health services, and encourage individuals to overcome personal or organizational barriers to get the care that they need. Schools were also viewed as a potential site for preventive or curative services for children, but were seen as not fully utilized in this regard.

"Take...prostate screening among African American males. Very difficult. And until it was made accessible frequently through congregations, through churches where it could be in the community with people that they trust, the prospect of [use was low]...there is a cultural difference among African American men about that."

"...if we had more school-based clinics where the actual child can be...seen while they're at school. That can prevent the child from having to go to the ER. I just think that we're letting kids down just by not having that available to them."

Sylvia relies a lot on her parents for help and they do the best they can. Her father constantly tells her to stay away from doctors and hospitals. He thinks that his home remedies are the cure for Nicole. Her mother tells her to go to the hospital if Nicole even sneezes. Really, they are not much help in these matters. But they watch her son during scheduled doctor visits so that Sylvia only has one child to juggle.

FAMILY

Focus group members were able to identify several areas in which the family had an impact on health care access. Participants felt that families fail to learn about preventive care and how to care for themselves when they do become ill. In black families, mothers and grandmothers were seen as strongly influencing the type of care sought. Family support was important in helping participants use services, particularly when hospitalized or confined to a nursing home. Residents felt that the quality of care was better when family members were present and able to observe and ask questions related to the care of their loved ones.

“...I’ve gotten on the phone and talked to the health center and we worked out a plan. Within three hours her mother or grandmother said, [take the baby to the emergency room]. ‘That baby is going to die...’ What do I know? I am just the nurse.”

“...there was a lady, she was in the bed [next to my mother]. They come in, look at her chart, do whatever they were going to do, and they were gone. No family came...she wouldn’t ask them any questions. So my mother got a different treatment, you know. She got put in a private room.”

The hands slowly turn on the wall clock above the nurse's station. Sylvia watches people come and go. Mostly old folks. A couple near her speaks a language that she doesn't understand. She chats with an elderly woman who has lived in the City all of her life. She talks about businesses that have moved out of the neighborhood and how much harder that makes things for her. Sylvia can relate to what she is saying. She has to take the bus west for her job and to get to supermarkets and discount stores.

ENVIRONMENT AND DEMOGRAPHICS

The decline in small businesses in the north City area was a serious concern. These businesses provided employment. They also provided basic needs like food and medication from markets and drugstores. Having to leave the neighborhood to shop makes transportation an issue here as well.

St. Louis City has a substantial elderly population whose health status is perceived to be worse than in other communities. Living on a fixed income exacerbates issues of poor diet, inability to purchase medicine, and access to physicians for care or prevention.

“...their medicine is literally wiping them out, totally wiping them out to where they can't even...they pay the rent, partial on utilities, medicine, and whatever they can basically scrounge from missions, canned goods, food, or whatever, and personally [I think] this is totally, totally wrong.”

HI Survey Result: *St. Louis residents age 65 and older appear to experience more health problems than do seniors nationwide despite the fact that they have similar utilization rates of regular and preventive care as their national counterparts.*

There is an abandoned newspaper on the chair next to Sylvia. Two headlines catch her eye: “Health Disparities Continue for African Americans” and “Medicaid Cut to Balance State Budget.” Sylvia sighs. By now Nicole is feeling better. But they are here. So they will wait.

MEDIA

The tone of reporting on health was viewed as very negative in the City. For example, although residents expressed concern over ConnectCare, they believed that it was not treated fairly in the media. All of the reporting was seen as emphasizing its problems.

THE ISSUE OF RACE

Although not explicitly mentioned in Sylvia’s story, no discussion of the health care situation in St. Louis City would be complete without a mention of race as a factor. Its impact is often disguised by ability to pay, which directly impacts access to services. The impact of race is

subtler, occurring through discriminatory actions and the perception that one is not welcome in a certain place. The effect of race also results from a lack of trust in the system or understanding of care.

