



Putting a Face on the Uninsured

October 2003

The Gilead Outreach and Referral Center
312.906.6024 - www.gileadcenter.org
info@gileadcenter.org



Research conducted by Metro Chicago Information Center
312.580.2878
www.mcic.org

Gilead Outreach and Referral Center: Putting a Face on the Uninsured

BACKGROUND	3
METHODOLOGY	3
FORMERLY INSURED, 40 – 55 YEARS OLD	4
OTHER INSURED/UNINSURED IN HOUSEHOLD.....	5
JOBS AND HEALTH INSURANCE.....	5
COBRA.....	6
NEEDED HEALTH CARE	6
DELAYED CARE	7
SELF PAY	8
HIGH-INCOME HOUSEHOLDS WITH UNINSURED MEMBERS	8
LOSING COVERAGE.....	8
OTHER INSURED/UNINSURED IN HOUSEHOLD.....	9
JOBS AND HEALTH INSURANCE.....	10
COBRA.....	10
NEEDED HEALTH CARE	10
WHERE FOUND HEALTH CARE	11
DELAYED CARE	11
PAID FOR CARE.....	12
SMALL BUSINESS OWNERS	12
BUSINESS PROFILES	12
OFFERING HEALTH INSURANCE.....	13
EMPLOYEE COVERAGE	13
GETTING HEALTH CARE	14
BUSINESS IMPACT.....	15
PRIORITIES.....	16
POLICY RECOMMENDATIONS	16
SUMMARY OF KEY INFORMANT INTERVIEWS	19
PRACTICE/SERVICE AREA CHARACTERISTICS AND CHANGES.....	19
CHANGES IN INSURANCE/LACK OF INSURANCE/REIMBURSEMENT/PAYOR MIX	20
UNCOMPENSATED CARE – WHO GETS IT? WHAT ARE THE IMPACTS?.....	20
WHO ARE THE UNINSURED? WHERE DO THEY GET SERVICES?.....	21
WHAT OTHER CHALLENGES ARE FACING THE HEALTH CARE SYSTEM?.....	22
IN CONCLUSION: FOUR THEMES	23
BOARD OF DIRECTORS.....	25

Background

The Gilead Outreach and Referral Center is a non-profit organization that connects uninsured individuals and families throughout metropolitan Chicago with affordable health care programs for which they are eligible. Founded by United Power for Action and Justice — a broad, metropolitan coalition of religious organizations, labor unions, health care organizations, community organizations, and other interested groups — the Gilead Center seeks to narrow the gap between affordable health care and community need.

To advance its mission, Gilead Center conducts research and advocacy to raise awareness of the uninsured in Illinois. In winter 2002, the Gilead Center released a report, [The Uninsured in Illinois: Who They Are and Where They Live](#), a statistical analysis of the March 2002 Supplement to Current Population Survey dataset on health insurance. As a companion to that report, Gilead Center hired MCIC (Metro Chicago Information Center) to conduct qualitative research to enrich the statistical perspective with the personal stories and experiences of some of the key groups profiled in the statistical report.

Methodology

This research included two parts: key informant interviews with hospital administrators and primary care physicians representing Chicago, the suburbs, and downstate Illinois, and series of small-group guided discussions conducted with three different types of groups. Findings from the key informant interviews informed the discussion guides for the small focus groups. A summary of those interviews is included in this report.

This research targets three different groups whose circumstances and experiences are particularly illustrative of the expanding nature of the crisis of uninsurance in Illinois: formerly insured people ages 40-55, those with household incomes above \$75,000 per year, and small business owners.

- The members of the formerly insured group ages 40-55 are typically unemployed or underemployed. This age group may be facing the strain of supporting children and parents while unemployed and subject to increasing health care needs as they age. In addition, they may face particular challenges in the current labor market.
- The high-income group included individuals from households with incomes of \$75,000 or more that have one or more uninsured household members.
- Small business owners were included because so many people get their health insurance through their jobs, and small business owners are particularly sensitive to two factors in the current crisis: the recent weakness of the economy and soaring health care costs.

To recruit individuals for these groups MCIC used a number of strategies. The first was asking key informants interviewed for the first phase of the research for their suggestions and any helpful contacts they could provide. The most effective suggestion was placing advertising in local papers. Ads placed in the *Chicago Reader*, a free weekly alternative newspaper distributed in Chicago and the surrounding suburbs, were particularly

Gilead Outreach and Referral Center: Putting a Face on the Uninsured

effective; almost all of the participants in the groups conducted in Chicago were recruited through ads in the *Chicago Reader*. MCIC also placed ads in suburban papers, the *Springfield Journal-Register* and the *Decatur Herald & Review*. MCIC also tried cold-calling businesses and distributing information in person to local businesses in Naperville. Other strategies included soliciting the cooperation of local social service agencies in posting fliers in their facilities or telling staff and clients about the project. Focus group participants were paid a stipend of \$125 - \$200 for their participation, and attendance rates were consistently high in the Chicago area. Despite vigorous recruitment efforts, participation in the Springfield area was significantly lower, probably due to the smaller market size and lower familiarity with focus group research

MCIC conducted small group discussions with a total of 37 people: 20 people in Chicago, 14 people from the suburbs surrounding Chicago, and three people downstate. Response was greatest for the unemployed group and weakest for the \$75,000+ households, as the table below illustrates:

Participation by Group/Site	Chicago	Suburbs	Downstate
Uninsured, 40-55	8	5	2
\$75K+ Household	6	4	0
Small Business Owners	6	5	1

This report will combine the participant information for each type of group, noting any differences linked to geography. Quotes are identified by geography and gender of the speaker in parenthesis after the text.

