

## V. BARRIERS TO ACCESSING THE HEALTH CARE SYSTEM: A CONSUMER PERSPECTIVE

### *Key Findings of Section V*

*The medically underserved encounter barriers that significantly limit their ability to access the safety net health care system. these include the following:*

#### *System Barriers*

- *Lack of information about available safety net medical services*
- *Lack of transportation*
- *Shortage of specialty care providers and dentists*
- *Policies and hours of operation of institutional safety net providers*
- *Disruption of services for children with special needs entering adulthood*
- *Limitations of the voucher/purchase order system*

#### *Financial Barriers*

- *Lack of insurance*
- *Cost of care and medical debt*
- *Prioritization of other needs over health care*

#### *Cultural Barriers*

- *Stigma associated with safety net care*
- *Lack of respect toward safety net patients*
- *Cultural barriers for minorities*
- *Cultural and linguistic barriers for new Americans*
- *Lack of health literacy*

A recent RHC survey found safety net capacity sufficient to meet the current demand for primary care services (See Section IV.B for detail). Currently, an estimated 82% of the total safety net population in St. Louis City and County utilize these safety net institutions in a given year.<sup>5.1</sup>

Despite the apparent availability of primary care services, the region suffers from poor health outcomes and wide disparities. A focus group participant in a recent study conducted by the Episcopal-Presbyterian Charitable Health and Medical Trust articulated the problem:

*“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? You name the group, there are services for them, but there never seems to be utilization that’s even close to expected.”*<sup>5.2</sup>

As this comment indicates, having an available supply of health care services is not enough to ensure that people will access the system. This section discusses barriers that limit people’s ability to use health care services in our region. Much of the information is drawn from several recent studies that examined access issues in focus groups of safety net patients, providers, and other community residents across the region. These studies include the following:

- *A Crisis of Care: The community’s perspective on health care in St. Louis City.* by Richard Kurz, Ph.D. and Darcell P. Scharff, Ph.D. Sponsored by the Episcopal-Presbyterian Charitable Health and Medical Trust.<sup>5.2</sup>
- *Speak Out Report: St. Louis Community Voices on Health Care* by Rosetta Keeton and Katie Plax, M.D. Sponsored by Metropolitan Congregations United (MCU), ACORN, and other community organizations.<sup>5.3</sup>
- *Public Health: Understanding Our Needs* prepared by Louise Quesada. Conducted by the City of St. Louis Department of Health.<sup>5.4</sup>

\* There may be a slight overstatement in the percent of the safety net population that utilized safety net primary care services due to potential double-counting of patients seen at different sites within the safety net system

These studies and other research referenced throughout this section identify multiple barriers to optimal medical care, beyond the issue of primary and specialty care availability:

#### *System Barriers*

- Lack of information about available safety net medical services
- Lack of transportation
- Shortage of specialty care providers and dentists
- Policies and hours of operation of institutional safety net providers
- Disruption of services for children with special needs entering adulthood
- Limitations of the voucher/purchase order system

#### *Financial Barriers*

- Lack of insurance
- Cost of care and medical debt
- Prioritization of other needs over health care

#### *Cultural Barriers*

- Stigma associated with safety net care
- Lack of respect toward safety net patients
- Cultural barriers for minorities
- Cultural and linguistic barriers for new Americans
- Lack of health literacy

Each of these barriers to access is discussed in more detail on the following pages.

## A. System Barriers

### 1. Lack of Information about Available Safety Net Medical Services

Lack of information about available safety net medical services is a major barrier to health care access. In a focus group conducted by the St. Louis City Department of Health, one participant explained, “People don’t know how to access available health services.”<sup>5.4</sup> A participant from another focus group noted, “People often do not realize the types of services offered.”<sup>5.3</sup>

Many safety net patients and providers find the health care system to be complicated and confusing. Kurz and Scharff found that a lack of information regarding how to access the safety net system often led people to go to Emergency Departments for primary care or to not seek care at all. The safety net system can appear particularly complex to those in need of follow-up care. Safety net patients “were not clear on how and with whom to follow up if a problem was identified”.<sup>5.2</sup>

This barrier to care is especially problematic for those who are illiterate or who have limited education. Some patients have difficulty understanding written information such as explanations of services and would like the information presented in a different format.<sup>5.2</sup> Some medically underserved people also believe that information on available medical services is “more available at ‘richer clinics’ or private physician offices”.<sup>5.2</sup> One focus group participant explained:

*“The public places such as—let’s use for instance \_\_\_\_\_, the places around here as opposed to out in West County...They (West County) may have more variety of things?”*<sup>5.2</sup>

### 2. Lack of Transportation

Transportation is consistently identified as a barrier to accessing health care in St. Louis City and County. According to the Episcopal-Presbyterian Trust, focus group participants “viewed transportation as a problem that affected their health and access to health services.”<sup>5.2, 5.3</sup>

In an analysis of clinic locations and transportation routes, the RHC, in conjunction with the Bi-State Development Agency, found that primary care sites are accessible from most locations in the region within a 20-minute bus ride. (See Section IV. B for map of clinic locations and transportation routes.) However, this analysis does not account for bus stop wait times, cost, safety, or ease of using the bus system, particularly for after-hours, urgent medical care.

Many focus group participants “viewed transportation as a more complex issue than merely moving an individual from one point to another. For those dependent on public transportation, the transportation system was viewed as lacking flexibility with greater availability of service during the daytime rather than evening hours”.<sup>5.2</sup>

Safety net providers make an effort to reduce transportation difficulties for their patients. Thirteen of the institutional safety net providers surveyed by the RHC offer bus vouchers to their patients. The institutional safety net providers also reported operating a total of 15 vans to provide free transportation for patients. In addition, 21 of the institutional safety net providers contract with private cab companies, and five contract with OATS (Older Adult Transportation Services), to provide free transportation through a voucher system.<sup>5.1</sup>

State Medicaid and MC+ Plans also fund free transportation services for Medicaid and MC+ recipients. In addition, several organizations provide mobile care services in which medical vans visit underserved areas to provide screenings and other medical services.

