HRSA ILLINOIS STATE PLANNING GRANT

INTERIM FINAL REPORT TO THE SECRETARY

October 29, 2001

EXECUTIVE SUMMARY

Background

Under the auspices of a grant from the U.S. Department of Health and Human Service Health Resource and Services Administration, Illinois developed a multi-tiered plan to: (1) identify the qualitative and quantitative demographic characteristics and needs of the uninsured population in the state, and (2) through a consensual and participatory process to develop policies and procedures that would allow all individuals in the state access to affordable health insurance. The Illinois Department of Insurance (DOI) served as the lead agency and coordinated with other key agencies and organizations including the Illinois Department's of Public Health, Public Aid, Commerce and Community Affairs, Human Services, and the Illinois Comprehensive Health Insurance Plan (high risk pool).

Research for the grant was undertaken by two major universities: Southern Illinois University at Carbondale (SIUC), in conjunction with Program Evaluation for Education and Communities, completed a compilation and synthesis of 27 focus groups and 15 key informant interviews; and the University of Illinois-Chicago (UIC), in collaboration with the Health Research and Policy Centers and the Survey Research Laboratory (at UIC), developed and administered a random digit dial population based survey of the uninsured and newly insured population. Both institutions divided the state into five stratified regions: Northwestern, Central, Southern, Cook County and the Collar Counties of Cook County.

The Behavioral Risk Factor Surveillance System (BRFSS) and the Illinois Center for Health Statistics in the Illinois Department of Public Health provided an expansion of ongoing research and data analysis pertaining to the uninsured population in the state. The staff of the State Planning Grant (SPG) developed a three volume Research Guide containing: original review articles of topical interest (crowd-out, purchasing pools, tax credits, etc.), and articles relating to public and private sector initiatives in other states or localities considered to be of specific interest to the Illinois project; a collection and organization of the works of other researchers working on the grant; and an analysis of public programs in twenty plus states. Short stories were written or adapted to provide insights into the plight of the uninsured, a "Must Read" list was developed, and a website was created for ease of communication with constituents.

Highlights of Research Results

The greatest likelihood is that the rate of uninsurance falls between 9.7% and 13.4%. According to the UIC random digit dial survey there are fewer uninsured persons in the state (9.7%) than reported in the U.S. Census Current Population Survey (13.4%). This conclusion is supported by BRFSS research which indicated that 9.8% of adults aged 18 to 64 are uninsured.

Approximately 64% of the uninsured are currently employed and nearly half of the working uninsured do not have employer-sponsored health insurance available. Almost 61% of the uninsured are employed by firms with fewer than 50 employees and are most likely to work in

service occupations in service industries. Seasonal and part-time employees frequently do not have access to employer-sponsored insurance, and some employees have not been with an employer long enough to qualify for employer-sponsored insurance. The uninsured tend to be low to very low-income persons or families.

Cost/affordability is the single most important reason given for failing to acquire employer-sponsored or private health insurance. The uninsured state that premiums, co-payments, and/or deductibles make health insurance costs prohibitive. Other reasons include: limitations on eligible health care providers; perceptions that pre-existing conditions limit qualification for employer-sponsored insurance; plan quality; and life style choices.

Awareness of public programs is a major issue for individuals and families who are eligible and fail to take-up public health insurance. Additional considerations include: perceptions of "taking charity"; perceptions of "poor quality"; perceptions of or previous experience of being badly treated; a complex and burdensome application process; little or no access to health care providers; cultural barriers or documentation issues; and a belief of lack of need.

The uninsured are obtaining their medical needs through emergency rooms, various community health centers, charity from doctors, and home remedies.

Consensus Building Process

The Illinois Assembly on the Uninsured (Illinois Assembly) was the main source of public input. Members of the Illinois Assembly represented a diverse group of stakeholders, which included employers, labor unions, social service advocates, commercial insurers, insurance agents, healthcare providers including medical practitioners and others. Results of the quantitative and qualitative research were presented to the Illinois Assembly. This group of public and private stakeholders was charged with engaging in dialogue and moving toward consensus on how to reduce the number of uninsured.

The Illinois Assembly allowed the key stakeholders to meet in a structured, mediated environment to reach as much consensus as possible, on the problem of uninsurance and on ways to move the number of uninsured as close as possible to zero. The members of the Illinois Assembly shared more common ground on this issue than they might have believed, but they rarely have had a chance to work cooperatively towards addressing this issue. The Illinois Assembly convened in Springfield, Illinois for an introductory meeting in January 2001 followed by a three-day meeting in July and a final meeting in September.

Strategies Selected

The Illinois Assembly process resulted in three general areas being identified for priority consideration in specific strategy development. To date we have not rejected any of the policy options developed through the consensus building process of the Illinois Assembly. One area of agreement that emerged during the process is that to successfully decrease the number of uninsured change must be incremental. Our next step is to develop specific models in the framework of these options. The following are the three options that received the greatest degree of support from stakeholders during the participatory process and appear to be the most compelling for priority consideration:

COVERAGE OPTION A. Family Care: This option is to support the extension of the KidCare Program to parents as described in the Family Care Bill (HB 23) introduced in the Illinois General Assembly last session. The Family Care Bill was proposed to include family members and guardians of children for KidCare (SCHIP) which would allow adults to participate up to 185% of the FPL and children to participate up to 200% of the Federal Poverty Level (FPL). Current estimates of eligibility indicate that approximately 200,000 adults and another 12,000 children would be targeted by expansion of KidCare. As of the date of this report the bill has not passed.

COVERAGE OPTION B. Incentives for Small Employers: Small employer incentives received a considerable amount of support throughout the Illinois Assembly process. Our next step is to develop specific employer incentive programs. Substantial information from the literature review and materials developed pertaining to the performance of incentive programs in other states will prove of value in developing policies and strategies regarding employer incentives.

COVERAGE OPTION C. Education and Marketing of Insurance Programs and Products: Enhancement of education, marketing and enrollment processes and procedures was identified as a strategy during the Illinois Assembly process. There was interest in increased education about both public and private insurance programs. Many of the agencies and organizations that provide public programs such as KidCare (SCHIP) have already made significant strides in these areas. While efforts have been made to increase education, enhance marketing and improve enrollment processes this is identified as an area of ongoing need. A host of ideas were generated in these areas.

SECTION 1. SUMMARY OF FINDINGS: UNINSURED INDIVIDUALS AND FAMILIES

Illinois developed a multi-tiered plan to study the qualitative and quantitative demographic characteristics and needs of the uninsured population of the state. Two major universities, Southern Illinois University at Carbondale and University of Illinois-Chicago received contracts to develop primary data on the uninsured. The Illinois Department of Insurance, the Illinois Department of Public Health, and the Illinois Center for Health Statistics also contributed substantially to the research effort.

The University of Illinois-Chicago (UIC), in collaboration with the Health Research and Policy Centers (HRPC) and the Survey Research Laboratory (SRL), (at UIC), developed and administered a random digit dial population based survey. The sample design was a disproportionate stratified sample with 5 strata: Northwestern Illinois; Central Illinois; Southern Illinois; Cook County; and the Collar Counties of Cook County. Interviews were conducted by telephone throughout the state. The sample of 25,735 telephone numbers was released over a period of about three months, from mid-January through mid-April, 2001. Data collection ended May 6, 2001 with a final response rate of 52%. Many of the conclusions resulting from this survey appear in responses to questions relating to quantitative analysis of the uninsured. References to this data hereinafter are referred to as UIC random digit dial.[1] This report is attached in Appendix 3 Illinois Reports.

Southern Illinois University at Carbondale (SIUC), in conjunction with Program Evaluation for Education and Communities (PEEC), completed a compilation and synthesis of findings from 30 focus groups conducted across the state in the same five regions listed above. Focus groups were comprised "of small business owners offering health insurance, small business owners not offering health insurance, representatives of health and social service agencies, members of the insurance industry, medical providers, members of local governments, and the uninsured themselves." These results are referenced in the report as focus group results and key informant interviews.[2] This report is attached in Appendix 3 Illinois Reports.

SIUC also conducted, compiled, and synthesized 14 key informant interviews. These interviews were conducted with high profile persons in government, business, community activism and social service organizations. Focus groups and key informants were asked a series of predetermined questions intended to generate answers that would provide texture and nuance to the quantitative data generated by UIC. While the qualitative data generated by SIUC is not intended to be used to generalize to a broader population it does enrich and enhance the quantitative data by telling some of the "insider's story" of many of the stakeholders involved.

The Behavioral Risk Factor Surveillance System (BRFSS) was an important source of data pertaining to insurance coverage and insurance access in Illinois. BRFSS is a state-based survey of the non-institutionalized population 18 years of age or older. Respondents were asked about past coverage and details of their health insurance plan. Information collected regarding demographic characteristics and health coverage can be utilized to alert the state to emerging trends in health coverage and health care. BRFSS also did a survey of each county in Illinois.

BRFSS enhanced its ongoing survey with the addition of questions regarding: insurance availability; reason(s) for declining employment-based coverage if available; and awareness of alternative sources of health insurance. References to this data hereinafter are referred to as BRFSS. [3] This report is attached in Appendix 3 Illinois Reports.

The Illinois Center for Health Statistics (ICHS), in the Illinois Department of Public Health (IDPH), was responsible for ongoing survey enhancements and expanded data analysis. ICHS used the BRFSS analysis of certain data obtained from the Illinois Health Care Cost Containment Council and analysis of data pertaining to the uninsured in Illinois from the March 2001 Supplement of the Census Bureau's Current Population Survey.

The Illinois Department of Insurance (DOI) Planning Grant Staff developed a variety of background research information for use by the Illinois Assembly participants, state and federal agency personnel, Illinois legislators, and others who might seek information regarding the uninsured.