Formerly Insured, 40 – 55 years Old

In the United States most people under 65 years of age obtain health insurance as an employer provided benefit option for the individual employees and often this benefit can be extended to the dependent family members of the employee. When the employment ends options to continue that insurance coverage are available for various periods of time.

Discussion groups talked about losing health insurance when their employment ended. A total of 15 people participated in focus groups for unemployed or underemployed people age 40 to 55. Eight of the 15 were male and seven were female. None of them had health insurance, and the majority had not had health insurance for over a year. Each group contained participants with a range of time without health insurance. The shortest time without health insurance was two months, and the longest was seven years.

Loss of Insurance Coverage

The majority of unemployed focus group participants lost their health insurance when they or their spouse lost their jobs that had provided their health insurance. Other causes for loss of health insurance that were mentioned were divorce, rising costs, and being dropped by the insurer.

Gilead Outreach and Referral Center: Putting a Face on the Uninsured

- *When I lost my job, I lost my insurance. My husband lost his job after me. The only job he can take is out of state, and I have a home, I don't want to do that. (Chicago)*
- *I have a chronic disorder; I was dropped from my insurance. I wouldn't be insured even if I was working. They said we will cover you for a cold, for your health, but not for the essential problem, nothing related to the ongoing problem. The insurance company paid \$11,000 for a procedure, and asked, "Is he going to get better?" Well, no. So they don't want to pay that much every time you have to have a procedure, and it is not making you better... They're an insurance company, they can do whatever they want. (Chicago man)*
- *I had that same insurance for years and years. I stopped because I don't have any money. It's a family situation (Suburban woman).*

Other Insured/Uninsured in Household

The majority of the participants in the unemployed groups report that there are no insured people in their households. About half of these completely uninsured households are single-person households, but a number of participants reported that their partners or children also lacked health insurance.

- *I have a young son who is not insured. I live with a woman who works part-time, and is not insured. (Chicago woman)*
- *I live alone. (Suburban man)*
- *No one in our household is working so we can't get health insurance. My husband is overqualified for everything. (Chicago woman)*

Jobs and Health Insurance

The comments of unemployed group participants suggest that changes in the labor market and the insurance industry have significantly increased the challenge of securing a job with health insurance. It is harder to find jobs; perhaps particularly for people in this age group, and available jobs are less likely to offer health insurance.

- *[When you apply for a job] you don't wait for them to call you anymore, you have to call them. They make you take all these personality tests, then the insurance is not that good anyway. (Chicago man)*
- *You don't think, "I need to go find a health plan," you think you need to go find a job. And with that job comes health insurance. I got this job in Lincoln Park and went the first day, and when they said there's no health insurance, I just didn't go back. (Chicago man)*

Gilead Outreach and Referral Center: Putting a Face on the Uninsured

- *I used to have an old guy working for me when I ran my own business. He had a heart condition. His health insurance rates kept going up, up to 25 percent a year. I told him that I would only cover him on half of the increase. He quit because of the loss of pay. This was a responsible guy, a highly skilled asset to my business. I couldn't pay for him because he had health problems. He retired and gets Medicaid. (Springfield man)*
- *I have no problem working for small jobs. People want work done. I can't find enough work to pay for health care or health insurance though. (Springfield man)*
- *They don't want to hire full time but on a contractual basis. It doesn't supply a stable income. How can you possibly budget \$340 a month for health insurance? (Springfield man)*

COBRA

Nearly all the focus group participants were familiar with COBRA, and a number of them had been offered the opportunity to continue their health coverage through the act. Very few had ever been on COBRA, citing the high cost and their lack of income.

- *You should be able to get COBRA after you've been let go, but you have to pay the whole cost. That's like a car payment! (Chicago woman)*
- *But how can you pick it up when it's \$450 [and you're unemployed]? (Chicago man)*

Needed Health Care

Most of the unemployed participants in the Chicago and Suburban focus groups reported needing health care, dental care or eyeglasses at some point when they were uninsured. Neither of the Springfield participants reported that they needed health care other than dental services or eyeglasses during the time they had been uninsured.

- *I don't go to the doctor that often, so some of the things that are offered to me, I don't use. As I have gotten older, I realize that there are some things I need, health wise, that I did not need before. (Chicago woman)*

The majority of participants in the Chicago group and a couple from the suburban group sought care through Cook County and talked about their good and bad experiences with the old Cook County Hospital and the new Stroger Hospital. Many believed that you could get good quality care if you were willing to wait. A number of participants mentioned the University of Illinois at Chicago Dental School as a provider of free dental care, but they noted that the clinic will only see the first 50 patients in line each day. On the whole, they were able to find some of the care they needed, but noted significant challenges in meeting their health care needs.