While these programs provide important services, people are sometimes not aware that they are available.

### 3. Shortage of Specialty Care Providers and Dentists

As noted in Section IV, there is a shortage of safety net specialty care providers and dentists. This shortage makes it difficult for patients to access needed services. Particularly in the case of specialty care, provider shortages result in long wait times.<sup>5.3, 5.2</sup> This is confirmed by a recent RHC survey of safety net providers which found that while primary care appointments are almost universally available within 14 days of patient request, wait times for subspecialty medical/surgical care are inordinately long (See Section IV.C). For example:

- 57% of patients seeking a cardiology appointment wait longer than five weeks to see a physician.
- 60% of gastroenterology patients wait longer than nine weeks to see a physician.

Several focus group participants discussed their frustration with excessive appointment wait times. For example:

*“You know it’s months down the line to get an appointment for the referral.”<sup>5.2</sup>*

### 4. Policies and Hours of Operation of Institutional Safety Net Providers

Several operational issues at health centers pose barriers to patients. First, policies and documents required to verify eligibility for reduced fees vary from clinic to clinic. These differences in standard operating procedures make it difficult for patients to know what documentation they must present, for what types of services they are eligible for reduced fees, and the amount they may be required to pay at a particular health center.

This is confirmed by a recent phone survey of a representative sample of 10 safety net clinics in St. Louis City and Saint Louis County conducted by the community action group Metropolitan Congregations United (MCU). In these calls, MCU found that some safety net clinics told potential patients that they must present an income tax statement, picture identification, and a Social Security number at time of registration if they wanted to qualify for reduced fees. For children, the parents were instructed that they must present the income tax form on which the child was claimed. If the patient was unemployed, some clinics asked for proof that the patient had filed for unemployment. These eligibility requirements for reduced fees increase the barriers to accessing health care services for people who do not have these documents readily available.<sup>5.5</sup>

Some safety net providers reported that they offer a range of documentation options for reduced fees, including allowing patients to present a check stub at their next visit or an unemployment letter.

Beyond the barriers posed by eligibility requirements for reduced fees, limited health center hours of operation are also seen as a barrier to accessing care.<sup>5.4</sup>

As a participant of the City of St. Louis's focus group explained:

*“Time clinics are open [is a problem] – we need extended hours.”*<sup>5.2</sup>

The RHC found that only one institutional site is open Sundays and that only four sites offer evening care – three until 8:30 p.m. and one until 10:00 p.m. In addition, the sites that offer care evening care only do so on Tuesdays, Wednesdays, or Thursdays. The limited availability of after-hours care may partially account for the high use of Emergency Departments for non-emergent care. Overall, 35% of patients in city and county hospital Emergency Departments present with non-emergent conditions. Half of these non-emergent patients arrive for care between 4:00 p.m. and midnight.<sup>5.1</sup>

### *5. Disruption of Services for Children with Special Needs Entering Adulthood*

Children with special health care needs – defined as those with disability or chronic illness—often encounter difficulties in accessing services when they enter adulthood. Services during childhood are fairly accessible because such children are often covered under their parents' insurance or are more often Medicaid – eligible because of their disability or their ability to take advantage of special Medicaid enhancements available only to children. In addition, the two children's hospitals in St. Louis often offer multidisciplinary clinics to improve access to all the caregivers required to optimize the outcomes of their special challenges.

As these children move to adulthood, they face a range of problems in accessing services. They are often no longer eligible for family coverage once they reach age 19. Eligibility for Medicaid for those over 18 is much more restrictive. Private insurance with these pre-existing conditions is costly and premiums are beyond the budget of most of these young adults. Adult providers, both primary care and specialty care, are less likely to accept Medicaid. In some cases, providers may avoid these patients because they are unfamiliar with many of their problems. Improved pediatric services are allowing children to reach adulthood with some problems for which adult specialists were never trained. Furthermore, most adult practitioners do not practice in multidisciplinary settings, so one-stop service is no longer available and case management becomes much more difficult.

### *6. Limitations of the Voucher/Purchase Order System*

While the ConnectCare Voucher/Purchase Order Program is extremely important, there are certain limitations under this system, as noted below (the voucher/purchase order system is explained in more detail in Section IV. A):

1. The funds to pay for the voucher system are limited and come from the DSH waiver allocation received by ConnectCare. Loss of ConnectCare's DSH payments would therefore eliminate the funding source for the current voucher program.
2. The voucher program is based upon the same guidelines used by Medicaid and Medicare (InterQual) for authorizing services. Accordingly, vouchers may not be issued for all services that require hospitalization or that may be requested by a patient or physician. For example, psychiatric care, cosmetic surgery, and certain pregnancy-related services are not covered by the ConnectCare voucher program.
3. Elective procedures must be pre-authorized at least 72 hours in advance to allow ConnectCare's Utilization Department to verify patient eligibility for the voucher program, i.e., lack of health insurance or other financial means. This preauthorization process is industry standard, and is not different than what is typically done throughout the health care industry.
4. As with private health insurance, ConnectCare preauthorizes only the specific service requested by the referring physician. Some patients and physicians do not want to seek additional vouchers for services beyond their initial request, and desire open-ended or "reusable" vouchers.
5. Vouchers are only available to uninsured patients. Underinsured patients such as those covered by Missouri Medicaid are not eligible for the ConnectCare voucher program.