“So this young lady that was down there, uh, she was white... We was just talking and all of a sudden she was saying to me that she had this injury and this is what she was getting therapy on, you know, the very same injury that I had but she was taken care of more so than I was...”

[Summary and Next Steps]

Sylvia and actual City residents face many obstacles in accessing health services. Focus group participants identified a total of 66 barriers related to accessing health care. [See Appendix for complete list.] These barriers can be summarized in four broad categories:

DELIVERY FAILURES

- Long Waits
- Fragmented Care
- Lack of Continuity
- Disrespect

INDIVIDUAL BURDENS

- Health Literacy
- Distrust
- Insurance Status

SUPPORT PROBLEMS

- Churches
- Schools
- Employers
- Family

COMMUNITY CHALLENGES

- Poverty
- Education
- Environment
- Demographics
- Transportation
- Media
- Racism

As a next step, four community forums, comprised of residents, health care providers, funders, and health policy makers, respectively, were held. Participants were asked to consider these barriers and to identify primary concerns that were also changeable. This process served as a form of “validation” of the residents’ concerns. A final activity during the forums allowed participants to begin a process of seeking solutions. This process of community involvement will continue in early spring 2003 when these groups will come together to integrate their views and identify concrete approaches for overcoming many of these obstacles.

For City residents, there were two primary responses to these barriers to their care: resilience or resignation. Individuals either resigned themselves to a system that would not change or figured out how to use the system to some advantage for their health. St. Louisians believe that everyone concerned with the health of City residents must demonstrate resilience and not resignation. Actions must be taken to reduce or eliminate barriers and create conditions that produce health outcomes for City residents that are equivalent to those of the nation as a whole.

“I carried this [book] just for waiting here. I keep it with me all the time to keep my mentality straight and not go off the handle...I carry a little bag, too. I carry my own juice and crackers. I just make myself content. Now, when I decide I don’t want to sit anymore, I go to the receptionist and let her know I have to leave now. I was in at such and such a time and I know you’re busy, or maybe you’re short-handed and I have compassion for that, but I have to go. And usually they’ll try to help you, help you out.”

[Appendix]

MORTALITY COMPARISONS

TABLE 1: MORTALITY RATES AMONG ST. LOUIS, MISSOURI, AND U.S. ADULTS (PER 100,000)

	St. Louis	St. Louis White	St. Louis Black	Missouri	Missouri White	Missouri Black	U.S.	U.S. White	U.S. Black
All Causes	1141.3	979.8	1361.2	888.4	858.1	1223.4	857.9	800.1	1099.9
Heart Disease	362.7	334.2	403.9	293.1	286.8	373.4	270.5	254.8	323.8
Cancer	242.8	207.5	301.6	198.8	192.3	284.3	199.0	186.9	246.5
Stroke	68.5	59.4	81.4	62.6	61.2	78.2	58.6	54.0	76.6
Pneumonia and Influenza	41.2	38.9	43.6	36.2	36.0	38.4	31.7	30.0	32.9
Chronic Obstructive Lung Disease	39.1	40.2	36.4	41.2	41.7	34.2	38.1	38.9	28.4
Diabetes	32.1	24.6	43.6	21.1	19.5	42.7	22.5	19.5	44.1
Infant Mortality	12.7	7.4	15.6	7.8	6.4	15.5	7.7	6.4	15.3
AIDS	24.8	23.0	27.8	6.4	4.7	20.2	15.0	10.7	47.7

Source: City of St. Louis Department of Health. Public Health: Understanding Our Needs, Volume 1, 2001

[Appendix]

CONCERNS

The following is a list of concerns related to health care access as identified by focus group participants.