- *Since then I have been going to the county. I had an operation and had my tonsils removed. My name was missed in their records and I had to write down*

Gilead Outreach and Referral Center: Putting a Face on the Uninsured

everything again...I had to wait three weeks and I was sick as a dog. I went to Rush. It was \$1,300 and paid out of pocket by my sister. This was two years ago. (Suburban woman)

- *I haven't had anything major happen to me where I had to pay for it monthly. If I did, then I am going to go to Stroger. If you have a certain amount of money, why pay the doctor, save that, pay off some bills and go to Stroger instead. (Chicago man)*
- *It doesn't matter how much you wait, if you don't have the money, you don't get the honey. You could need a bypass and they wouldn't give it to you if you can't pay. (Chicago man)*
- *I had to stop seeing my psychiatrist. I set up an appointment for an evaluation. You get free evaluation through the county. I can't get in until September. I have enough of one medicine. I'm hoping and praying about something for work. ... I am trying to get a job. I will have to buy some on my own. ...I am halfway afraid of looking into getting my own [health insurance] because of my preexisting conditions. (Suburban woman)*
- *I wanted to get good care, and I did not want to have to wait too long at Cook County. So I ended up going to Rush. I didn't want to have to wait. And I wanted a good doctor. (Chicago woman)*

Delayed Care

Participants report delaying care, particularly for dental problems, and not getting preventative care and screenings. They delay care primarily because they cannot afford it, but also because they fear what they might find and not be able to get treated. Some, particularly in the Springfield group, are ashamed that they do not have health insurance. A provider in Springfield noted that they see some people without insurance who are so ill they can barely breathe and who have put off treatment because they could not afford to incur the additional expense.

- *I don't have the money for the three crowns [dental]. I don't know what I will do. You will have to come up with it upfront.(Chicago man)*
- *I put off getting a physical. I got that superflu in January when I did have health insurance. I live day to day. I'm 44 and not getting a younger. There is a history of cancer but I can't get screened. (Suburban man)*
- *I am worried about PSA for prostate cancer. I can't afford it. Also, I had high triglyceride and cholesterol. I don't want to go in and get it checked. I am trying to eat healthy. (Suburban man)*
- *Is there shame? He lost his job. He didn't want to come. He didn't want to talk about it. I am not proud of it. (Springfield man)*

- *I am ashamed for not having health care. I just put off dental. (Springfield man)*

Self Pay

A number of participants reported getting free health care through Cook County and the University of Illinois at Chicago Dental School. Others reported paying for small medical expenses, dental care or eyeglasses out of pocket. Several reported seeking screenings and treatment through health fairs and research studies. Very few of the unemployed focus group participants reported carrying a large health-related debt, but several knew people with health-care debts.

- *I hate to wait. I have a doctor who takes care of me for minor things. I pay for it. (Chicago woman)*
- *Yes, free samples, my doctor gives me free samples. (Chicago woman)*
- *I know there are studies here and there. I am a smoker and I was going to do it. It was a three-year study. I worry. (Suburban man)*
- *I have a friend with a couple of girls. She finally got health insurance working for the state. She was in debt from [medical] bills and had to finally file bankruptcy. (Springfield man)*
- *I know people carrying debts. Pretty much lifetime. I don't think it will go away paying what they are each month. They cut a deal from the hospital. For approximately \$50,000. (Springfield man)*

High-Income Households with Uninsured Members

A total of ten individuals from Chicago and the suburbs participated in two group discussions for members of households with annual incomes of \$75,000 or more where one or more members are uninsured. Eight were male and two were female. Seven of the participants themselves had no health insurance.

Losing Coverage

Participants were about evenly divided between those who were uninsured because of their work status (either losing their job or not receiving health insurance through their job) and those who lacked insurance for reasons unrelated to their work status. Divorce was a common reason for people to lose health insurance coverage, particularly for self-employed men.

- *There's no one else in the household anymore since I am divorced. My children are covered by my ex-wife's insurance. (Chicago man)*

Gilead Outreach and Referral Center: Putting a Face on the Uninsured

- *I was on the company plan, but I'm now self-employed. I had it but think it is ridiculous. For me it is not good. I have been out of a plan about a year and a half but still looking. (Chicago man)*

Some people are more adept or luckier than others at navigating the system to obtain coverage when they need it. One participant was confident that she could find a job that would provide health insurance. Another participant reported that his wife was uninsured because she was excluded during the waiting period due to a pre-existing condition.

- *Some temp agencies offer insurance if you work for them long enough. There are part time jobs out there that will cover you too. I worked at the Chicago Chop House, and agreed to work 20 hours a week if they gave me health insurance. (Chicago woman)*
- *My wife had coverage. She has a preexisting condition. She is in the waiting period. She is not getting any insurance. I believe it is a 12-month waiting period... If you have continuous coverage without a break there's no problem, but if there is a break, you could have trouble. (Suburban man)*
- *My mother is diabetic and also has liver problems, due to Hepatitis C from a blood transfusion in Mexico in the 80s. She goes to Cook County and they have some of the best doctors. I would love to have insurance for her, but now no one would take her. (Chicago woman)*

For about a third of the participants in the high-income uninsured groups, the issue of not having health insurance seemed to be conscious choice of not pursuing available options. Health insurance is expensive, and some of the participants were willing to risk not having coverage.

- *I could get insurance now, but it is more than I want to pay. I gamble for a living, so it's just another gamble, until I get married to another schoolteacher. I refuse to pay what they're asking. (Chicago man)*
- *For a young, healthy person, it seems unnecessary. (Chicago man)*

Other Insured/Uninsured in Household

Most of the households represented by participants in the high income groups had only one uninsured member. Four were single person households; in other cases the uninsured individual did not qualify, was not offered, or did not ask to be covered by the insured persons' policies. The high-income households with more than one uninsured member tended to include grown children.