## ***B. Financial Barriers***

### *1. Lack of Insurance*

In 2002, the Institute of Medicine released a comprehensive report regarding the consequences of being uninsured on health status. They found “a consistent and statistically significant relationship between health insurance coverage and health outcomes for adults.” They concluded that “working-age Americans without health insurance are more likely to:

- Receive too little medical care and receive it too late;
- Be sicker and die sooner;
- Receive poorer care when they are in the hospital even for acute situations like a motor vehicle crash.”<sup>5,6</sup>

Likewise, the Kaiser Commission on Medicaid and the Uninsured reports substantial barriers to care for the uninsured and underinsured. They note that nationally:

- Nearly 40% of uninsured adults and 25% of uninsured children have no regular source of health care. Coupled with a fear of high medical bills, many delay or forgo needed care.
- Uninsured children are 70% more likely than insured children not to have received medical care for common conditions such as ear infections, and 30% less likely to receive medical attention when they are injured.
- Nearly 40% of uninsured adults skipped a recommended medical test or treatment, and 20% say they needed but did not get care for a serious problem in the past year.

- Both uninsured adults and children are less likely to receive preventive care. Uninsured adults are over 30% less likely than insured adults to have had a checkup in the past year. Similarly, one-third of uninsured children did not see a doctor in the past year.
- The uninsured are more likely than those with insurance to be hospitalized for conditions that could have been avoided, such as pneumonia and uncontrolled diabetes.
- The uninsured with various forms of cancer are more likely to be diagnosed with late-stage cancer. Death rates for uninsured women with breast cancer are significantly higher compared to women with insurance.<sup>5,7</sup>

According to the U.S. Census Bureau, the number of people without health insurance rose by 1.4 million individuals, up to 41.2 million total uninsured, which represents 14.6% of the population in the United States. There was also a decline in employment-based insurance of 1 percentage point, down to 62.6% of the population.<sup>5,8</sup>

Despite the Medicaid program, the U.S. Census Bureau reported that 10.1 million poor people, or 30.7% of the poor, had no health insurance of any kind during 2001. It is estimated that approximately 10.3% of Missouri residents were uninsured in early 2002 according to U.S. Census Bureau data. Missouri ranked 37th in 2002 in the number of uninsured, meaning that 36 states had a higher percentage of uninsured individuals than Missouri. The rate of uninsured among the non-elderly population in Missouri is approximately 11%.<sup>5,8</sup>

## 2002 ESTIMATE OF UNINSURED BY STATE—U.S. CENSUS BUREAU, MARCH 2002 CENSUS POPULATION SURVEY

STATE	% UNINSURED		% UNINSURED	
	ALL AGES*	RANK	NONELDERLY**	RANK
UNITED STATES	15%	—	17%	—
TEXAS	24%	1	26%	2
NEW MEXICO	21%	2	26%	1
CALIFORNIA	20%	3	21%	4
LOUISIANA	19%	4	21%	6
OKLAHOMA	18%	5	22%	3
ARIZONA	18%	6	19%	8
FLORIDA	18%	7	21%	5
GEORGIA	17%	8	17%	16
MISSISSIPPI	16%	9	17%	17
ARKANSAS	16%	10	18%	9
NEVADA	16%	11	18%	12
IDAHO	16%	12	18%	10
WYOMING	16%	13	18%	14
ALASKA	16%	14	19%	7
COLORADO	16%	15	17%	15
NEW YORK	16%	16	18%	13
UTAH	15%	17	15%	24
NORTH CAROLINA	14%	18	16%	18
ILLINOIS	14%	19	15%	21
MONTANA	14%	20	18%	11
WEST VIRGINIA	13%	21	16%	19
ALABAMA	13%	22	15%	20
NEW JERSEY	13%	23	15%	23
WASHINGTON	13%	24	15%	25
OREGON	13%	25	14%	26
KENTUCKY	12%	26	15%	22
MARYLAND	12%	27	13%	31

STATE	% UNINSURED		% UNINSURED	
	ALL AGES*	RANK	NONELDERLY**	RANK
SOUTH CAROLINA	12%	28	14%	27
INDIANA	12%	29	13%	28
KANSAS	11%	30	13%	29
TENNESSEE	11%	31	12%	37
IOHIO	11%	32	13%	32
VIRGINIA	11%	33	13%	33
MICHIGAN	10%	34	11%	40
MAINE	10%	35	13%	30
CONNECTICUT	10%	36	12%	34
MISSOURI	10%	37	11%	41
HAWAII	10%	38	11%	39
NORTH DAKOTA	10%	39	12%	35
VERMONT	10%	40	10%	46
NEBRASKA	10%	41	11%	42
NEW HAMPSHIRE	9%	42	10%	44
SOUTH DAKOTA	9%	43	12%	36
DELAWARE	9%	44	11%	38
PENNSYLVANIA	9%	45	10%	45
MASSACHUSETTS	8%	46	10%	43
MINNESOTA	8%	47	9%	48
RHODE ISLAND	8%	48	9%	49
WISCONSIN	8%	49	9%	50
IOWA	8%	50	9%	47