A three-volume Resource Guide was developed for use by the Illinois Assembly participants and as a reference for stakeholders and other interested parties. (See Section 5.2 for information on the Illinois Assembly process.):

Volume I: A research compendium was generated containing several review articles written by the DOI Grant Staff and SIUC faculty on topics such as buy-ins, purchasing pools, crowd-out, adverse selection, etc. Additionally, articles from other sources that were considered helpful in dealing with the issue of the uninsured in Illinois from a public and private perspective were included. Descriptions of specific state and local programs from other regions of the country that were beginning to gain national recognition were also included;

Volume II: A collection and organization of the works of the other researchers working on the grant was created. This included the preliminary research reports of focus group and key informant interviews done by SIUC; the random digit dial survey of the uninsured and newly insured by UIC, and the expanded risk factor survey by the Behavioral Risk Factor Surveillance System (BRFSS); and

Volume III: An examination of public programs in 21 states that are designed to reduce the uninsured population was undertaken. The DOI Planning Grant Staff researched these states to determine how public programs and funds have been utilized to increase access to insurance for the uninsured.

Additional research materials developed by the DOI Planning Grant Staff included a bibliography in excess of sixty pages and more than 479 citations. Also a "Must Read List" which included citations of articles of particular significance was created and sent to members of the Illinois Assembly and other interested parties.

The research materials developed by all researchers was made available in hard copy and web page formats for use by participants in the Illinois Assembly.

1.1 What is the overall level of uninsurance in your State?

The level of uninsurance in Illinois can best be described as a range. The range is somewhere between 13.4% (Current Population Survey - March 2001) and an estimated 9.7% (UIC random digit dial). BRFSS data shows 9.8% of all adults (18-64 Years of Age) during the period of December 2000 through May 2001 were uninsured which supports the UIC figure. Other states have also found that the U.S. Census Bureau figures to be higher than state generated figures. Because of the disparity in various estimates of the number and percent of uninsured the U.S. Census Bureau recently added a health insurance verification question to the previous survey questions relating to insurance coverage. The effect of the verification question was to reduce previous Census estimates of the percent of persons without insurance.[4] It should be recalled that the census information was not originally designed to develop statistical information on the uninsured.

1.2 What are the characteristics of the uninsured?

University of Illinois-Chicago random digit dial data includes information on both the uninsured and the newly insured (respondents who obtained health insurance within 6 months prior to the survey interview). BRFSS research did not include the newly insured and only examined persons aged 18-64. The responses below contain various comparisons. We compare uninsured versus newly insured; we compare varying groups of uninsured or varying groups of newly insured.

Income: According to the BRFSS data over 36% of the uninsured were in households with incomes less than $15,000 and almost 29% were in households with incomes between $15,000 and $35,000. UIC random digit dial data shows that approximately 77% of the uninsured had incomes less than 185% of the Federal Poverty Level (FPL) while only 60% of the newly insured had incomes below 185% of the FPL. Approximately 12% of the uninsured had incomes above 250% of the FPL while 23% of the newly insured had incomes above 250% of the FPL. The uninsured had lower incomes relative to the newly insured. While this does not prove a causal relationship between income and insurance coverage it seems to lend credence to qualitative responses that insurance is unaffordable for those with lower incomes.

Age: UIC random digit dial data showed over 33% of the uninsured were aged 45-64, compared to 26% of the newly insured. In comparison to the uninsured, a greater proportion of the newly insured were aged 18-24 (13% vs. 8%) or aged 65 or older (8% vs. 3%). BRFSS data shows 14.2% of young adults (aged 18-29) are uninsured, 8.1% of adults (aged 30-64) are uninsured and that 39.4% of uninsured aged 18-64 are young adults and 60.6% are adults.

Gender: UIC random digit dial data showed men and women were equally likely to be uninsured versus newly insured. However, nearly 67% of the uninsured and newly insured were women. BRFSS data showed 55.3% of uninsured aged 18-64 were women and 44.7% were men.

Family Composition: Single-person and multiple-person households were equally likely to be uninsured versus newly insured: 32% of the newly insured and 35% of the uninsured were in single-person households.

Health Status: BRFSS data showed that individuals with health insurance were more likely to take advantage of health screening examinations than those without insurance.

Employment Status (including seasonal and part-time employment and multiple employers): UIC random digit dial data showed the majority of newly insured and uninsured respondents were working at the time of the population survey. Newly insured were more likely to be employed than uninsured respondents (75.5% vs. 64.3%, respectively), but were less likely to have been working for the same employer for over a year than the uninsured (46.7% vs. 62.2%, respectively). BRFSS data showed the highest percentage of uninsured aged 18-64 were in the following industries: Food Service 25.8%; Health Care Support and Personal Care 14.9%; Arts, Design, Media and Sports 13%, and Construction, Maintenance, Production and Transport 11.9%. Our study did not address seasonal and part-time employment and multiple employers.

Availability of Private Coverage (including offered but not accepted): Over half (53%) of the employed uninsured did not have coverage offered through their employer. Uninsured workers were more likely than the newly insured (61% vs. 46%) to work in small companies.

Most of those surveyed who were uninsured had never applied for private insurance with an insurance company. Of the 8% of the uninsured who had at one point applied for coverage, less than 1% had obtained coverage. Among the newly insured less than 17% had ever applied for a direct purchase policy from an insurance company. More than 70% of those who applied were denied coverage.

Availability of Public Coverage: There are public programs available for select populations of the uninsured. Medicaid and KidCare (SCHIP) are available for certain lower income individuals. The Illinois Comprehensive Health Insurance Plan (ICHIP) is available for medically uninsurable individuals or those who are federally eligible under the Illinois Health Insurance Portability and Accountability Act. Lack of awareness of public programs seems to be the major deterrent to enrollment. About 88% of those surveyed were not familiar with ICHIP. Of the approximately 11% who had heard of ICHIP about 33% did not think they were eligible, about 25% felt they could not afford coverage, and about 10% thought the coverage was inadequate to meet their medical needs. Similar results were found with the KidCare program. Of the surveyed population, 38% of the parents with uninsured children whose incomes were less than 185% of the FPL thought they had heard or read about KidCare. Of those who were aware of KidCare about 45% stated they wanted to enroll but were told they would have to enroll in Medicaid and they therefore refused to enroll. Approximately 43% stated they did not know where to apply and 30% lacked the documentation for application.

Race/ethnicity: Among the uninsured, 22% were African American, 21% were Hispanic and 57% were non-Hispanic White. Among the newly insured, 15% were African American, 19% were Hispanic and 66% were non-Hispanic White. BRFSS data showed 32.2% of the uninsured

aged 18 to 64 are non-White and 67.8% are White while 17.6% of the insured are non-White and 83.7% are White.

Immigration Status: UIC random digit dial data showed citizens and non-citizens had similar rates of being uninsured versus newly insured; 90% of the newly insured and 86% of the uninsured were citizens.

Geographic Location (as defined by state -- urban/suburban/rural, county-level, etc.): UIC random digit dial data showed individuals within different regions in the state were equally likely to be uninsured versus newly insured. In comparison to the population distribution within the state, however, Cook County had disproportionately more uninsured and newly insured individuals and Southern Illinois had disproportionately fewer uninsured and newly insured individuals. BRFSS data showed 35.8% of the uninsured aged 18 to 64 live in Chicago, 45.5% live in other metropolitan areas and 17.6% live in rural areas while 17.2% of the insured live in Chicago, 63% live in other metropolitan areas and 19.8% live in rural areas.

Duration of Uninsurance: The length of time without insurance coverage varied for the uninsured versus the newly insured. The newly insured tended to have been without coverage for a shorter period of time than individuals who were uninsured. For the newly insured, the largest percentage (49%) had been without coverage for less than 6 months; 16% had been without coverage over 60 months. For individuals who were uninsured at the time of the survey, 33% had not had coverage within the past five or more years, and almost 50% had not had coverage for more than 24 months.

Other(s): not applicable

1.3 Summarizing the information provided above, what population groupings were particularly important for your State in developing targeted coverage expansion options?

Based on preliminary information available prior to the Illinois Assembly meeting in July regarding the quantitative and qualitative results of our research, as well as the literature review and other research conducted by the State Planning Grant staff, five target populations were identified to be analyzed in depth during the Illinois Assembly: the working uninsured, Hispanics and other racial/ethnic minority groups, young adults, small employers, and children. National data, other state data, and information from other state agencies indicated the population groupings chosen to be considered were those which would contain the greatest percentage of uninsured individuals. The Medical Expenditure Panel Survey (MEPS) and our own researchers reconfirmed these choices.

1.4 What is affordable coverage? How much are the uninsured willing to pay?

Affordability is the most frequently cited reason for failing to take up group, individual, or employer-sponsored insurance coverage. Based on the results of the UIC random digit dial survey the median amount that individuals would be willing to pay was approximately $78

(mean=$93) a month for coverage and the median that families would pay was about $100 (mean=$131) a month. There is an inverse relationship between the stated willingness to pay and the cost of coverage ranging from 66% of respondents at the $100 level to 34% at the $250 level for individual coverage, and from 43% of respondents at the $250 level to 31% at the $400 level for family coverage.

1.5 Why do uninsured individuals and families not participate in public programs for which they are eligible?

Affordability: Some public programs charge participants premiums, co-payments or deductibles. KidCare has premiums and co-payments. The Illinois Comprehensive Health Insurance Plan (ICHIP) has deductibles and premiums. ICHIP premiums are set by statute at 125%-150% of the premiums charged in the private market. Both programs are perceived by some to be expensive and unavailable to uninsured individuals and families.