- *My brother is also without health insurance. We are all living at home but too old to be on our parents' insurance. I was in sales, but they just said adios, laid me off. (Suburban man)*

- *My partner has insurance, and I could probably get coverage, but he would have to ask his boss, and he does not want to ask his boss. Even though we have lived together for 10 years, we are not married and we're not going to get married, so he doesn't want to ask his boss. (Chicago woman)*

Jobs and Health Insurance

The current jobless economic recovery is a negative indicator for the currently uninsured individual and small business employers.

Like most insured individuals, the insured participants with high incomes all received their health insurance coverage through their jobs. Most of those who were uninsured were self-employed, unemployed, or working for a company that did not provide health insurance.

- *I have insurance through my job at the Chicago Public Schools and, I take advantage of having insurance. They have good health insurance through CPS. I wish I could get my mom on my health insurance. (Chicago woman)*
- *I will get it under my current employer [after the waiting period ends]. There generally has to be a better way. (Chicago man)*

COBRA

Most of the focus group participants were familiar with COBRA and were able to accurately describe the provisions of the act to the one person who was not familiar with it. Several people had considered extending their coverage through COBRA but either decided against it or dropped it after a few months, citing the expense, their general good health and their expectation of finding another job soon.

- *I knew the job market would be way down, and because I knew I would be temping, I wouldn't make the money that I would need to cover COBRA. (Chicago man)*
- *I was eligible. But I thought I was going to get another job so I didn't take it (Suburban man).*
- *For a young, healthy person, it seems unnecessary. (Chicago man)*

Needed Health Care

Needing health care and having pre-existing conditions were important factors cited by a few people as reasons for why they or someone in their household did not have health insurance. While the majority of participants did not discuss significant health problems, many of them reported receiving health care, dental care or eye care while they were uninsured.

Gilead Outreach and Referral Center: Putting a Face on the Uninsured

- *Yes, she got it through a friend. They charged a sliding scale. I think that a lot of doctors will work with you. My ophthalmologist said that he would work with me. It shouldn't get to that point if I ever become uninsured. But what about a catastrophic problem? I would lose my savings and worse. (Suburban man)*

Where Found Health Care

Most of those who needed health care obtained it from the private sector, although a couple of respondents reported that they or the uninsured members of their household received care through the public sector at Cook County Hospital. A hospital administrator in Chicago noted that recent hospital closing and the conversion of two hospitals from non-profit to for-profit shifted the burden of caring for the uninsured to the remaining non-profit hospitals.

- *There are always people who help you to a degree. I have a gynecologist who gives me a cut rate because I don't have insurance. (Chicago woman)*
- *My doctor is a family friend. I call him and he calls in the prescriptions that I need. Then I pay for them. My annual physical I paid for out of pocket. (Chicago man)*

Participants in Chicago groups had higher levels of awareness of and comfort with care provided at Cook County Hospital. In the suburban group respondents were less aware of any resources for low-cost health care.

- *Yes, [Cook County Hospital is free] if you don't have insurance and you don't have a job... if you go to the ER you take a risk that you will wait a very long time, but they have very good doctors. (Chicago woman)*
- *I went to Cook County and waited 6 hours, then went to St. Joe's and they treated me fine. If you have a problem, go to St. Joe's; they told me what was wrong. They didn't fix it, but I don't need to worry about it because I know what it is. (Chicago woman)*

Delayed Care

Some participants in the high-income group may delay some care, particularly routine preventative services, but many seem to have the resources to seek care when they feel they really need it.

- *I take medication that I have to pay for, but I haven't been to the doctor. (Chicago man)*
- *I have had a leg problem and toe fungus, and I haven't been able to get medicine because it would be like \$800. I think I'll have to wait on that until I get health insurance at some point. (Chicago woman)*

Gilead Outreach and Referral Center: Putting a Face on the Uninsured

- *I'll probably just die anyway. If I got sick I'd have to just pay for it – I'd sell the house, the car, and the boat if I had to. (Chicago man)*

Paid for Care

Most of the uninsured that reported getting health care reported paying significant sums out of pocket. Two of the participants in the Chicago group were effectively self-insured. Both were single and had either a personal history or family history of health problems.

- *You walk into a doctor's office and they say you need a 45-minute procedure and it will set you back \$40,000. I went home, and I had to sell the car and assets. The alternative was debilitating. At that point you're self-funded. (Chicago man)*
- *Yes, that's why I work so many hours a day. I went into debt to get the medical care I needed. (Chicago man)*

Participants noted that the health care system is currently built on the assumption that people use insurance to pay for care.

- *If you walk in and pay for it, you are treated as a 2nd class citizen. (Chicago man)*
- *I've had lots of rejection trying to get care without insurance. Even dental. I have had two dentists turn me down. (Suburban man)*
- *I would disagree and say its medical technology that is raising cost. Why have an MRI when an X-ray would do the trick? (Chicago man)*

Small Business Owners

A total of 12 small business owners who do not offer their employees health insurance participated in these discussion. Six were male, and six were female. Seven of the participants owned white-collar businesses such as computer consulting, travel agents, and legal or financial services. Three were primarily blue collar, including landscaping and trucking, and two were retail establishments. Their businesses ranged from four full-time employees to a franchisee with a total of 120 part-time and full-time employees at over a dozen stores.

Business Profiles

Employer participants had been in business for varying lengths of time, ranging from less than a year to 19 years. While several reported things had been tough during the past couple of years; most said that business was good or improving.