\* Percent of 2002 estimated total population

\*\* Percent of 2002 Under 65 estimated population

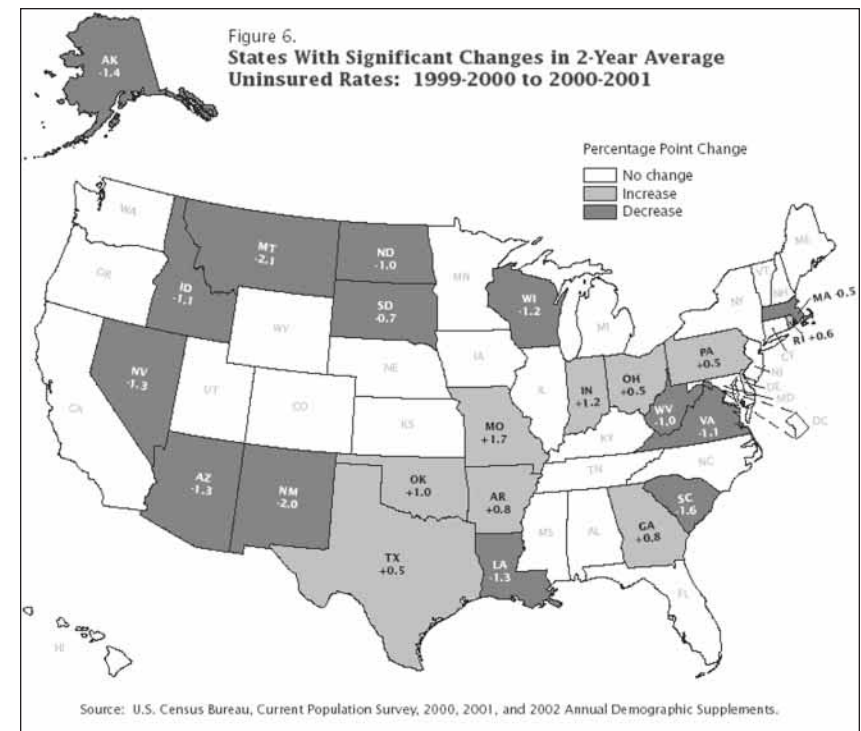
2002 Uninsured Population by State. Data from from the U.S. Census Bureau's 2002 Current Population Survey (CPS) Annual Demographic Supplement.

**FIGURE 6: STATES WITH SIGNIFICANT CHANGES IN 2-YEAR AVERAGE UNINSURED RATES: 1999-2000 TO 2000-2001**

Note: The U.S. Census Bureau uses a two-year average of uninsured rates in many of its analyses to increase the reliability of the estimates at the state level. The Census Bureau also considers that the data collected in the annual March supplement are reflective of persons' situations during the prior year. Therefore, data collected in March 2002 are labeled as 2001 in the Census Bureau's reports of CPS data (as is the map above). Many experts feel that for some of the items in the survey, particularly the question regarding insurance status, people surveyed respond with their status at the "point" of time of the survey, or March 2002. Further discussion of the challenges of estimating the number of uninsured is contained in Appendix 9 of this report.

While Missouri has a lower rate of uninsured individuals than many states, it is important to note that the availability of insurance alone does not assure access to health care services for safety net patients. Another important component is the availability of providers willing to accept individuals in insurance programs such as Medicaid. As noted in Section IV of this report, Missouri Medicaid reimbursement levels are in the lower quartile of the nation, and a severe shortage exists in safety net specialists, dentists, and mental health providers in the St. Louis region. Thus, many individuals covered under the Missouri Medicaid program face similar barriers to access as the uninsured population.

In addition, comparing two-year moving averages (1999-2000 and 2000-2001), *the number of uninsured individuals rose 1.7% in Missouri*, which was significantly more than the increase of uninsured in any other state, as noted in the map below. This increase in the uninsured does not take into account the fact that over 30,000 more individuals are no longer eligible for Medicaid benefits due to Missouri legislative action in 2001. These rates could be even more substantially impacted by proposed legislative action in the 2003 Missouri General Assembly to reduce the number of eligible residents covered under the Missouri Medicaid program, as discussed in greater detail in Section IV of this report.



*Estimates of the Uninsured—St. Louis City and Saint Louis County*

Data on the number of uninsured in St. Louis City and Saint Louis County are not regularly collected or reported, and the number is difficult to estimate given statistical challenges inherent in any current estimating method. A full discussion of this challenge, and various methodologies used to estimate the uninsured, is found in Appendix 9.

For purposes of estimating the number of uninsured in St. Louis City and County, state-wide rates of uninsured for the non-elderly population by federal poverty level from the CPS for Missouri were applied to the numbers of non-elderly persons in the City and County by federal poverty level.

The St. Louis City and County population data by federal poverty level was taken from the U.S. 2000 Census. These estimates were then multiplied by the rates of uninsured for Missouri from the March 2002 CPS survey, the most recent data available to the RHC. This technique results in an estimate of approximately *128,555 uninsured persons* in the two areas without insurance at the time of the CPS survey. This number has been rounded to 129,000 uninsured individuals in St. Louis City and Saint Louis County as of 2001, and used in Section IV in analyses that estimate the total number of safety net patients in the region.

The table, below, shows the number of uninsured by St. Louis City and Saint Louis County, separately and combined utilizing the data from the US Census Bureau.<sup>5,8</sup>

	BELOW POVERTY	ABOVE POVERTY	TOTAL
A. POPULATION AGED 60 TO 65 IN STL CITY (US 2000 CENSUS)	77,476	224,171	301,647
B. RATES OF UNINSURED FOR MO (US CENSUS, MARCH 2002 CPS)	25%	9%	–
C. NUMBER UNINSURED IN STL CITY (COLUMNS A X C)	19,369	20,175	39,544 (13.1%)
D. POPULATION AGED 60 TO 65 IN STL COUNTY (US 2000 CENSUS)	62,463	815,496	877,958
E. RATES OF UNINSURED FOR MO (US CENSUS, MARCH 2002 CPS)	25%	9%	–
F. NUMBER UNINSURED IN STL COUNTY (COLUMNS D X E)	15,616	73,395	89,011 (10.1%)
G. NUMBER OF UNINSURED IN STL CITY & COUNTY (COLUMNS C + F)	34,985	93,570	128,555 (10.9%)

While the rate of uninsured persons is higher in the City of St. Louis, it is important to note that approximately 70% of the uninsured in the combined region live in Saint Louis County.