Knowledge Issues: Many uninsured individuals are eligible but not enrolled in public programs because they are not aware of the existence of the programs, they are not aware that they are eligible for the programs or they are not aware of the actual costs of the programs. Some programs may not be adequately publicized or advertised. People without access to televisions, radios, telephones, or newspapers are likely to be uninformed of the programs.

Perception of Public Programs: There seems to be a stigma associated with public insurance programs. Many uninsured persons do not want to be "lumped together with those who are freeloading," or feel that public assistance is not for them. Some do not want to be seen applying for public insurance (privacy issue), while others perceive they will be treated badly (like second class citizens) if they are on public insurance. Some feel that public health programs provide poor care and inadequate benefits. There is a certain level of mistrust of public or government programs.

Poor Treatment: Many expressed the belief that they had been treated poorly in the past, or resented being treated as if they were abusing the system. Women of certain racial-ethnic minority groups seem especially sensitive to issues of poor treatment. The "System" had treated them badly and they did not care to subject themselves to poor treatment again. The staff in public offices may or may not be supportive of individuals who seek assistance. People may be turned down even if eligible for a public program.

Not Necessary: Some individuals think that insurance is unnecessary. If they are healthy they feel they can do without insurance. Males seem to feel this way more than females, and younger persons express this point of view more than older persons.

Application Process: Some focus group participants expressed the opinion that the bureaucracy is burdensome, the application process is unfamiliar, and the forms are complex and difficult to understand.

Cultural Barriers: Occasionally, due to cultural or ethnic background, some people do not like to answer the questions necessary to ascertain eligibility or to apply for public assistance.

Access to Care: Some individuals feel they will be unable to find a physician or they lack access to a physician or other health care provider. There is a long waiting period for legal immigrants to become eligible for public insurance support. There may be no providers available in the geographic area or there may be a lack of in-network providers.

Legal Issues: Lack of immigration documents makes some individuals unwilling to seek health care and undocumented persons are not eligible for public insurance. Aliens may fear deportation. Those who owe child support or back taxes may choose not to apply.

Positive Perceptions: Some people thought there was good service and coverage with public health insurance; minimum hassles in KidCare enrollment; that public insurance had provided a safety net and salvation from financial ruin.

1.6 Why do uninsured individuals and families disenroll from public programs?

There was limited response in focus groups or key informant interviews regarding why individuals and families disenroll from public programs. The primary reasons given were:

Loss of Eligibility: Some individuals qualify while unemployed but lose eligibility when employment is accepted.

Providers Leave System: Some health care providers cease accepting Medicaid or other public programs, and individuals and families leave the system because they do not know how, or are otherwise unable, to change providers.

1.7 Why do uninsured individuals and families not participate in employer-sponsored coverage for which they are eligible?

Affordability: (a) Some individuals can afford their part of the employer-sponsored premium, but cannot afford to insure their families. These families fall in the "gap" where family income is too high to be eligible for public insurance and too low to purchase employer-sponsored insurance or private health insurance. Some persons work for small businesses and felt that premiums were too expensive. (b) Even if the insurance premiums are affordable the cost of the co-payments or deductibles are prohibitive to maintain and use the insurance benefits. (c) Basic living choices have to be made, between health care and daily living expenses (diapers, milk). Health care can sometimes be afforded but it becomes difficult to afford a hospital stay. Other bills have to be paid and hospitals have to wait.

Insured Elsewhere: Some have health insurance through a spouse or parent and choose not to "take-up" employer-sponsored insurance at their place of employment. This may be because the

spouse has better benefits at lower costs than the employee's own group plan. Sometimes employees are not primary wage earners and choose to opt out of their own group plan.

Life Style Choice: Some choose not to enroll in employer-sponsored plans. Younger people may not enroll because the employer does not pay 100% of the premiums. Some individuals express the sentiment that health insurance is a "bet" with an uncertain payoff in the future and unless the loss is "in your face" it is not a good bet.

Poor Economy: If individuals feel the economy is poor and their jobs are at risk they may feel that the dollars spent on insurance today are not worth those same dollars saved for necessary purchases tomorrow, when they may be without a job.

Physician Choice: Some individuals feel that it is difficult to find a good doctor who accepts the plan, or that the physician of choice is not a participant in the plan.

Pre-existing Condition: Some individuals reported that they did not qualify for employer-sponsored insurance because of a pre-existing condition or illness. While denying health insurance coverage based on health status in an employer-sponsored plan violates both federal law and Illinois law, it is permissible to have pre-existing condition exclusion periods. It is possible that employees do not understand that while they must wait for coverage for the pre-existing condition, they will have coverage for any new conditions. The may also be unaware of the Health Insurance Portability and Accountability Act (HIPAA) provisions requiring employers to credit previous insurance coverage against pre-existing condition. Also there are anecdotal reports that employees are informally discouraged from signing up for coverage because their condition will result in a higher cost for the rest of the group.

Quality of Plan: According to respondents to the UIC random digit dial survey they may reject plans they deem to be low quality.

1.8 Do workers want their employers to play a role in providing insurance or would some other method be preferable?

The response from the focus groups, while limited, was that employer-sponsored insurance would be well received by the uninsured population, particularly if premiums were fully paid. The Illinois Assembly expressed support for employer-sponsored insurance.

1.9 How likely are individuals to be influenced by:

Availability of Subsidies: A percentage sliding scale subsidy was considered by some to be a good idea. Specifications for a subsidy ranged from 5% of income to a subsidy from zero percent of salary up to some cap, based on the level of income. The idea of subsidies was attractive to most respondents, but the level of such subsidies was not defined.

Tax Credits or Other Incentives: Generally the response from the uninsured is that, with a low net income or with a minimal tax obligation, a tax credit, unless fully refundable, would not be

helpful. Even fully refundable tax credits would not be particularly helpful unless they are prospective rather than retrospective. The use of tax credit will allow people to access private programs and avoid the stigma attached to public assistance programs.

1.10 What other barriers besides affordability prevent the purchase of health insurance?

Pre-existing Conditions: Many individuals and groups identify pre-existing conditions as a serious barrier to obtaining health insurance. In the individual health insurance market, insurers may deny coverage on the basis of health status. They may also attach riders to policies excluding certain conditions or charge higher premiums for persons with certain conditions. Individuals in the 55–64 year age group have particular trouble obtaining individual health insurance policies because of pre-existing conditions. Chronic health problems create a major hardship for families and contribute significantly to the inability to obtain individual health insurance. In spite of the HIPAA law there is some perception that when changing jobs a pre-existing condition may disqualify employees from obtaining health insurance from the new employer's group plan.

Portability Concerns: People who leave jobs have trouble maintaining health insurance during the transition period because of the expense of COBRA or state continuation. Short-term coverage can also be expensive. If employees fail to exercise their continuation rights they lose their HIPAA individual portability rights.

Seasonal and Part-time Employees: Employers frequently do not offer health insurance to seasonal or part-time employees.

Time in Position: Some plans have "time in employment" waiting period requirements. If the employee has not had enough time employed he/she would not qualify for the employer-sponsored plan until the waiting period expires.

Cultural Barriers: Frequently immigrants are unaware of what is available to them or how the system works. Many ethnic and minority groups or individuals are afraid to seek medical help or lack knowledge of what is available. Cultural difficulties can range from language barriers to edicts against a female being uncovered in front of anyone other than her spouse. Lack of familiarity with the infrastructure of the American system is also an inhibitor to some ethnic groups; many immigrants come from countries that have no institution of insurance, consequently they do not opt for it even if the opportunity is made available.

Lack of Awareness: Individuals (and families) may be unaware of the need for insurance or what is available or how to obtain it.

1.11 How are the uninsured getting their medical needs met?

From the research that was undertaken it appears that a large number of the uninsured are not getting many of their needs met. Some of the uninsured say they can sometimes afford routine

health care but cannot afford a hospital stay. Others are delaying treatment and ignoring health needs until the problem goes away or a major crisis develops. Ways of meeting medical needs in the absence of insurance included:

Emergency Rooms: When treatment becomes mandatory, or a critical condition becomes apparent, emergency rooms are utilized. Frequently by the time help is sought the situation is often too severe to respond to routine treatment.

Various Community Health Centers: Free clinics, public health centers, and community programs are used on an as needed and required basis. As with emergency rooms preventive care is seldom a primary consideration.

Charity from Doctors: The medical community has many physicians and health care providers who provide free care, or formal charitable activities.

Home Remedies: Home remedies are regularly utilized by many individuals and families.

1.12 What is a minimum benefit?

At this juncture no minimum benefit has been agreed on in Illinois. There are general characteristics that everyone seems to agree should accompany a minimum benefit but a precise definition is elusive. Following are areas wherein a degree of consensus seems to exist:

There are certain specific benefits that should be included among minimum benefits, such as catastrophic insurance, hospitalization, preventive medical care, mental health treatment, and prescription drugs. There was less agreement that rehabilitation (acute, chronic, and addictive conditions), vision care and dental care should be minimum benefits.

Minimum benefits should be funded in such a way as to maintain affordability, including, but not limited to, reasonable deductibles, beneficiary contributions, sliding scale premiums, cost control mechanisms, and some kind of control over rate increases.

1.13 How should underinsured be defined? How many of those defined as "insured" are underinsured?

While the Illinois State Planning Grant process was not designed to address the issue of the underinsured there were enough responses in our qualitative research to be of interest. It should be noted that the concept of underinsurance is subjective. All plans are underinsured if they do not have every single benefit available (on paper) to Medicaid recipients. To define underinsured it would first be necessary to establish a definition for minimum benefit. If an insurance plan failed to include the minimum benefit package then an enrollee could be identified as underinsured. Some of the elements that were considered to define underinsurance are:

High Deductibles: Health insurance with high deductibles may effectively make one underinsured. If income is small and deductibles are large (unaffordable) then insurance is of little benefit.