- *Business is ok, and it is starting to pick up again. (Suburban computer consultant)*
- *Business was pretty good until 2001. We are not a necessity business. We deal in the luxury world and are doing about sixty percent of our original sales pre-*

Gilead Outreach and Referral Center: Putting a Face on the Uninsured

2001. Things go in cycles and we will stick it out. We have two families in the store a father and two sons. We are committed to make it go. It's too bad, but what are you going to do? (Chicago antique store)

- *It has been slow, but starting to improve now. We laid off over the last year and a half. We laid off half. We were at 20 and now at ten. We are not seeing getting that business back. (Suburban computer consultant)*

Offering Health Insurance

The franchisee offers health insurance only to his full-time managers, and none of the small business owners offered health insurance to their employees. Four of the participants reported that they did not have health insurance for themselves. The remainder had coverage through a spouse's job, retirement benefits, or private purchase coverage for themselves and their family.

- *I don't have it for myself. It has been so expensive. I pay as I go. I don't have catastrophic. (Suburban landscaper)*
- *I'm covered through my husband. He works for the city. (Chicago antique store)*
- *My health insurance is through Fortis. We were told to shop every 2 to 3 years to get the best rate. I am in a PPO. We have one plan for the managers and one plan for the partners. The managers are on a different PPO plan, which is not as good. They only pay \$40 a month but we don't cover family. (Springfield franchisee)*

While only one of employers had offered employees health insurance in the past, many are currently interested in offering employee health insurance. Several have explored the options and found them prohibitively expensive.

- *I had Blue Cross. It was \$500 a month for an employee. It was getting too expensive so I dropped it. (Chicago antique store)*
- *I've looked into it, priced it out, but it is so expensive and you have to have a certain number of people in the plan or it's even more expensive or they just won't even give it to you. (Suburban computer consultant)*

Employee Coverage

Employers report that some of their employees are uninsured. Most of those who are insured are covered through their spouse, although some may be covered through their parents, a retirement package, COBRA or individual coverage.

- *I have one employee without [insurance]. With the economy turning around, some have COBRA. Three are part-time. They got laid off and are looking permanent, full-time jobs. They can afford to pay it, but they will think about*

Gilead Outreach and Referral Center: Putting a Face on the Uninsured

leaving to find full-time jobs with health insurance. (Suburban computer consultant)

- *I have two employees with and two without health insurance. One is covered with her parents. She is still in college. (Suburban computer consultant)*
- *A majority have it through a spouse. It is more cost efficient through a spouse under one plan. (Suburban accountant)*
- *We have two employees who don't have health insurance. One is just out of college. One is a divorced woman. She does not have health insurance because of the divorce. (Suburban computer consultant)*
- *One employee has coverage. Most are young and don't have families. Men. They don't think about it. The one who has it has a family. (Suburban trucking company)*

Getting Health Care

Most participants reported that they were not sure what their uninsured employees did when they needed health care. Those in Chicago or Cook County guessed that they probably used Cook County Hospital. Others mentioned other sources of free or low cost care that they or their employees could access. In addition to government programs, several reported using health fairs as a source of free screening and health information.

- *My employees are young. I don't know what they would do or if they think about it. (Chicago landscaper)*
- *I was born at Cook County hospital. I know many people who go there because it is free. (Suburban accountant)*
- *Have you gone to those places. Waiting for eight hours. I haven't done it. A friend went to Cook County...waited in the wrong line. The sliding scale is about waiting. Who has all day to wait? How good of a doctor are they? (Chicago mortgage broker)*
- *In the past well baby and free immunizations. We helped them with that information. I used to work for a doctor's office. I know about the Will County clinics. I let them know about the free services. (Suburban trucking company)*
- *I know of places for the free stuff. KOMED. Passing out flyers. Go to free health screenings. (Suburban accountant)*
- *I had it when I worked for someone else. I thought about a night job/part time just to get the coverage. Like at Wal-Mart. It is a benefit you can count on. It has been at least 3 years since I had it. A mall had "check your cholesterol". Get new patients for new clinic. I used a free screening. (Chicago consultant)*

- *They get care at a Northwest community hospital public aid program. There are a couple of places like "Sister" in Wheeling. (Suburban computer consultant)*

Business Impact

The focus group participants reported that not offering health insurance impacted their business' ability to attract and retain employees and people's perceptions of their company. While the slow economy offset the issue somewhat because many people were desperate for a job, not offering health insurance definitely makes it more difficult to hire and retain skilled employees.

- *In order to be seen as a real company, you have to offer something fifty-fifty or something along those lines. (Chicago antique store)*
- *I am not sure since I have not offered it. It is something. Having insurance will help keep them. Also to be seen as a real company. To get the people that will stay with you and be more committed. It is something that I may need. (Chicago mortgage broker)*
- *It would attract better people. Being able to offer a package. It would be like a big business. It is another tie. A few of those ties will create employee loyalty. (Chicago mortgage broker)*
- *I would sleep better. The thought of retraining an employee – it's much better to keep an employee than have to train a new one. It [offering health insurance] makes them want to stay. (Chicago antique store)*
- *I will probably lose my divorcee because of her circumstances. She has health concerns and we cannot help. We would help her get a job. (Suburban computer consultant)*
- *No, they knew this [that we do not offer health insurance]. For the two that did not have it... they were glad to be working. (Suburban accountant)*
- *We don't give on benefits; we give flextime and they work out of their homes. We have a lot who work at home and stay with their kids. This compensates for no daycare and no benefits. It is a big tradeoff. (Suburban computer consultant)*
- *I think offering health insurance to the assistants that would stabilize the positions. The best employees would care. (Springfield franchisee)*
- *Mostly about money for the young men. I usually lose a guy a year. I was talking about it. I made some calls. I think that I wouldn't need to look for new people all the time. (Chicago landscaper)*

Priorities

Offering health insurance is a priority for several of the employers. This may reflect a bias in the response to the groups; business owners who are interested in offering employee health insurance participated in the group while those with no interest in the issue did not respond.