While the U.S. Census Bureau annual data have been used to estimate the uninsured, these estimates can be considered “point-in-time” snap-shots that do not fully reflect the total level of uninsurance, since research has shown that they may not reflect estimates of the impact of uninsurance on the citizenry over a “period-of-time”.<sup>5,8</sup>

In order to account for the flux in the number of individuals that are uninsured throughout the calendar year, a period-of-time estimate of uninsured persons in St. Louis City and County was made through a complex modeling process utilizing data from both the Current Population Survey (CPS) and the Behavioral Risk Factor Surveillance System (BRFSS). This model produced an estimate of approximately *151,000 persons* in the area who were without insurance for some amount of time during a 12-month period, as follows:

*TABLE 5. Number of Uninsured Persons in St. Louis City and Saint Louis County by Length of Time without Insurance*

LENGTH OF TIME W/O INSURANCE	EST. TOTAL NO. OF PERSONS PER YR
1-2 MONTHS	7,377
3-5 MONTHS	18,328
6-8 MONTHS	7,612
9-12 MONTHS	5,974
13+ MONTHS	111,856
TOTAL	151,147

This number is approximately *22,000 more persons* than the point-in-time estimate of uninsured persons.

Using the above techniques, the total number of uninsured in the region can be estimated as:

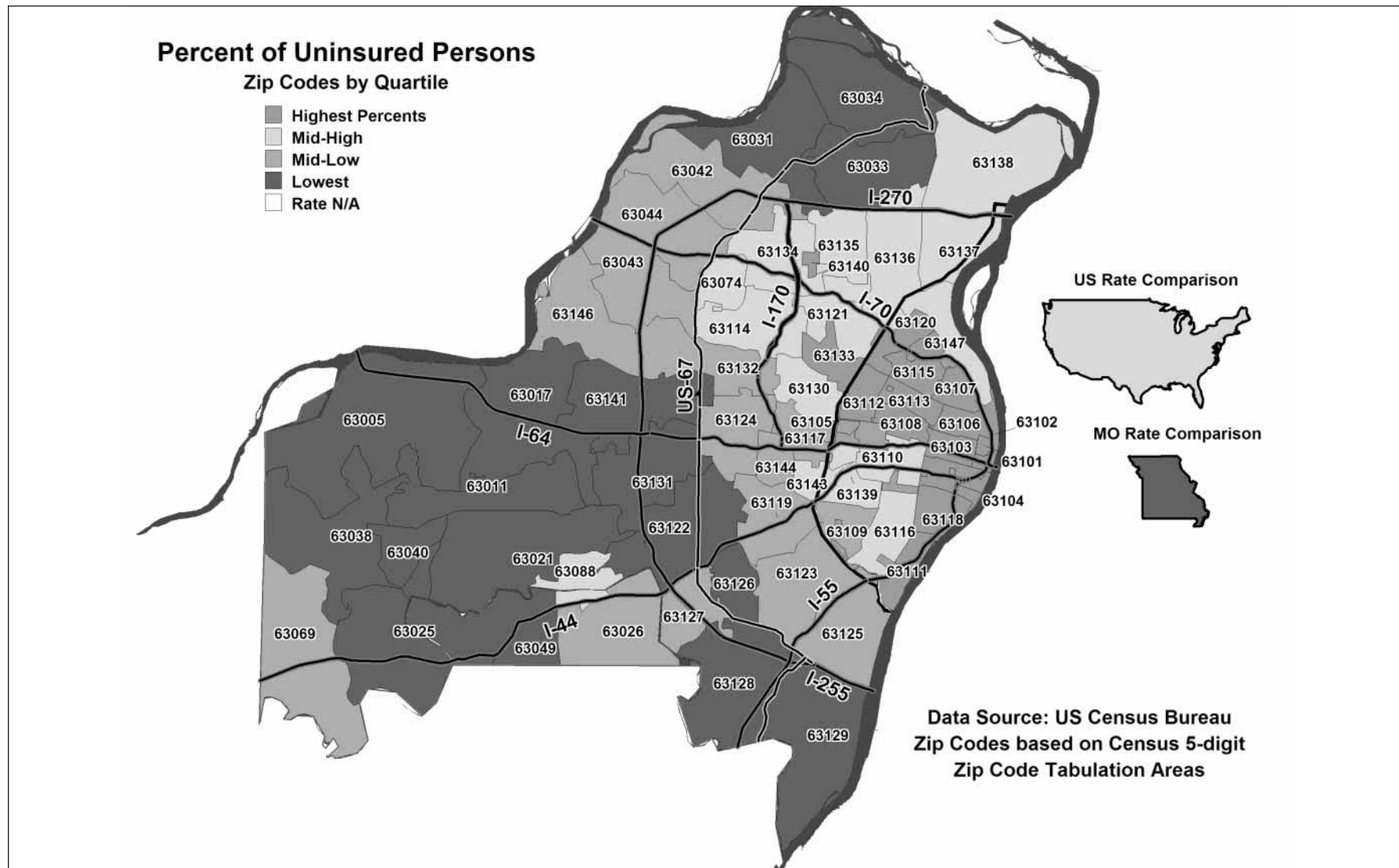
129,000	UNINSURED AT ANY POINT IN TIME
22,000	ADDITIONAL UNINSURED FOR SOME PERIOD OF TIME OVER A YEAR
151,000	TOTAL UNINSURED INDIVIDUALS DURING A 12-MONTH PERIOD OF TIME

For a more robust description of this topic and the modeling techniques that were utilized, please refer to Appendix 9 of this report.<sup>5,9</sup>

To be conservative in its estimates, the RHC has chosen to use the figure of *129,000 uninsured in the region* for planning calculations utilized in Section IV. However, it must be acknowledged that this figure represents the low end of the range for the potential number of uninsured in the region, and that at least 22,000 additional individuals may be impacted by the problems associated with a lack of insurance in any given year. It also must be reiterated that this estimate does not take into account the fact that thousands of individuals in St. Louis City and Saint Louis County are no longer eligible for Medicaid benefits due to Missouri legislative action in 2001. Also, these rates could be even more substantially impacted by proposed legislative action in the 2003 Missouri General Assembly to reduce the number of eligible residents covered under the Missouri Medicaid program, as discussed in greater detail in Section IV of this report.