Lack of Preventive Care: Policies which do not pay benefits for preventive care, or which apply deductibles to preventative care could be deemed underinsured.

No Basic Health Insurance Coverage or No Catastrophic Coverage: People with basic health insurance and no catastrophic coverage would be considered underinsured. Similarly, people with no basic health insurance and catastrophic coverage would be considered underinsured.

Gaps in or Caps on Coverage: Plans with gaps in or low caps on care, including such coverage as vision, dental, or mental health care, may qualify as underinsured.

Specialty Policies: Cancer, or other specified disease policies, in the absence of basic and catastrophic coverage, would leave the policyholder underinsured.

SECTION 2. SUMMARY OF FINDINGS: EMPLOYER-BASED COVERAGE

Illinois' planning grant process did not include any significant quantitative research on employers. The questions in this section are answered from information obtained through research completed by SIUC, UIC, BRFSS, and their respective research partners, or by the SPG staff, especially from focus group results.

2.1 What are the characteristics of firms that do not offer coverage, as compared to firms that do?

Employer Size: Uninsured workers are more likely to be employed by small firms (less than 50 employees) than by larger firms (approximately 61% vs. 39%, respectively). Newly insured workers (almost 54%) are more likely to be employed by larger firms (over 50 employees) than smaller firms (46%).

Industry Sector: UIC random digit dial data showed among working adults, there were fewer industry differences versus occupation differences between newly insured and uninsured adults. Both the newly insured and uninsured were most likely to work in the service sectors than in any other sector. About twice as many newly insured adults (34.9%) were employed as managers, professionals, and technicians than uninsured (17.4%). More uninsured adults were employed in service occupations (26.4%) compared to newly insured (20.3%)

Employee Income Brackets: Information not available

Percentage of Part-time and Seasonal Workers: Information not available

Geographic Location: Information not available

Others(s): Information not available

For those employers offering coverage, please discuss the following:

Cost of Policies: Information not available

Level of Contribution: Information not available

2.2 What influences the employer's decision about whether or not to offer coverage?

Advantages: There are a number of advantages to employers for offering health insurance, including providing coverage for themselves and their families, attracting and retaining high quality employees, maintaining a competitive edge through greater productivity with a healthy work force, and a feeling of meeting a moral obligation to offer health insurance.

Maintenance: Maintaining health insurance can be a struggle for employers because of rate increases and affordability of employer contributions, employee expectations and naiveté regarding health insurance, problems with managed care systems, and hassles in yearly health insurance decisions.

The primary reasons given by employers for not electing to provide coverage are:

Affordability/Cost Increases: Employers are universally concerned about costs. Rate increases, and mandates, drive up costs. The impact of an employee illness can increase risk ratings, thereby driving up costs. Recently health insurance rate increases have been as much as 20% per year, so benefits may shrink, deductibles may increase, employees' share of premiums may increase and coverage may be eliminated.

Employment Status: Employers often choose to cover full time employees in order to remain competitive, or to satisfy negotiated contractual agreements. Frequently businesses choose not to provide certain benefits such as health insurance to part-time or seasonal employees. New hires often face waiting periods for coverage.

2.3 What criteria do employers offering health insurance use to define benefit and premium participation levels?

Competition: To remain competitive, employers must look at the marketplace to determine what benefit packages other employers offer and determine if theirs is competitive.

Employee Retention: If a benefit appears to be affecting employee retention then it will probably be offered.

Negotiated Benefits: In some cases health insurance benefits are union negotiated. Firms do not have the ability to unilaterally alter benefits, and benefits are changed in accordance with contract terms.

Costs/deductibles or Other Benefits: If health insurance costs increase then deductibles may increase or other benefits may be decreased to contain the total cost of employer-sponsored insurance to the employer. Many employers are responsible to shareholders, as well as employees, so unless revenue can be increased cost increases in one line item must be accompanied by decreases in another line item to keep shareholders from liquidating shares and driving up the cost of capital.

2.4 What would be the likely response of employers to an economic downturn or continued increases in costs?

This question was not asked directly in the focus groups or key informant interviews. Speculating, based on the totality of information available from the SIUC and UIC research, Illinois Department of Insurance – Planning Grant literature reviews, and on economic theory in

general, it can be assumed that firms would respond in typical economic fashion. If health insurance costs continue to escalate this will be perceived by firms as an increase in the cost of an input. Firms will attempt to protect revenue by containing or reducing costs. Cost reduction techniques as related to health insurance will probably include increasing deductibles and co-payments, reducing coverage or types of coverage, passing on costs to employees by increasing employee share of premiums (which will operate like a cut in real wage), or eliminating health insurance entirely (if that is an option, e.g. a non-unionized firm).

2.5 What employer and employee groups are most susceptible to crowd-out?

This question was not responded to systematically in our qualitative data gathering. As a part of our research effort a review of the crowd-out literature was undertaken and a bibliography was created with sources for reference information at such time as policy is drafted. It is expected that with the national information, as well as the information gained from other states, Illinois will be able to effectively capitalize on the experiences of others to address the issue of crowd-out. In both the focus groups and the key informant interviews no one really knew what crowd-out meant. People heard the term and created their own working definitions.

2.6 How likely are employers who do not offer coverage to be influenced by:

Expansion/development of Purchasing Alliances?: Some in the Illinois Assembly process indicated that purchasing pools/alliances might be attractive to businesses. Purchasing pools have met with mixed success across the country. A few have been quite well received, but many have made unsuccessful attempts to provide health insurance coverage options. Illinois has a very competitive private insurance market but the very small employer frequently finds the cost prohibitive. The ability to join with a group in a purchasing pool might make insurance more affordable to some of these businesses. There was a strong sentiment reflected by the insurance industry that the rules and policies governing operation of purchasing pools should be similar to those followed by private sector insurance companies. Small businesses seemed particularly interested in this idea if it could be made viable. The challenge would be to develop a program that includes key characteristics of the few successful plans and omits the characteristics of the failing plans.

Individual or Employer Subsidies?: This idea seemed to generate interest in focus groups. It was felt that employers might benefit substantially through some type of subsidy program and that such a subsidy might encourage employers to offer insurance to the currently uninsured. A direct subsidy to individuals that would pay for health insurance coverage is likely to be quite successful, particularly if the subsidy was prospective.

Additional Tax Incentives?: The general feeling is that tax deductions as they are currently in Illinois do not provide substantial help to businesses in contributing to offering health insurance. Further it was felt that tax deductions fail to overcome the increasing cost of health insurance coverage.

Refundable tax credits to businesses would almost certainly be beneficial in reducing the number of uninsured persons in Illinois. Businesses are quite likely to be influenced by refundable tax credits that would make health insurance more affordable. Tax incentives to employers that would cover the cost of health insurance to provide coverage to part time or temporary workers would also probably be successful in reducing the number of uninsured individuals.

2.7 What other alternatives might be available to motivate employers not now providing or contributing to coverage?

Cost Control: A focus on cost control measures would lead to greater interest in providing or continuing health insurance coverage. The rising cost of insurance is a significant issue among employers both in the initiation and continuation of coverage. Insurance costs are fueled by health care costs. Market based competition has traditionally been used to regulate rates in Illinois.

Education: During the State Planning Grant process there was an interest in enhancing education about the appropriate and realistic role of health insurance. There seemed to be agreement that employers should be made more aware of available products and coverage opportunities. If more employers recognized the advantages of insuring employees and could identify a product consistent with existing needs at an affordable price it would almost certainly reduce the number of uninsured individuals.

SECTION 3. SUMMARY OF FINDINGS: HEALTH CARE MARKETPLACE

3.1 How adequate are existing insurance products for persons of different income levels or persons with pre-existing conditions? How did you define adequate?

Adequacy can be defined in two steps. Whether insurance products can be obtained (are available and affordable) by the various segments of the population is the first question. Once it is determined that insurance products can be obtained, then adequacy is defined in terms of whether such coverage meets the needs of the individual being covered.

For individuals who fall somewhere in between those who access public programs and those who receive coverage through their employer or are otherwise able to afford purchasing a policy with the generally recognizable benefits of a major medical policy, there are really very few options available. For example, the average cost of one insurer's most popular products that would cover a family is $250 per month. If the principal breadwinner for a family without insurance earns $25,000 per year, this product, even though it provides major medical coverage, may be unaffordable for the family and thus be inadequate. Although existing products may be adequate for some segments of the population, they often are inadequate for the working poor due to cost. Only products that severely limit the benefits available for any one individual (such as hospital expense policies) would truly be considered affordable. It is unlikely that such products would be adequate in terms of benefits. Anecdotal evidence suggests that even these limited benefit products have become less popular as coverage options for individuals.

In terms of whether benefit packages available for major medical policies are adequate, there tends to be little coverage differentiation between products. When Illinois law was amended to allow for the provision of policies that contained minimum coverage options (often referred to as "bare bones" policies) for the small group market, such policies were not widely purchased and proved unpopular. In past conversations with the employer community, it was suggested that employers did not want to be seen as providing "inadequate" or less than average coverage for their employees. This is not to say there were not other reasons for the absence of participation in these products (specifically some groups pointed to the fact that these were not profitable products for agents to sell).