- *Pretty high up. Maybe one if not two. It is more a function of our niche [in computer consulting]. We will have to do it to retain staff. As we create ongoing revenue it will allow us to take on more fixed costs. I hope to offer health insurance in the next year. (Suburban computer consultant)*
- *We will have it in the next 24 months as long business trends keep going up. (Suburban computer consultant)*
- *Making more money. Money is the issue, particularly in starting and growing the business. Health insurance is not the first thing. First a bigger office and new equipment. Then we can think about insurance. (Suburban accountant)*

Policy Recommendations

Each key informant interview and group discussion concluded with participants offering their recommendations for policy changes they would like to see. All said the system had to change; some were leery of government intervention, and a number supported a variation of national health care.

- *The government is involved. You still have to wait for those who don't have health care. It is not a good private and not a good government system. The people who do have insurance must subsidize the ones who don't, particularly for those who work for big companies. It is a vicious cycle. (Chicago technical consultant)*
- *I think it is the health insurance. Do they need to be as high? The whole system needs to be reworked. Everyone is making money. Hospitals are struggling. Can't they lower their profit margin? Can't they make less profit? I don't mind paying my fair share. It works well for the companies, but not the people. (Unemployed Springfield man)*
- *I would like to see health care for everyone, especially children, but I am not comfortable with the government running it. They screw up everything they touch. (Unemployed Chicago man)*
- *I suggest that the same way they charge everyone taxes, they should put some money towards the benefit of everyone. (Unemployed Chicago woman)*

Gilead Outreach and Referral Center: Putting a Face on the Uninsured

- *I would like to see national health care. Our current plan is "National Health Care: Don't Get Sick" It shouldn't be that we are so desperate. What we supposed to do, just die? (Suburban unemployed woman)*
- *I have a Polish employee. He had to go back to Poland for surgery for his sinuses. Insurance is free there. We really need something like that here. (Suburban landscaper)*
- *The health insurance industry has a lot of masters. When you look at the fact that they need to demonstrate profitability to share holders it puts the burden on patients, on buyers of products and on physicians with the reimbursement and insurance companies play the parties against each other. In reality 3rd party insurance is set up to generate earnings. Really the system needs undoing so it becomes not for profit all the way around. (Chicago physician)*
- *I object to them having the government control. I would like some regulations like prescription drugs. Look at Canada. (Chicago mortgage broker)*
- *Canada doesn't work well at all. (Suburban computer consultant)*

There were also some concrete, potentially actionable recommendations, particularly regarding how health insurance coverage is provided. Small business owners favored changes that would make it easier to form associations for health insurance. Others stressed policies that encourage prevention as a means of reducing health care costs.

- *If our companies could get together as a group. We now have 25 employees. That would be prohibitive to their profits. You can create a consortium. I don't know why you would not be allowed. (Suburban computer consultant)*
- *The self - employed people really are the more difficult market because they have to spend high premiums - so many only get catastrophic policies with high deductibles or they go without. I think small business people, restaurants and neighborhood stores have to deal with the burden of not being able to buy insurance. Also, people are not being offered insurance because of pre-existing conditions. There should be a mechanism for self-employed to collectively buy insurance and get the same breaks that large corporations get on premiums. (Chicago hospital administrator)*
- *Insurers should offer discounts individually to people who take care of themselves. Like some companies who have gyms, they should get lower rates. If I could offer that with a tax benefit. (Chicago technical consultant)*
- *Anything that takes the direction of the nation toward what Oregon does, give toward prevention. (Chicago man in high-income household group)*

Gilead Outreach and Referral Center: Putting a Face on the Uninsured

- *It is very unfair if you have a family of two - you pay the same premium as someone who has many dependents. What value are you getting? (Suburban man in high-income household group)*
- *The insurance companies can be very persistent trying to sell coverage, but sometimes they don't listen, they don't get all the information, and sometimes they don't follow-through. I brought my whole staff in at 7 on a Saturday morning to listen to the insurance guy and he didn't show up. That costs me money. (Suburban landscaper)*

Summary of Key Informant Interviews

MCIC interviewed six key informants to get the perspectives of physicians (all family practice) and hospital administrators in three areas: Chicago, the suburbs of Chicago, and downstate Illinois.

To preserve their anonymity in this summary they are referred to by position and location; details that might identify them have not been included. The initial questions solicited information about the areas and patients they serve, and any changes that might impact patient mix.

Practice/Service Area Characteristics and Changes

The key informants from Chicago served patients from a wide area on the north side of Chicago. Recent changes in the surrounding neighborhoods (gentrification that tripled home prices in the past ten years) have displaced some of that hospital's established patients although some of these patients continue to come to the hospital and its clinics from greater distances.

The Chicago-based family practice physician has a hospital-based practice and also treats patients in freestanding hospital affiliated clinics and through the family practice residency program. As a family medicine physician, this physician treats patients of all ages and the practice is 70% Latino, 20% White, non-Latino, and 10% ethnically mixed.

The suburban health care administrator noted that the business community is generally doing poorly; businesses are closing, and that people who live and work in the community are hurting. The administrator felt that the hospitals are crucial economic engines in the community, and are facing significant problems with increasing costs and decreasing revenues and as a result are employing fewer people and therefore can not quickly respond to community needs.