Utilizing the U.S. Census Bureau data as referenced above, the uninsured in the St. Louis City and Saint Louis County region are estimated to be distributed across the region, as shown by the following map:<sup>5,8</sup>

DISTRIBUTION OF UNINSURED PERSONS IN ST. LOUIS CITY AND SAINT LOUIS COUNTY, BY ZIP CODE



## 2. Cost of Care and Medical Debt

The cost of medical care and prescription medications poses a serious barrier to care for safety net patients. One St. Louis focus group participant spoke to this problem:

*“...their medicine is literally wiping them out, totally wiping them out to where they can’t even...pay the rent, partial on utilities, medicine, and whatever they can basically scrounge from missions, canned goods, food or whatever, and personally, this is totally, totally wrong.”*<sup>5.2</sup>

The vast majority of the approximately 129,000–151,000 uninsured in St. Louis City and County are employed, but they have jobs that do not provide health care benefits. Due to eligibility requirements of the Medicaid program, governmental programs do not cover these individuals. At the same time, the cost of private insurance can be prohibitive for these citizens, especially since many of the jobs that do not include health insurance coverage are low paying as well. As discussed previously, lack of insurance is associated with decreased access to care and worse health outcomes. It also leads to medical debt, which has its own repercussions—and for more than the uninsured individual.

Medical debt may create a downward spiral capable of consuming all aspects of a person’s life: job, house, family, and social/psychological status. The spiral begins when an uninsured individual is either discouraged from seeking care or is unable to get it. The Access Project found that 46% of the people surveyed in a recent study were indebted to their safety net care center, and 26% said that their debt would deter them from seeking care in the future. This was noted by respondents as follows:

- *“I am ashamed to take my kids to the physician because I think they know I owe \$35.”*
- *“I still owe [for] the operation on my breast and I don’t visit the clinic because I am afraid that I won’t be able to pay.”*
- *“I am embarrassed by my old bill. The office staff makes you feel uncomfortable about the bill. So I pray I never have a dire emergency.”*<sup>5.10</sup>

A neglected medical condition then worsens, sometimes past reversible stages, and can exacerbate existing medical conditions or lead to new ones. (For example, an untreated leg injury decreases mobility, which pushes a weight-control problem into frank obesity with all its associated, long-term effects.) Often, care is postponed until the condition becomes unbearable, at which time the person comes (or is brought) to an Emergency Department, where they are treated at great cost to themselves, yet do not necessarily receive appropriate follow-up and ongoing care – the very care that might have prevented the problem to begin with. Meanwhile, more debt accumulates, raising the person’s threshold for seeking or being able to obtain care, for the underlying logic is unchanged. Little opportunity exists for breaking this downward spiral.

Eventually, the whole family may be pulled into the vortex. People with medical debt become the target of aggressive collection agencies. Many lose their credit, jobs, or job opportunities, and even their homes. In many states, “personal bankruptcy can be viewed as an insurer of last resort for families in that it allows them to protect certain assets such as their home or retirement accounts”.<sup>5.11</sup> A national survey found that one in every four people in debt identified an illness or injury of themselves or a family member as a reason for filing bankruptcy. “A good health insurance policy,” Daly concludes, “is protection against financial ruin for many Americans.”<sup>5.11</sup>

What financial assistance and/or counseling is available to help people with medical debt? Unfortunately, this has been a neglected aspect of health care delivery. The Access Project survey found that “while only 3 of 10 respondents said [hospital] staff ‘always’ offered to look into possible assistance for them, nearly half – 48% – said staff ‘never’ offered such help when financial assistance was offered, it was most often an offer to allow payment of the full bill in installments (32%), as opposed to discounting (12%) or waiving (13%) the bill”.<sup>5.10</sup>

There are many unintended consequences of the system. First, through this spiral, even insignificant amounts of medical debt can trigger very significant costs for the individual, their families—and eventually society. Second, people can actually be discouraged from obtaining a second or better job to help pay medical and other bills because, for example, their children might lose health coverage under the Children’s Health Insurance Program (CHIPs) as a result. Perhaps the cruelest irony is that medical care is often most expensive for those who can least afford it.<sup>5.10</sup> Almost one in five hospitals do not offer reduced rates to the uninsured, who are billed at higher rates than people who belong to large insurance plans that negotiate volume discounts.<sup>5.11</sup>

### 3. Prioritization of Other Needs Over Health Care

It is difficult for some uninsured and underinsured people to view health care, particularly preventive health care, as a priority because they are dealing with many other pressing needs, often associated with poverty.

*“Family crises, often created by poverty, made it difficult, if not impossible for participants to make health care decisions. This often placed the health of children or dependent family members at risk.”<sup>5.2</sup>*

One focus group participant described the need to choose between health care and paying the utility bill:

*“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.”<sup>5.2</sup>*

Another focus group member explained that for some low-income families, poor health is only one of many problems they face on a day-to-day basis.

*“We made a home visit on a family in north St. Louis to, um, because they had missed preventive care...Obviously they were in health crisis...but [the mother] didn’t know where to begin. There were so many layers to peel away from this family that to get to their health care was...and they definitely had health care needs.”<sup>5.2</sup>*

In many cases, people do not seek care until their health problems become serious. Some participants “reported that they waited until they could not take the pain or discomfort any longer and then went to the emergency room”.<sup>5.2</sup>

### C. Cultural Barriers

#### 1. Stigma Associated with Safety Net Care

Some uninsured and underinsured people are reluctant to seek care due to the stigma associated with relying on the safety net system. Kurz and Scharff found that some focus group members did not want to accept assistance.

*“Several participants expressed the belief that they were responsible for taking care of themselves and their families and had a desire not to have to rely on the system taking care of them.”*<sup>5.2</sup>

While services may be available, a desire to be self-reliant causes some people to choose not to seek them, particularly in non-urgent situations.