DELIVERY FAILURES

- The complexity of the structure of the health system
- The lack of a consistent or personal physician
- The inability to connect residents to the services that do exist
- The inadequate number of dentists, mental health professionals, pediatricians, and other health professionals
- The movement of health care providers out of the City
- The diagnosis and screening of people for illnesses without the ability to provide follow-up care
- The use of emergency rooms for primary care
- The cost of medications for families
- The cost of medications for the elderly
- The cost of health insurance coverage
- The cost of deductibles and co-insurance/co-payments for insurance plans
- The limited number of providers from which to choose on a health plan
- The time needed to find a primary care physician
- Problems in attempting to resolve bills
- The lack of choice of providers in Medicaid
- Treatment of applicants during the Medicaid eligibility process
- Getting approvals for use of coverage with Medicaid
- Problems with reinstatement to Medicaid after losing coverage
- Loss of Medicaid benefits under “welfare to work”
- The poor quality of medical and dental care received by the poor
- The limited access to primary care for the poor
- The limited access to secondary care for the poor
- The poor quality of medical and dental care received by African Americans
- The limited access to medical and dental care for African Americans
- Long waiting times to get an appointment with a physician
- Long waiting times to see practitioners in health centers
- Long waiting times for emergency room services
- Disrespectful treatment of the poor by physicians
- Disrespectful treatment of the poor by nurses and other professionals
- Disrespectful treatment of the poor by receptionists and other office or clerical staff
- Disrespectful treatment of African American residents by physicians
- Disrespectful treatment of African American residents by nurses and other professionals
- Disrespectful treatment of African American residents by receptionists and other office or clerical staff
- Less education among City residents resulting in a poor understanding of medical care and administrative processes
- Lack of information about the sites and types of services available to residents
- The use of home remedies as a substitute for the use of medical care services
- The change of treatment plans or drug regimens by residents to control the cost of care
- Delay in accessing care to control the cost of care
- Cutting back on other basic necessities to pay for medical care services
- The resignation of residents to poor-quality care, limiting their use of the health care system
- The need to eliminate family members from an insurance plan to reduce costs

INDIVIDUAL BURDENS

SUPPORT PROBLEMS

- Lack of knowledge of how managed care works
- Lack of knowledge of the benefits under Medicaid
- The inability of residents to explain the complexity of their health care needs due to the short meeting times with providers
- Lack of trust of the health care system resulting in reduced use of health care services
- Lack of trust of the health care system in the African American population
- Inadequate support services provided by medical care delivery settings
- The negative consequences of taking time off from work to respond to their health care needs
- The limited use of schools for preventive and treatment services
- The failure of family members to learn how to prevent illness
- The failure of family members to learn how to take care of themselves if they do become ill
- The inability of family members to provide child or elder care to assist residents in accessing care
- The inability of family members to be present to advocate for residents during hospital or nursing home confinement
- The inability to make health care decisions or use health care services due to family crises or other ongoing situations

[Appendix]

RESOURCES

COMMUNITY CHALLENGES

- The sustained poverty of many City residents
- The high percentage of elderly people in the City
- The high percentage of immigrants in the City
- The poor educational background of City residents
- The poor public transportation system
- The decline in small business activity
- Increased pollution in the environment and housing
- Negative reporting about health care in the media
- Bureaucratic and unsupportive welfare system
- Small increases in social security relative to expenses
- Racism in the City
- The self-interest of City residents regarding health care rather than social concern for it

Contact **Darcell P. Scharff, Ph.D.** at (314) 977-4009 or scharffd@slu.edu to receive the full reports addressed in this document:

- *Understanding Quality and Access to Care: Impression of City Residents* conducted by Saint Louis University, School of Public Health
- *St. Louis Health Care Needs Assessment Survey* conducted by HarrisInteractive

To contact the **City of St. Louis Department of Health**, call (314) 612-5100 or go to their website at <http://stlouis.missouri.org/citygov/health>. Click on *Understanding Our Needs: A St. Louis City Health Needs Assessment* to read this full report.

To learn more about the health issues that are specific to children in the St. Louis metropolitan area, contact **Vision for Children at Risk** at (314) 534-6015 or go to their website at <http://www.visionforchildren.org>. Click on CMSL report to read the most recent report *Children of Metropolitan St. Louis. Vision for Children at Risk: A Report to the Community, 2001*.