The suburban physician is in private practice and also sees patients in a local hospital and teaches residents in that hospital's clinics. This physician reported not being aware of major changes in the community that would significantly affect the number of uninsured, but noted that Lucent Technology had major layoffs.

The downstate hospital draws from a twelve county area. Recent plant closings in the small manufacturing and mining sector have increased the number of uninsured individuals in the hospital's service area.

The downstate physician, affiliated with an academic medical center, echoed these concerns. That physician was not specifically aware of any significant community changes but noted that the economy all the way around is hard; 40,000 people are

uninsured in the county and many small employers cannot afford to offer health insurance.

Changes in Insurance/Lack of Insurance/Reimbursement/Payor Mix

Hospital administrators and physicians identified several changes in the payor mix of the patients they serve: an increase in managed care (and the associated burdens), an increase in uncompensated care, and low reimbursements from government programs, i.e. Medicaid and KidCare. In addition, the administrator at a Chicago hospital noted recent closings or conversions to for-profit status of four hospitals that shifted the burden of caring for the uninsured and indigent to the remaining non-profit hospitals.

The physician practicing in the suburbs noted that over the last ten years there has been a shift from indemnity insurance to some form of managed care. A large percentage of patients have some form of managed care. Medicare managed care and uninsured patients are only a small percentage of this physician's practice, but the percentage of uninsured patients has increased slightly.

The physician practicing in Chicago reported the shift from fee for service towards managed care, particularly in the past three or four years and noted that frequent changes in employer-linked health plans make it hard for patients to stay in the same PPO system. This same physician felt that the effects of the shift to managed care are significant because the hospital has a lot of managed care patients. Although capitation is nice, there is still higher utilization of office services, which tends to negate what high capitation brings in. The physician stated that "We are reviewing if we have reached our limit of the number of managed care patients we can see."

The downstate hospital administrator reported that the hospital has seen a slow rise in uncompensated care and in Medicare patients and attributed the increase in uncompensated care to the hospital policy to "take all comers". The increase in Medicare patients was attributed to the aging of the population in the hospital service area.

The downstate physician, while aware of the trends impacting the health care system, reported that their practice, which used to be predominantly Medicaid patients, now had more insured patients because new providers in the group had gotten the practice into more insured programs.

Uncompensated Care – Who Gets It? What Are the Impacts?

All the hospitals and physicians provide some level of uncompensated care and view it as an obligation and cost of doing business. The hospitals report having established programs and criteria for charity care, and physicians report a willingness to negotiate reduced charges and payment plans, particularly for established patients who have lost their health insurance.

The recipients of uncompensated care are largely working and uninsured. Others are recently unemployed or self-employed who cannot afford health insurance through

Gilead Outreach and Referral Center: Putting a Face on the Uninsured

COBRA or an individual plan. In Chicago, some of the recent increase in uninsured patients was attributed to an increase in the number of immigrants.

The Chicago hospital administrator reported that the charity care policy is reviewed annually by corporate administrators. Last year the income limit for eligibility was 300% of the federal poverty level FPL and now it is 400%. “We review a growing number of cases with care needs and where insurance is a burden for these patients. Too many are falling in the gap with the working poor and those who clearly don't have resources.”

The downstate administrator reported that they couldn't refuse care, so they screen as best they can to determine whether uninsured patients may be eligible to enroll in Medicaid. “Seventy percent of pending Medicaid applications are approved, and the rest get charity care. The staff knows we have a program - patients can apply for it, but they need documentation, i.e. tax return for it, and the criteria are clearly laid out. Some patients we fee scale and some get free care. Most working poor are employed in jobs without benefits. Those with minimum wage jobs fall through the cracks and are not eligible for many programs.”

All the physicians interviewed reported providing care to established patients who have lost insurance coverage. The Chicago physician noted that they have mechanisms to establish payment plans as well as a charity program; they care for urgent needs immediately and address payment issues later. The suburban physician reported seeing established patients as best he/she can, regardless of changed insurance status.

The downstate physician figures the uncompensated care into the cost of practice and doing what is beneficial for the community but expressed frustration with ancillary services such as pharmacy, lab testing, etc., noting that while he/she can write off services or have minimal charges for patients in need ancillary, services don't tend to participate in uncompensated care systems, which can leave patients in terrible debt.

Who Are the Uninsured? Where Do They Get Services?

Hospital administrators and physicians largely agree on who are the uninsured: the poor without resources, the unemployed, immigrants, and the working poor. In Chicago, the hospital administrator noted that small business owners and employees are also often uninsured. There are some people who are not poor who choose not to carry insurance or have coverage with very high deductibles, but they are not perceived as the main issue for providers or administrators.

The Chicago hospital administrator acknowledges that there are certainly holes in the safety net and noted that many people don't have access to health care or use the ER as their primary care source. Now fewer physicians accept patients who are truly uninsured, instead they direct them to free clinics or public health departments that deliver low cost care in Cook County. The administrator reported that there is a new clinic in the area started by several physicians who wanted to open a free clinic, and the hospital donated a service building that was not being used. Another local hospital gave startup money for

Gilead Outreach and Referral Center: Putting a Face on the Uninsured

this clinic (approximately \$100,000), and it is staffed with volunteer physicians and nurses.

The Chicago physician reported that their hospital-based practice has really made an effort to reach out for the KidCare program and the hospital where they practice is certified to take the application. When uninsured patients come in, they start an application for them on site. This physician noted that the city has the Health Department free clinics and that other free clinics exist in the neighborhood.