#### 2. Lack of Respect Toward Safety Net Patients

The quality of personal interactions between safety net patients and their health care providers is often mentioned as a reason people avoid seeking care.<sup>5.3, 5.2</sup> Kurz and Scharff found that “many participants felt that health care providers did not respect them.”<sup>5.2</sup> Often, the health care providers included not only the physicians but also the nursing, reception, and auxiliary staff.

Participants reported situations in which they felt they were treated disrespectfully:

*“I would say that—again, it wasn’t discrimination, but I wasn’t treated well in the office of a pediatric doctor. He was just talking around me, you know. And when I went to pose a question to him, it was like, ‘Okay, this, this, and this—don’t you understand? Don’t you know?’”*

*“...I had been going to that doctor for a long time and he had some new receptionists, which they were very arrogant. I mean when I say arrogant, I do mean arrogant.”*<sup>5.2</sup>

While this example is from a private physician’s office, patients report similar situations at safety net clinics. In particular, safety net patients felt they were treated differently than patients with private insurance.

Focus group participants also reported being treated poorly during registration:

*“Well, one, when I entered the place, they didn’t even acknowledge me for one. For two, I’m standing at the desk, I sign my name in, which two more other people come in – I’m still standing here...They talked over me talking to them as if I wasn’t even standing there. I’m just a piece of the furniture at this point.”*<sup>5.2</sup>

Participants cited an “uncaring atmosphere”<sup>5.3</sup> and a concern that “administrative processes took precedence over medical care”.<sup>5.2</sup> Many participants in the Episcopal-Presbyterian Trust study commented that although a health care provider might not think patients were being treated disrespectfully, the situation was “interpreted that way by patients, and therefore was very real to them.”<sup>5.2</sup>

#### 3. Cultural Barriers for Minorities

There are significant cultural barriers to care that limit access for minority populations to the health care system and possibly result in minorities receiving either inappropriate or inadequate care. The cultural differences between health care providers and patients can shape the health care encounter and affect the quality of care received by the patient.<sup>5.12</sup>

The cultural barriers include but are not limited to:

- Ethnic, racial and other forms of discrimination that interfere with appropriate diagnoses and treatment.
- Lack of culturally sensitive providers.
- Cultural values about health care that limit how and when minorities seek health services.
- Historical discrimination and medical mistreatment that result in distrust of the health care system.

One significant cultural barrier to health care is the discrimination experienced by some minorities who feel they are victimized because of negative stereotypes about their race, gender, or other demographic grouping. These negative patient-provider encounters result in the development of a general mistrust of the medical and health care system.

A recent study by a Georgetown University doctor found that black patients complaining of heart pain were 40% less likely to be referred for a top-notch diagnostic test for heart disease. The researchers believe the disparity in care occurs because some doctors perceive black patients to be poorer than white patients.

Many minorities perceive the health care system as hostile and culturally insensitive to the needs of minority populations. Historical evidence of medical mistreatment and neglect, combined with confirmed cases of inhumane treatment of minorities, such as the infamous Tuskegee Experiments, which intentionally left African-American men untreated for syphilis, only serve to reinforce minorities' suspicions concerning the health care system.<sup>5.13</sup>

Some minority populations have historically preferred traditional, ancestral, or spiritual healing over western medicine and only seek the health care system when other interventions fail. These cultural values about health care create a significant barrier to health care and may impede the ability of the health professional to properly diagnose the patient.

Also, the lack of culturally sensitive providers may cause patients to be apprehensive about seeking care. Fearing they may be stigmatized by health care professionals, patients may postpone care or not seek care at all. When these patients access care they are at risk for being misdiagnosed. For example, some patients seeking psychological help have tended to communicate their sense of distress to health care professionals as physical complaints, such as non-specific pain, weakness, and/or fatigue. This phenomenon reflects culturally traditional modes of seeking help and views of what is relevant to bring to a medical setting, and may result in improper diagnosis and treatment.

Finally, the cultural competence of the provider is another significant barrier to health care. A large body of literature has documented significant racial and ethnic disparities in health care and health outcomes, with minority patients receiving less health care and suffering worse health. Many minorities face barriers to accessing health care and to receiving appropriate treatment.<sup>5.14</sup>

Providers can unknowingly impose their own cultural understandings and values upon patients from differing cultures. This can impede the provider's ability to collect information regarding the patient's medical history and present problems in the context of the patient's cultural background.<sup>5.15</sup>

#### 4. Cultural and Linguistic Barriers for New Americans<sup>1</sup>

The immigrant and refugee population in St. Louis City and Saint Louis County has grown rapidly over the past two decades, and now makes up approximately 5% of the total population in our region, according to data from the 2000 U.S..

*Foreign-Born Residents—Bureau of the Census, 2000*

COUNTY	EUROPE	ASIA	AFRICA	N/S AMERICA	TOTAL	% OF TOTAL POPULATION
STL CITY	8,543	6,538	1,500	2,961	19,542	5.6%
STL COUNTY	14,042	19,198	2,306	7,156	42,702	4.2%
TOTAL	22,585	25,736	3806	10,117	62,244	4.6%

Although more recent Census data is not available, community groups that work with new American<sup>1</sup> populations believe that the number of foreign-born residents is actually greater than 62,244 due to a significant influx of immigrants and refugees since 2000, as well as significant undercounts in Census data, particularly for undocumented and recent arrivals.<sup>5,16</sup>

The influx of foreign-born residents is reflected in the populations served by the safety net providers. In a survey of Institutional Safety Net Providers in the St. Louis community, 13 of the 33 sites reported that over 10% of their clients do not have English as their primary language. Of these 13 sites, five reported seeing over 10% Spanish-speaking residents, four reported seeing over 10% Bosnian/Serbian/Croatian residents, and one reported seeing over 10% Vietnamese residents.<sup>5,1</sup>

It is anticipated that the number of new Americans seen by safety net providers will continue to grow as the refugee and immigrant population increases, and as foreign-born residents access the health care system in greater numbers.