For persons with pre-existing conditions, Illinois relies on HIPAA protections to ensure continuity of coverage for those who have maintained coverage. For persons who have never had coverage, or who have surpassed the 63-day HIPAA protection period (for group coverage) or the 90-day period (for ICHIP, HIPAA alternative mechanism coverage) there are a few alternatives. For new enrollees under group coverage, Illinois limits the pre-existing waiting period to 12 months for conditions that were present in the 6 months prior to coverage. For individual policies, the pre-existing waiting period is limited to 12 months for conditions that were present in the 24 months prior to coverage. For persons who are otherwise uninsurable, the Illinois Comprehensive Health Insurance Plan's (ICHIP) state funded plan will cover pre-existing conditions after six months. The HIPAA CHIP plan for federally eligible persons has no pre-existing condition exclusion. However, ICHIP coverage under either plan is required by statute to be priced at 125% to 150% of premiums in the private market. While this would

appear to be unaffordable for low income persons, 20% of ICHIP enrollees have incomes below $20,000 and 55% have incomes below $40,000. Low income parents can turn to Illinois' KidCare program for their children, or to Medicaid. One of the strategies suggested during the Illinois Assembly process was to expand KidCare eligibility to family care.

3.2 What is the variation in benefits among non-group, small group, large group and self-insured plans?

The variations of benefits required for individuals and group coverage are not substantial. There are a few provisions that apply to only group and not individual. Two of the most significant are inpatient treatment of alcoholism and infertility. Many of the new statutes addressing mandated benefits applied to both individual policies and group policies. Anecdotal evidence suggests that many self-insured plans, even though they are not required to, include the mandated benefits required by Illinois statutes. We have listed the benefits required for non-group coverage, small group coverage and group coverage below:

PROVISIONS	NON-GROUP	GROUP	SMALL GROUP (2-50)
Alcoholism		X	X
Breast Implant Removal	X	X	X
Cancer Off-Label Drugs	X	X	X
Colorectal Cancer Screening		X	X
Diabetes Self Management		X	X
Infertility		X	(Only applies to groups of more than 25 employees)
Mammograms	X	X	X
Post Mastectomy Care	X	X	X
Mastectomy Reconstruction	X	X	X
Complications of Pregnancy	X	X	X
Post Parturition Care	X	X	X
Prenatal HIV Testing	X	X	X
Serious Mental Illness		X	
Organ Transplants	X	X	X
Pap Smears		X	X
Prostate Specific Antigen Testing		X	X
Adopted Children	X	X	X
Continuation/Spousal Continuation		X	X

Conversion/Conversion for Spouse		X	X
Handicapped Dependent Children	X	X	X
Newborn Coverage	X	X	X

3.3 How prevalent are self-insured firms in your State? What impact does that have in the State's marketplace?

Most if not all firms with 500 or more employees are self-funded. A significant number of firms with 100 to 500 employees are self-funded. Almost all state employees have the option of a variety of health care plans, ranging from point-of-service and HMO type plans to a medical indemnity plan that offers a wide range of benefits plus major medical coverage. According to the Illinois Department of Central Management Services approximately 44% of the 344,636 covered lives in the state health plans are in the medical indemnity plan, which is a self-funded plan. The existence of self-funded plans reduces the size of the market.

3.4 What impact does your State have as a purchaser of healthcare (e.g. For Medicaid, SCHIP and State employees)?

The Illinois health insurance market is huge; health insurance premiums in 2000 totaled more than $10 billion. The Illinois insurance industry, as a whole, feels that the State of Illinois, as a purchaser of health insurance coverage for its employees, public aid recipients and others, plays a significant role in this market. While the exact impact on each individual health plan differs depending on the plan's size, market share, its participation in non-commercial groups (i.e.: public aid, State sponsored risk pools) and other factors, the impact of the state on the market overall is important. Even though the effect of the state on premiums, health care availability, etc. may not be able to be accurately or quantitatively measured it does provide an important source of business for some plans and health care coverage for many Illinois citizens.

3.5 What impact would current market trends and the current regulatory environment have on various models for universal coverage? What changes would need to be made in current regulations?

We did not perform any analysis that would allow us to answer this question. The current regulatory environment is one of open competition.

3.6 How would universal coverage affect the financial status of health plans and providers?

We did not perform any analysis that would allow us to answer this question.

3.7 How did the planning process take safety net providers into account?

The planning process focused on providing insurance products. Safety net providers such as free clinics were briefly discussed during the Illinois Assembly process.

3.8 How would utilization change with universal coverage?

Presumably, utilization would increase depending on how the system was structured and what cost sharing measures were incorporated.

3.9 Did you consider the experience of other States with regard to:

Expansions of Public Coverage?: Public coverage in 21 states was exhaustively examined. Information was collected in hard-copy form and also placed on the SPG website for use by Illinois Assembly members and other interested parties.

Public/private Partnerships?: Purchasing pools and other partnership arrangements were considered in depth. Two original papers were generated regarding purchasing pools and placed on the SPG website. Other partnership arrangements that were identified as particularly unique or interesting, such as the California Plan or the Muskegon, Michigan plan, were discussed during the July 10-12 meeting of the Illinois Assembly, as well as included in hard-copy and posted on the website.

Incentives for Employers to Offer Coverage?: A large number of articles on incentives for employers were reviewed.

Regulation of the Marketplace?: No, regulation of the marketplace was peripheral to our process.

SECTION 4. OPTIONS FOR EXPANDING COVERAGE

The planning grant process to date has placed us in a position based on our research and consensus building to move forward with policy considerations and development of implementation procedures. We will continue to draw on Illinois Assembly work for some time into the future as resources and need allow. Our next step is to develop specific strategies in connection with these options. After that we may use a number of alternatives for consideration and discussion of these strategies, including but not limited to public meetings across the State, sessions with key legislators, and various types of communication with stakeholder groups.

At this point we have not rejected any of the policy options developed through the consensus building process of the Illinois Assembly. The Illinois Assembly process (described in detail in Section 5 of this report) allowed us to identify three options which we will focus on in developing specific strategies: (A) Extension of KidCare program to parents; (B) Employer Incentives, and (C) Education and Marketing of Insurance Products and Programs. Questions 4.1 through 4.17 will be addressed separately for each of these three options as 4.A.1 through 4.A.17, 4.B.1 through 4.B.17, and 4.C.1 through 4.C.17, respectively. Each of these three options had relatively strong support in the Illinois Assembly process. Question 4.18 and 4.19 will be answered once.

4.A.1 Which coverage expansion options were selected by the State (e.g., family coverage through SCHIP, Medicaid Section 1115, Medicaid Section 1931, employer buy-in programs, tax credits for employers or individuals, etc.)?

COVERAGE OPTION A. Family Care: This option is to support the extension of the KidCare Program to parents as described in the Family Care Bill (HB 23) introduced in the Illinois General Assembly last session. The Family Care Bill was proposed to include family members and guardians of children for KidCare (SCHIP) which would allow adults to participate up to 185% of the FPL and children to participate up to 200% of the Federal Poverty Level (FPL). Current estimates of eligibility indicate that approximately 200,000 adults and another 12,000 children would be targeted by expansion of KidCare. As of the date of this report the bill has not passed.

This is a program designed to complement the current KidCare program in Illinois. According to the available literature and our research this would enhance the likelihood that many more children, parents or guardians would commit to health coverage, both preventive health care and health maintenance. Support for the Family Care Bill was recommended by almost every small group for each of the five target populations in the Illinois Assembly process. In so far as is possible the strong endorsement for the Family Care Bill will be communicated to policy makers in the state.

4.A.2 What is the target eligibility group under the expansion?

The target eligibility groups under consideration in this policy option include parents or guardians of KidCare eligible children and approximately 12,000 eligible but unenrolled KidCare children. It is believed that if this Bill passed in its previous form it could provide coverage for 12,000 children and 200,000 adults that currently are uninsured.

4.A.3 How will the program be administered?

The Family Care expansion would be administered through the KidCare process.

4.A.4 How will outreach and enrollment be conducted?

Enrollment will be conducted through the KidCare process.

4.A.5 What will the enrollee (and/or employer) premium-sharing requirements be?

Not addressed yet.

4.A.6 What will the benefits structure be (including co-payments and other cost-sharing)?

Not addressed yet.

4.A.7 What is the projected cost of the coverage expansion? How was this estimate reached? (Include the estimated public and private cost of providing coverage.)

It was projected that the cost for FY 2002 would be $396 million with federal matching funds. The state share is estimated to be $139 million and the federal share $257 million. The Illinois Department of Public Aid developed this estimate.

4.A.8 How will the program be financed?

See 4.A.7 above. The program will be financed with federal and state matching funds.

4.A.9 What strategies to contain costs will be used?

Not addressed yet.

4.A.10 How will services be delivered under the expansion?

Not addressed yet.

4.A.11 What methods for ensuring quality will be used?

Not addressed yet.

4.A.12 How will the coverage program interact with existing coverage programs and State insurance reforms (e.g., high-risk pools and insurance market reforms), as well as private sector coverage options (especially employer-based coverage)?

Not addressed yet.

4.A.13 How will crowd-out be avoided and monitored?

This proposal is for an expansion of an existing program to include parents or guardians of eligible children. It is anticipated that the techniques used for the KidCare program will be used for the expansion. Little evidence exists that there is any serious problem with crowd-out at this time with the KidCare program in Illinois.

4.A.14 What enrollment data and other information will be collected by the program and how will the data be collected and audited?

Not addressed yet.

4.A.15 How (and how often) will the program will be evaluated?

Not addressed yet.

4.A.16 For each expansion option selected (or currently being given strong consideration), discuss the major political and policy considerations that worked in favor of, or against, that choice (e.g., financing, administrative ease, provider capacity, focus group and survey results). What factors ultimately brought the State to consensus on each of these approaches?

UIC random digit dial data and national data show that the majority of uninsured adults are employed. While not all parents or guardians of KidCare eligible children are employed, a significant number are employed and uninsured. Certainly children are among our most vulnerable population. There is a base of support from advocacy groups and various other stakeholders. The availability of federal funds was influential in garnering support for the

option. There was strong support for this bill in the Illinois Assembly from the outset of the process.