To learn more about the **Regional Health Commission** and to offer comments about health care in St. Louis, go to www.stlrhc.org or call (314) 534-9270.

To learn about programs and projects funded by local health foundations, refer to the following list of names and contact information:

- **Episcopal-Presbyterian Charitable Health and Medical Trust**
(314) 588-8200

- **Danforth Foundation**
(314) 588-1900
- **Deaconess Foundation**
(314) 436-8001, www.deaconess.org
- **Daughters of Charity Healthcare Foundation of St. Louis**
(314) 802-2060,
www.daughtersofcharityfdn.org
- **Incarnate Word Foundation**
(314) 773-5100,
www.incarnatewordfund.com
- **Lutheran Foundation** (314) 231-2244,
www.lutheranfoundation.org
- **Missouri Foundation for Health**
(314) 345-5500, www.mffh.org
- **St. Louis Community Foundation**
(314) 588-8200, www.stlcf.org
- **Whitaker Foundation** (314) 241-4352

The names and contact information of health centers located in the City of St. Louis are provided below.

- **Grace Hill Neighborhood Health Centers** (314) 539-9500,
www.gracehill.org
- **Family Care Health Centers**
(314) 481-1615,
www.familycarehealthcenter.com
- **Myrtle Hilliard Davis Comprehensive Health Centers**
(314) 367-5820
- **People's Health Centers**
(314) 367-7848, www.phcenters.org
- **Community Health in Partnership Services (CHIPS)** (314) 652-9231
- **La Clinica** (314) 664-5565,
www.accionsocialcomunitaria.org
- **ConnectCare** (314) 879-6300,
www.saintlouisconnectcare.com

[Appendix]

METHODS

HARRISINTERACTIVE STUDY

A 20-minute telephone survey was conducted with a representative sample of 907 adults, 18 years of age or older, living in the City of St. Louis. The interviews were conducted between March and April, 2001. In addition, 100 in-person interviews were conducted to over sample phone-less households. Over 1,000 [closed-ended, multiple-choice] questions related to health status, access, quality, insurance, and utilization were asked. HarrisInteractive analyzed the data and generated a comprehensive report consisting of tables and graphs.

FOCUS GROUP STUDY

A total of 13 focus groups were conducted in the City of St. Louis: 10 were comprised of citizens and three were comprised of health professionals. The citizen focus groups were held in various community locations (e.g., schools, community centers) and the professional focus groups were held at the Saint Louis University School of Public Health. Participants for the citizen focus groups were identified through zip codes with the greatest proportion of residents below poverty. Neighborhood associations that fell into these zip codes were identified through the St. Louis Association of Community Organizations (SLACO) web site and by community leaders with whom we had previously worked or who had been in contact with others at the School of Public Health. Professional focus groups were divided into three groups with varying purposes: health care providers, health care or other supporting agencies, and health care funders. Organizations (and individuals who represented these agencies) were identified through brainstorming

efforts by the investigators, as well as through lists provided by various boards and coalitions. Focus groups consisted of five to 12 participants and each group lasted approximately 1.5 hours. They were conducted between December 2001 and March 2002. Focus group questions were based on the HarrisInteractive findings. A total of 12 main questions guided the focus group interviews. A professional transcriptionist transcribed the focus groups interviews verbatim. Additionally, a research assistant transcribed notes taken during the groups. Data were organized and analyzed by the Saint Louis University investigators using a complex, two-phase coding process. A report was generated and provided to the Trust. Several quality assurance methods were in place for both of the studies.

THIS REPORT WAS PREPARED BY

Richard S. Kurz, Ph.D., Professor and
Chair of Health Management and
Policy, and Darcell P. Scharff, Ph.D.,
Assistant Professor of Community
Health, Saint Louis University School
of Public Health, St. Louis, Mo.

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HarrisInteractive, Inc., New York, NY.

Design: 501creative, inc., St. Louis, Mo.

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