The suburban administrator reported that a new Federally Qualified Health Center (FQHC) recently opened in Chicago Heights. The opening of that center picks up some of the slack for treating the uninsured but utilization in ER has increased in the last three years.

What Other Challenges Are Facing the Health Care System?

During the interviews, physicians and administrators highlighted other systemic issues impacting providers and consumers in the health care system. The complexity of these interrelated issues suggests the need for far-reaching reform.

Fundamentally, the health insurance industry is not working for the best interests of patients or health care providers. The Chicago physician noted that the health insurance industry has a lot of masters. “When you look at the fact that they need to demonstrate profitability to share holders, it puts the burden on patients, on buyers of products and on physicians with the reimbursement and insurance companies play the parties against each other. In reality the third party insurance system is set up to generate earnings. Really the system needs undoing so it becomes not-for-profit all the way around.”

The for-profit managed care system leaves patients and providers frustrated. The suburban physician reports that a lot of patients are frustrated because they feel that they are not getting the health care they have paid for through their insurance premiums. They do not understand the restrictions on testing and treatment that managed care places on physicians. Physicians are also frustrated by the restrictions placed by managed care - there are fewer panels of physicians to refer to and fewer tests to order, potentially compromising patient care.

Low reimbursements from Medicaid also challenge providers serving uninsured and Medicaid patients and limit the availability of health care for these vulnerable populations.

The downstate administrator identified the problem by saying “What we are paid doesn't cover our costs. Medicaid is an embarrassment – it's better than nothing, but it's only 70 cents on the dollar.”

The Chicago administrator expanded on the impacts of treating a high percentage of uninsured or Medicaid patients and said that ultimately it impacts your future. “My hospital has not been operating in the black for the last few years and there is a significant correlation with number of PA (public aid/Medicaid) and uninsured patients.

Gilead Outreach and Referral Center: Putting a Face on the Uninsured

Hospitals in the suburbs with low numbers of Public Aid and uninsured patients are doing well. It is the converse in the city. Not having a lot of resources means not being able to replace equipment, develop new programs, renovate. Lots of hospitals in Chicago have closed in the last 15 years.”

The Chicago physician noted that budget cuts resulted in staff reductions to improve the finances of the center and that there are now more waiting times and less efficient patient care.

The Chicago administrator reported that more and more physicians are unwilling to serve large numbers of the uninsured. In the past they would take call in the ER and now they won't unless hospital pays them to do it. The costs of treating the uninsured, particularly in light of the high cost of malpractice insurance, make it impossible to treat the uninsured and stay in business. In addition there are areas, particularly on the south side of Chicago, where no physicians are willing to practice because of the lack of private insurance coverage. You can go miles without seeing another hospital or physician's office.

The suburban administrator concluded that Chicago physicians have never been more demoralized and that it relates to the rising cost of liability insurance premiums and frequently getting minimal or no payment for services provided.

In Conclusion: Four Themes

Having conducted a series of key informant interviews with hospital administrators and primary care physicians who daily encounter the challenges of delivering health care services and small-group discussions (focus group format) with individuals whose range circumstances and experiences illustrate the typical circumstances of the non-poor uninsured in Illinois we encountered four pervasive themes.

- Individuals who do not have health insurance face major challenges when they seek health care. Emergency care is available but access to non-emergent or preventive care is limited.
- Individuals who are unemployed or whose employment does not offer the option of health insurance coverage often cannot obtaining individual private market health insurance coverage because of limitations due to preexisting conditions and / or the cost of the premiums.
- There is no health insurance safety net for employed middle-income individuals. People who work at jobs that do not provide the option of affordable health insurance and whose income is above the eligibility limit for government sponsored health care programs struggle to obtain routine and preventive health care. They tend to avoid or delay health care services or seek them only in an emergency.

Gilead Outreach and Referral Center: Putting a Face on the Uninsured

- Business owners understand that providing the option of employee health insurance would help to stabilize their workforce and strengthen their businesses. Those who currently offer employees the option of health insurance are challenged by the increasing insurance premium rates. Those employers who do not offer health insurance as an employee benefit often find their small group rate is prohibitively expensive.

Board of Directors

Officers

Michael Savage
President
CEO, Access Community Health Network

Vincent Keenan
Vice-President
Executive Vice-President
Illinois Academy of Family Physicians

Dr. Lawrence Haspel
Treasurer
Senior Vice-President, Metropolitan
Chicago Healthcare Council

Nancy E. Cross
Secretary
Vice-President
Service Employees International Union,

Directors

Elena Butkus
Executive Director
Illinois Association of Health Plans

Steve Derks
CEO
American Cancer Society – Illinois Division

Shirley Fleming
First Deputy Commissioner
Chicago Department of Public Health

Robert Kieckhefer
Vice-President
BlueCross BlueShield of Illinois

Peter Lott
Third Baptist Church of Chicago

Syed Najiullah
Council of Islamic Organizations of Greater
Chicago

Linda Diamond Shapiro
Special Assistant to the CEO
University of Chicago Hospitals

Michael S. Taitel, PhD
Trustee, B'nai Jehoshua Beth Elohim
Synagogue
Clinical Director, First Health

Rev. Jerry Wagenknecht
Senior Vice-President
Advocate Healthcare

Ex Officio

Stephen Roberson
United Power for Action and Justice

Executive Director

Margaret Schmid, PhD