4.A.17 What has been done to implement the selected policy options? Describe the actions already taken to move these initiatives toward implementation (including legislation proposed, considered or passed), and the remaining challenges.

Legislation has been drafted and introduced in the Illinois General Assembly during the 2001 regular session. Coalitions have formed to support the legislation. Remaining challenges include identifying state funds to match the federal funds as well as the need for a federal waiver to implement the project.

4.B.1 Which coverage expansion options were selected by the State (e.g., family coverage through SCHIP, Medicaid Section 1115, Medicaid Section 1931, employer buy-in programs, tax credits for employers or individuals, etc.)?

COVERAGE OPTION B. Incentives for Small Employers: Small employer incentives received a considerable amount of support throughout the Illinois Assembly process. Substantial information from the literature review and materials developed pertaining to the performance of incentive programs in other states will prove of value in developing policies and strategies regarding employer incentives. The following areas are possibilities for consideration:

1. Develop Local, Regional, or Statewide Purchasing Pool(s): Implementation tools may include: the possibility of state sponsorship; marketing techniques; evaluation of the success(es) or failure(s) of purchasing pools in other states; employer education regarding the advantages and disadvantages of purchasing pools; the possibility of amending state law to allow for pools based on geographic regions; expanded Department of Insurance regulatory powers over pools; inclusion of a reinsurance component; coverage of high and low risk occupations; a requirement that all risk classes participate; development of employee targeted subsidies to reduce cost; and the creation of a task force of various constituencies to develop a purchasing pool plan. Before entering into this venue the state would build on the existing research regarding reasons for both the success and failure of some of the more visible pools in an attempt to emulate the successes and avoid the failures.

2. Consideration of Reinsurance for Small Employers: Reinsurance could be implemented in a number of ways to enhance the private insurance marketplace. The California Plan and the Muskegon, Michigan Plan are both interesting models when considering selection criteria for evaluation. Reinsurance could enhance the private insurance marketplace.

3. Subsidies: Subsidy programs could be developed to encourage employers to offer insurance coverage.

4.B.2 What is the target eligibility group under the expansion?

Small employers and their employees and dependents, especially those with low to mid-level income that currently lack insurance would be the target eligibility group.

4.B.3 How will the program be administered?

Not addressed yet.

4.B.4 How will outreach and enrollment be conducted?

Not addressed yet.

4.B.5 What will the enrollee (and/or employer) premium-sharing requirements be?

Not addressed yet.

4.B.6 What will the benefits structure be (including co-payments and other cost-sharing)?

Not addressed yet.

4.B.7 What is the projected cost of the coverage expansion? How was this estimate reached? (Include the estimated public and private cost of providing coverage.)

Not addressed yet.

4.B.8 How will the program be financed?

A number of suggestions came out of the Illinois Assembly process which will be given consideration. Possible funding sources include: state seed money for start-up; state establishment and provision for a stabilization fund; employer and employee cost sharing; cost sharing or total cost coverage from the state, foundation funds; or federal funds; reallocation of existing resources within the state; tapping into new funding mechanisms; mixture of state, federal, employer, employee and insurance company money to fund creation of pool; and tax credits to employees and employers.

4.B.9 What strategies to contain costs will be used?

Not addressed yet.

4.B.10 How will services be delivered under the expansion?

Not addressed yet.

4.B.11 What methods for ensuring quality will be used?

Not addressed yet.

4.B.12 How will the coverage program interact with existing coverage programs and State insurance reforms (e.g., high-risk pools and insurance market reforms), as well as private sector coverage options (especially employer-based coverage)?

Not addressed yet.

4.B.13 How will crowd-out be avoided and monitored?

A great deal of research was done relative to crowd-out during our planning process that will allow us to address this issue when we have a specific plan. A bibliography of the literature has been created, a review paper has been written, and experiences of other states have been thoroughly studied and documented.

4.B.14 What enrollment data and other information will be collected by the program and how will the data be collected and audited?

Not addressed yet.

4.B.15 How (and how often) will the program will be evaluated?

Not addressed yet.

4.B.16 For each expansion option selected (or currently being given strong consideration), discuss the major political and policy considerations that worked in favor of, or against, that choice (e.g., financing, administrative ease, provider capacity, focus group and survey results). What factors ultimately brought the State to consensus on each of these approaches?

Findings from the quantitative research indicate that more than 50% of the working uninsured do not have employer-sponsored insurance. Almost all groups of stakeholders endorsed some form of employer incentives. Key informant interviews supported the concept of purchasing pools. In

the Illinois Assembly meeting there was strong agreement to support some form of employer incentives. We still have to determine exactly what type of incentives to implement. For example, while some stakeholders strongly supported purchasing pools, others strongly opposed them.

Political Advantages: The majority of insured Illinois residents obtain coverage through their employers. Certain employer incentives available statewide that build on an existing system would be well received by citizens and more easily legislated and funded in the political arena.

Political Disadvantage: Certain employer incentives may be unpopular with some stakeholders. For example, the track record of purchasing pools in other states has been mixed, with a few strong successes and many failures. It may be difficult to "sell" such a program to legislators and constituents.

4.B.17 What has been done to implement the selected policy options? Describe the actions already taken to move these initiatives toward implementation (including legislation proposed, considered or passed), and the remaining challenges.

Since no option has been specifically identified, implementation has not begun. Illinois is poised at this point to move forward along several alternative paths in designing an employer incentive plan. The Project Director along with staff from the Governor's Office will be determining how to proceed with policy development, presentation and implementation.

4.C.1 Which coverage expansion options were selected by the State (e.g., family coverage through SCHIP, Medicaid Section 1115, Medicaid Section 1931, employer buy-in programs, tax credits for employers or individuals, etc.)?

COVERAGE OPTION C. Education and Marketing of Insurance Programs and Products: Enhancement of education, marketing and enrollment processes and procedures was identified as a strategy during the Illinois Assembly process. There was interest in increased education about both public and private insurance programs. Many of the agencies and organizations that provide public programs such as KidCare (SCHIP) have already made significant strides in these areas. While efforts have been made to increase education, enhance marketing and improve enrollment processes this is identified as an area of ongoing need. A host of ideas were generated in these areas. The following represent the general sentiments of the stakeholders, supported by the findings of the State Planning Grant researchers, regarding moving forward in these areas:

1. Education About Insurance Programs and Products: Consumers may need to learn about the benefits of having insurance coverage. Consumers may be unaware of the kinds of private and public coverage available in terms of benefits and price. Small employers may need to learn about the benefits of making insurance coverage available to their employees. Many individuals and groups are not aware of what programs are available and the specific eligibility requirements for particular programs. Concerted efforts need to be made to identify eligible persons for

specific programs and to concentrate education efforts among those least likely to be aware of existing programs. This might call for an increase in the number of languages used to communicate with targeted groups or to identify language specific media for education purposes.

2. Market Insurance Programs and Products: It is important to link eligible people to existing programs. Programs need to be marketed in a way that will increase take-up rates among various populations. Marketing strategies will almost certainly need to differ between various segments of the population and between different ethnic groups. If new programs are developed, effective public relations programs will need to be developed.

3. Enrollment Procedures: Enrollment procedures for public programs need to be routinely examined for possible simplification. The application should be reduced to a "bare-bones" process to the extent possible. Enrollment centers that should continue to be used include community health centers, neighborhood clinics, public and parochial schools, churches and advocacy groups.

4.C.2 What is the target eligibility group under the expansion?

All groups identified in the Illinois Assembly process will be targeted in this policy option. The need for additional education and marketing cuts across all the target populations: the working uninsured; young adults; Hispanics and other minority/ethnic groups; small employers; and children.

4.C.3 How will the program be administered?

Not addressed yet.

4.C.4 How will outreach and enrollment be conducted?

Not addressed yet.

4.C.5 What will the enrollee (and/or employer) premium-sharing requirements be?

Not addressed yet.

4.C.6 What will the benefits structure be (including co-payments and other cost-sharing)?

Not addressed yet.

4.C.7 What is the projected cost of the coverage expansion? How was this estimate reached? (Include the estimated public and private cost of providing coverage.)

Not addressed yet.

4.C.8 How will the program be financed?

A number of recommendations came out of the Illinois Assembly process. While not all will be used many will be given serious consideration. Possible methods of funding include: integrating insurance education into existing educational programs; seeking funds from the Illinois State Board of Education, Illinois Community College Board, Illinois Department of Revenue, and other state agencies; seeking federal/private grants; utilizing media outlets to provide additional public service announcements targeting the education of young adults on health insurance; targeting marketing and outreach programs to specific industries; seeking grants from public and private sources; seeking support from health plan providers, consumers and employers; developing partnerships between public and private sectors; obtaining federal funding for school-based clinics; and encouraging non-profit "in kind" contributions.

4.C.9 What strategies to contain costs will be used?

Not addressed yet.

4.C.10 How will services be delivered under the expansion?

Not addressed yet.

4.C.11 What methods for ensuring quality will be used?

Not addressed yet.

4.C.12 How will the coverage program interact with existing coverage programs and State insurance reforms (e.g., high-risk pools and insurance market reforms), as well as private sector coverage options (especially employer-based coverage)?

Not addressed yet.

4.C.13 How will crowd-out be avoided and monitored?

We do not anticipate that crowd-out will be a major issue for this strategy which is intended primarily to use education and marketing techniques to encourage enrollment in insurance programs or purchase of insurance products.

4.C.14 What enrollment data and other information will be collected by the program and how will the data be collected and audited?

Not addressed yet.

4.C.15 How (and how often) will the program will be evaluated?

Not addressed yet.