The RHC, in partnership with the International Institute and the City of St. Louis Mental Health Board of Trustees, recently conducted two focus groups concerning the ability of new Americans to access the health care system. The focus groups included physical and mental health care providers that frequently serve new Americans, as well as representatives from community organizations who work with this population. These sessions highlighted the fact that in addition to all the barriers listed in Section V of this report, refugees and immigrants also encounter unique barriers to accessing the health care system in our region, including:

- Language barriers
- Obtaining information on where to go for care, and how the American health care system works
- Fear of deportation or detainment, even for those that are legally in the country, especially given the amount of information asked for by health care providers
- Cultural barriers
- Fear and lack of understanding of “modern” medicine and westernized medicine providers

In addition, there are a number of physical diseases and conditions that particularly impact new Americans, including dental problems, nutritional deficiencies, untreated and under-treated chronic conditions and diseases, and disfigurement from trauma and war violence, which underscore the importance of adequately serving this community.

<sup>1</sup> The term “new Americans” generally refers to newly arrived immigrants and refugees, and also includes undocumented and migrant workers.<sup>5,16</sup>

Refugees and immigrants are also disproportionately affected by mental health issues, often due to trauma associated with war or violence in their home countries or difficulty in adjusting to a new language and culture. Some specific mental health issues include:

- Post Traumatic Stress Disorder (PTSD) and other consequences of oppression and trauma experienced by refugees
- Depression
- Anxiety
- Adjustment to new culture
- Grief

A more detailed analysis concerning the particular barriers faced by new Americans in our community can be found in Appendix 10.

### 5. *Lack of Health Literacy*

The Institute of Medicine’s recent report, “Priority Areas for National Action: Transforming Health Care Quality”<sup>5.17</sup>, identifies health literacy/self-management as one of 20 top priorities in health care. It is also one of only two (along with care-coordination) identified as “cross-cutting:” applicable to people of any age, race, gender, income level, and health status. As such, health literacy is a cornerstone of an effective health care delivery system. A person is health literate if she/he is able to comprehend and act on basic health information. Although low health literacy affects mostly white, native-born Americans, it disproportionately impacts minorities, the elderly, and the poor (50% of Hispanics, 40% of blacks, 33% of Asians, 66% of the elderly, and 45% of the poor)<sup>5.18</sup>.

There is a correlation between basic literacy and health literacy. Approximately 92 million U.S. adults (46%) are either functionally illiterate or marginally literate, according to the National Adult Literacy Survey (AMA, 1999). In other words, almost half of adults read at or below the 8th grade level. According to an article in the *New England Journal of Medicine*:

*“Educational materials for patients and informed-consent documents present highly complex information that must be understood by patients. This complexity is a major barrier to comprehension for...American adults with low literacy skills. A low level of literacy is independently associated with poor health outcomes and billions of dollars of additional annual health care expenditures...The text of informed-consent documents can be written at a 4th grade level.”*

A survey by the American Medical Association (AMA) found that 46% of U.S. adults are functionally illiterate in dealing with the health care system. The AMA estimates additional direct and indirect U.S. expenditures due to health illiteracy at \$73 billion annually, with employers shouldering up to 17% of this burden.<sup>5.19</sup> No comparable studies for St. Louis or Missouri have been performed to our knowledge.

Being health literate is essential for staying healthy, and for actively participating in one’s own management when medical care is required. Multiple research studies demonstrate that people with low health literacy are more likely to be non-compliant with treatment plans,<sup>5.20</sup> make medication errors<sup>5.21</sup>, and require hospitalization<sup>5.22</sup> than health literate people.<sup>5.23</sup>

However, other studies indicate that health education alone is not always enough to markedly change health outcomes. An example is a famous study, the “Multiple Risk Factor Intervention Trial,” performed in the 1970s. The study included over 12,000 men at risk for cardiovascular disease. Men in the control group had results of a screening exam and laboratory tests sent to their primary physicians, with no other intervention. The treatment group additionally received extensive counseling on behavioral modifications to reduce risk factors for cardiovascular disease, focusing on hypertension, cholesterol, and smoking. The counseling was performed both individually and in group sessions, by a team of physicians, nurses, nutritionists, and behavioral scientists, every four months for six years. The study found real but small changes in risk factors, and no statistically significant difference in mortality, between the two groups.

Several smaller recent studies reach conclusions of a similar vein. The Institute of Medicine’s previously mentioned report identifies a few noteworthy examples. Examining the impact of self-management education and regular practitioner review on adults with asthma, one study found statistically significant decreases in episodes of nocturnal asthma, hospitalizations, emergency room visits, unscheduled doctor visits, and days lost from work.<sup>5.25</sup> A more recent analysis by Gibson et al. of similar randomized controlled trials concluded that education influenced outcomes only when coupled with goal-oriented treatment plans involving self-monitoring and regular physician review.<sup>5.26</sup> Likewise, an analysis of self-management training for diabetics by Norris et al. concludes that “factors other than knowledge are needed to achieve long-term behavioral change; ... improved motivations are more effective than knowledge in improving metabolic control in type II diabetes”.<sup>5.27</sup>

This body of evidence suggests that improving health outcomes through interventions aimed at increasing health literacy and self-management requires the following (short of a raise in educational levels in general):

- *Presentation of health information in a culturally sensitive manner and tailored to the educational level of the patient.* It is important to recognize that one size does not fit all. For example, the patient is a health-care professional, give her/him a medical review article; if college educated, pamphlets and an Internet web site; if Spanish speaking and educated, the same—in Spanish (if available); if Spanish speaking and undereducated, pictographs with bilingual instructions. Verbal communication must accompany written and graphic material.
- *Personal contact and active review by practitioners in a goal-oriented treatment program, preferably in an ongoing doctor-patient relationship.*
- *Motivation of the individual to be a participant in his/her own care.*