4.C.16 For each expansion option selected (or currently being given strong consideration), discuss the major political and policy considerations that worked in favor of, or against, that choice (e.g., financing, administrative ease, provider capacity, focus group and survey results). What factors ultimately brought the State to consensus on each of these approaches?

Education and marketing of insurance programs and products is expected to be a politically attractive policy alternative. The cost of new programs would be significantly larger than the cost of enhancing efforts to publicize existing programs. The cost factor alone should make this attractive to policymakers. Additionally, there was substantial support for this option from focus group participants, key informant interviews, and participants in the Illinois Assembly.

4.C.17 What has been done to implement the selected policy options? Describe the actions already taken to move these initiatives toward implementation (including legislation proposed, considered or passed), and the remaining challenges.

Since no option has been specifically identified, implementation has not begun. Illinois is poised at this point to move forward along several alternative paths in designing an implementation plan to increase education and marketing. The Project Director along with staff from the Governor's Office will be determining how to proceed with policy development, presentation and implementation.

4.18 Which policy options were not selected? What were the major political and policy considerations that worked in favor of, or against, each choice? What were the primary factors that ultimately led to the rejection of each of these approaches (e.g., cost, administrative burden, Federal restrictions, constituency/provider concerns)?

At this juncture no policy options have been have been rejected. All of our work with the Illinois Assembly process has led us to the position that forward movement must be incremental. Consequently while a few options are under consideration for more immediate consideration there is a plethora of remaining options that may be brought forward when funds and the political environment allow. Nothing has been discarded and we have documented a large range of other activities that may be considered at some future time.

4.19 How will your State address the eligible but unenrolled in existing programs? Describe your State's efforts to increase enrollment (e.g., outreach and enrollment simplifications). Describe efforts to collaborate with partners at the county and municipal levels.

Illinois looked at five target groups in moving toward solutions on how to make insurance available to the uninsured. Those target groups were the working uninsured, Hispanics and other minority/ethnic groups, young adults, small employers, and children. During the Illinois Assembly, outreach, marketing, education and enrollment simplification were identified as critical needs. Also, according to the quantitative and qualitative research, awareness continues to be a necessary component of any effort.

Some considerations that will be discussed prior to completing the policy/implementation strategies include: developing performance requirements for participating agencies; linking people to programs, identifying existing programs and the type of marketing strategies that might be most effective in acquainting eligible persons with such programs; working through neighborhood clinics in targeted hard-to-reach communities; direct marketing toward employers that are likely to hire targeted populations; using language-specific media; enlisting the help of religious leaders and advocacy groups in churches and public/parochial schools; making programs culturally specific, removing language barriers and making programs culturally specific with products that are unique to populations; marketing programs directly to employers with an education component to employers to support encouraging employees to opt for employer-sponsored insurance; and making enrollment and sign-up procedures as simple as possible for individuals, employees, employers, parents, etc.

For KidCare, Illinois has implemented a very successful, multi-pronged approach to outreach. Through a variety of strategies, Illinois, with its partners, has spread the word about KidCare, which has resulted in the enrollment of over 95,000 children and pregnant women through April 2000. The state believes its outreach efforts to date have been very successful. In addition to persons applying at local state offices, the central KidCare enrollment unit continues to receive an average of 300 applications on a daily basis.

SECTION 5. CONSENSUS BUILDING STRATEGY

5.1a What was the governance structure used in the planning process and how effective was it as a decision-making structure?

This project was governed by a Steering Committee composed of representatives of the Governor's office, state agencies and state universities. The Illinois Department of Insurance served as the lead agency and coordinated the project. Initially, the Steering Committee met every other week and occasionally on a weekly basis to monitor the project. An executive committee or core management group of the Steering Committee was established to handle interim decisions. Staff of the Department of Insurance communicated regularly with all participants to assure that action steps were being undertaken and that time lines were met. The Department of Insurance served a fiscal role, authorizing and monitoring the expenditure of grant funds. The Department prepared and maintained all necessary accounting records and submitted all required accounting reports. The Steering Committee structure proved effective in incorporating a variety of viewpoints in the decision making process. It allowed for needed flexibility as the planning process was implemented.

5.1b How were key State agencies identified and involved?

Six key state agencies were identified because of their understanding of the subject matter under consideration and with the recognition that implementation of policy initiatives might be administered through one or more of those agencies. Representatives of these agencies served as members of the Steering Committee.

Department of Insurance is charged with protecting the rights of Illinois citizens in their insurance transactions and monitoring the financial solvency of all regulated entities through effective administration and enforcement of the Illinois Insurance Code.

Department of Public Health promotes the health of the people of Illinois, primarily through the prevention and control of disease and injury. IDPH endeavors to assess health status and the determinants of health, develop policy options to address health priorities, and assure that Illinois residents have access to the health services that they need. IDPH efforts, intended to benefit the entire population of Illinois residents, are conducted through nearly 200 programs that focus on specific health issues; through local health departments that provide services in Illinois counties and municipalities; and through collaborations with a broader system of partners with interests and concerns related to the health of the state's population.

Department of Public Aid is the state Medicaid agency. It administers the $7 billion Medicaid program that provides health care to the indigent population of Illinois.

Department of Commerce and Community Affairs (DCCA) is the lead economic development agency for the State of Illinois. As a part of DCCA, the FirstStop Business Information Center focuses on providing information and advocacy to Illinois' small business community. A top

issue arising from the Governor's Small Business 2000 Summit conducted by DCCA in January was affordable and accessible health care for small business owners and their employees.

Department of Human Services assists Illinois residents to achieve self-sufficiency, independence, and health to the maximum extent possible by providing integrated family-oriented services, promoting prevention, and establishing measurable outcomes, in partnership with communities.

Illinois Comprehensive Health Insurance Plan is the state's high-risk pool for uninsurable or federally eligible individuals.

5.1c How were key constituencies (e.g., providers, employers, and advocacy groups) incorporated into the governance design?

Throughout the planning process the Steering Committee worked with numerous stakeholders including local government agencies, public health and social service agencies, faith groups, insurance companies and agents, employers, health care providers, health issues interest groups, community groups, members of Public Health Futures Illinois (a partnership to promote a broad public health system with prevention as the key component) and other groups. Representatives of these groups participated in the Illinois Assembly project (see question 5.2).

State Planning Grant Staff regularly attended Public Health Futures Illinois (PHFI) meetings and discussed and obtained feedback about the progress of the grant process. The momentum of the PHFI strategic planning partnership, which was formed in 1997, strengthened Illinois policy formulation related to the State Planning Grant (SPG). The PHFI effort has been led by the Illinois Department of Public Health and driven by the collaborative energies of a broadly inclusive group representing public, private, and voluntary institutions. The PHFI process has been funded by the State of Illinois and a grant from the Robert Wood Johnson Foundation. Participants have included health care providers, businesses, academics, state and local governments, charitable and social services, and faith communities. Access to care is a priority concern identified within the PHFI strategic plan, *Illinois Plan for Public Health Systems Change*. The plan calls for the establishment of an Access to Care Consortium in the state to utilize data to assess need and design access initiatives, with a goal of assuring that all Illinoisans have adequate access to care, including health insurance coverage.

5.1d How were key State officials in the executive and legislative branches involved in the process?

Officials were brought into the process as members of the Illinois Assembly and the Steering Committee. The Executive branch had representatives from the Governor's office and from the executive agencies (Departments of Insurance, Public Health, Public Aid, and Commerce and Community Affairs, Human Services). The legislative branch had representation from Democrat and Republican staff members from both chambers of the Illinois General Assembly (House of Representatives and Senate). Legislators were included in key informant interviews.

5.2 What methods were used to obtain input from the public and key constituencies (e.g., town hall meetings, policy forums, focus groups, or citizen surveys)?

The Illinois Assembly on the Uninsured (Illinois Assembly) was the main source of public input. Members of the Illinois Assembly represented a diverse group of stakeholders, which included employers, labor unions, social service advocates, commercial insurers, insurance agents, healthcare providers including medical practitioners and others. Results of the quantitative and qualitative research were presented to the Illinois Assembly. This group of public and private stakeholders was charged with engaging in dialogue and moving toward consensus on how to reduce the number of uninsured.

The Illinois Assembly on the Uninsured was a modified version of the American Assembly Model, first pioneered by Dwight Eisenhower when he was President of Columbia University. The Illinois Assembly allowed the key stakeholders to meet in a structured, mediated environment to reach as much consensus as possible, first on the basic facts and data related to the problem of uninsurance, and then on ways to move the number of uninsured as close as possible to zero. The members of the Illinois Assembly shared more common ground on this issue than they might have believed, but they rarely have had a chance to work cooperatively towards addressing this issue.

The Illinois Assembly convened in Springfield, Illinois for an introductory meeting in January 2001 followed by a three-day meeting in July and a final meeting in September. Former United States Senator Paul Simon, now a professor and director of the Public Policy Institute at Southern Illinois University at Carbondale, provided the introduction and charge to the Illinois Assembly members. Mr. Mike Lawrence, Associate Director for the Public Policy Institute at SIUC, helped guide the Illinois Assembly activity.

The July session consisted of three components:

1. Reports on research[5] results from the random digit dial survey of uninsured households; stakeholder focus groups and key informant interviews; the expanded Behavioral Risk Factor Surveillance System (BRFSS); and a review of programs currently in use in Illinois and/or highlights of strategies in use in other states were presented.

2. Participants were then divided into eight small heterogeneous groups to discuss strategies to provide coverage to the uninsured. The group composition was designed to reflect balance among the various constituencies that participants represented.

3. Each group met for five sessions, guided by trained facilitators. Each session focused on separate target populations: small employers, children, young adults, working uninsured, and Hispanics and other minorities. Each of the eight groups produced strategies for each of the five target populations. These reports were compiled and distributed to caucus groups (employers, providers, insurers, and consumer advocates and public health professionals) for review.

Initially, the Illinois Assembly planned to prioritize the results of the small group deliberations during the July meeting. Due to the volume of strategies produced and a desire by members to consult with their constituencies, Illinois Assembly participants requested that they be given time to digest the material prior to setting priorities (those who chose, were given the opportunity to indicate preliminary priorities during the meeting). A ballot was prepared and distributed to each participant soon after the July meeting. Participants selected their first, second and third choice of strategies for each target population and in an overall category. The ballots were tabulated and the results distributed for comment to all those on the Illinois Assembly distribution list. A draft report describing the Illinois Assembly process and results was prepared for discussion at the September meeting.

During the September meeting Illinois Assembly participants affirmed the three areas of consensus that emerged from the balloting and are reported as our policy options in Section 4 of this report. Some participants expressed concern that insufficient attention had been paid to cost of strategies and that some of the proposed strategies were unrealistic or would be ineffective. All groups endorsed the idea of creating a subcommittee of stakeholders to take these general options and develop them into detailed strategies. The participants at the September meeting also offered suggestions for revisions of the draft Report of the Illinois Assembly. A revised report was prepared and sent for final comment to the participants. The final Report of the Illinois Assembly can be found in Appendix 3 of this report.

We also conducted focus groups and key informant interviews to obtain input.

5.3 What other activities were conducted to build public awareness and support (e.g., advertising, brochures, Web site development)?

The development of a website for the project proved most beneficial. The site provided visitors with information with regard to the quantitative and qualitative components of the project. Another section of the website included an area titled "Sources on Issues Surrounding Health Care and the Uninsured." This section listed over 475 citations ranging from academic, business and public policy journals and books, to articles which appeared in the popular press. A "Must Read List" section listed 10 articles that covered the essential issues related to health insurance coverage. Other sections included a "Links" page to public and private organizations and government entities, a "Steering Committee" page listing all members of the committee and an area for updated information related to meetings and conferences.

Another successful component was the role that technology played in providing information and raising awareness to the members of the Steering and Executive Committees, and the members of the Illinois Assembly on Uninsured. Communication methods utilized included regularly scheduled conference calls, facsimiles when necessary and electronic mail messages.

5.4 How has this planning effort affected the policy environment? Describe the current policy environment in the State and the likelihood that the coverage expansion proposals will be undertaken in full.

The planning process has increased awareness of the problem of lack of health insurance. Illinois Assembly participants convened their own meetings to further discuss the issue. New relationships were fostered between diverse stakeholders. Coverage expansion proposals that will successfully increase the number of insured in Illinois will need to be implemented on an incremental basis. Cost will be a major issue. Political interest groups who are interested in healthcare issues such as physicians and insurers have considerable influence in the political process. Legislators and interest groups will have to be convinced that proposals be effective and efficient yet not create new problems.

Illinois, like all states, is considering how best to allocate its resources as a result of the terrorist activities that occurred September 11, 2001. Estimates of state revenues are being reduced. There could be changes in political direction with regard to social policy for financial reasons. Necessary new safety precautions are creating a drain on budgets. Also, thousands of jobs have been lost due to the decline in the airline and other industries. Even with the federal bailout programs announced on September 24, 2001 there will be tremendous suffering and financial hardship among many sectors of the state economy. The retreat of the tourism industry is also affecting the economy in terms of jobs lost and reduction of services across the state. Because of these factors many priorities will be shifted for some time in the foreseeable future. Until this crisis situation has passed it is impossible to tell how quickly the state will be able to move forward with the implementation of any recommendations made at this time.

SECTION 6. LESSONS LEARNED AND RECOMMENDATIONS TO STATES

6.1 How important was State-specific data to the decision-making process? Did more detailed information on uninsurance within specific subgroups of the State population help identify or clarify the most appropriate coverage expansion alternatives? How important was the qualitative research in identifying stakeholder issues and facilitating program design?

State-specific data will be important to the planning, development, and implementation of priorities that were recommended by the Illinois Assembly. The data was also important in the Illinois Assembly process itself. As data flowed in from various sources it was placed on the State Planning Grant website for consideration by all stakeholders and constituent groups. It was also used and relied on by the Steering Committee and the Executive Committee and throughout the consensus building process.

There were five major research methods used to gather data: (a) the random digit dial population-based survey of uninsured in Illinois (UIC); (b) expansion of the state's Behavioral Risk Factor Surveillance System (BRFSS); (c) analysis of existing data sets to augment and contextualize primary data collection efforts (UIC and BRFSS); (d) focus group discussions with key stakeholders (SIUC); and (e) personal interviews with strategic informants (SIUC). Research techniques and methodologies were complementary and were not substitutes for one another. Although some small but limited overlap of data did occur the overlap served to validate the research findings of the other research entities. Research methods provided unique and independent data that proved useful for the duration of the project, and will be necessary for future policy development and implementation.

Initially, the data sets were used by the Executive Committee to confirm the incidence of uninsurance within specific subgroups of the state population. After groups were identified based on preliminary findings the topical agenda was finalized for the meeting. The entire agenda was structured around the largest and/or most vulnerable groups of uninsured individuals in the state. These identified groups (children, young adults, Hispanics and other minority groups, small employers, and the working uninsured), were then targeted as the major subjects for discussion.

The primary purpose of the July meeting was to set priorities for strategies to make insurance available for the uninsured residents in Illinois. Information regarding details of the target populations clarified the development of strategic priorities where similar strategies might be used to facilitate insuring the uninsured across subgroups.

Qualitative research was extremely important in the development of the policies and strategies identified by the Illinois Assembly. It was used extensively in identifying stakeholder issues and facilitating prioritization of strategies at the Illinois Assembly meetings. It can be used by a variety of stakeholder groups to classify real or perceived issues and problems among stakeholders. Qualitative research has proven an extremely valuable complement to quantitative data. There are occasions that it picks up information that quantitative research does not identify

or address. It adds nuances and context to the quantitative data and brings a human perspective to the "numbers" that are under consideration. The qualitative research puts a face on the uninsured and makes the solution to solving the plight of the uninsured a very personal issue.

State-specific data was critical to the type of decision process used in Illinois. Qualitative and quantitative research both play a significant and vital role in identifying, clarifying, and understanding the necessity of making insurance available to the uninsured in the state. State-specific data was also imperative in the prioritization of strategies for providing insurance for the uninsured. Without state-specific data it would have been impossible to rationally rank priorities among and between groups in any significant way. Further, using the data provided by the qualitative and quantitative research will allow implementation in a way that will best meet the needs of the target populations and address issues within these groups. The inclusion of the qualitative data certainly improves the chances of successfully making insurance available to all of the uninsured in the state.

Program design issues will be dependent on the qualitative research. While the quantitative data provides the numbers required for actuarial analysis, qualitative data provides the information necessary for the enrichment of program administration and implementation. For programs to be successful, they must address both real and perceived needs of the specific target populations.

6.2 Which of the data collection activities were the most effective relative to resources expended in conducting the work?

It would be useful and practical to be able to identify which research activities were most, or least, economically efficient. However, we are unable to state definitively that any given data collection activity was more "effective relative to resources expended" than another. The essence of the questions asked in our planning process and the complementary nature of the research activities led to a highly integrated research product. Each research organization provided a unique product that contributed to the final overall outcome.

UIC, BRFSS, and SIUC all made major contributions in determining information relating to the demographic, economic and health-related characteristics of the uninsured in Illinois. While some data overlapped the greatest portion of all the research endeavors was complementary and research units could not have served as substitutes for one another, nor could any one unit have been eliminated or truncated without damage to the completed data acquisition and analysis.

The initial goal of the research on the uninsured was three-fold: (1) to develop reliable and accurate estimates of the number of uninsured persons in the State of Illinois and for each of five identified regions within Illinois; (2) to define demographic, economic, and health-related characteristics of the uninsured in the state to be used to craft strategies to increase coverage, and (3) to collect sufficient information to facilitate the design of an effective communication plan to inform the uninsured of the availability of any programs emerging from the SPG.

One of the more important research findings from UIC indicates that the rate of uninsurance in Illinois is estimated at approximately 9.7% *versus* the 13.4% estimate that has been provided

from a national source. The UIC finding is reinforced by the BRFSS finding that 9.8% of adults aged 18 to 64 are uninsured. It is critical when developing policy and strategic program design to have a more refined and accurate count of the uninsured for budgeting, resource allocation purposes and program implementation.

The research activities undertaken under the auspices of the State Planning Grant have allowed Illinois to develop a research base that will meet the goal of supporting data-driven policy development and program design. Given the state-specific data that has been developed, stakeholders are in a much-improved position to move forward with the development of detailed strategies to be considered to attain our final goal.

The comprehensive literature review undertaken by the State Planning Grant staff and SIUC has been of tremendous help in achieving our goal. The comprehensive literature review resulted in a lengthy bibliography (almost 500 sources) that is posted on the State Planning Grant website. This site continues to be available for use by a variety of sources including Illinois Assembly members, stakeholders and other researchers. The literature review has created an information base regarding activity in the national arena, as well as in other states, that has, and will continue to be, most helpful to Illinois throughout the completion of the state efforts.

6.3 What (if any) data collection activities were originally proposed or contemplated that were not conducted? What were the reasons (e.g., excessive cost or methodological difficulties)?

All research activities that were formally proposed or contemplated in the SPG have been conducted. Two activities that were contemplated but not implemented relate to the acquisition and development of comparative data among states in public and private sector programs. Activities under consideration in Illinois included: (1) a national survey of other states addressing the status of health insurance and health care activities as they relate to the uninsured, including particulars on elements that contributed to the success and/or failure of specific programs and/or (2) a national telephone survey of programs in other states with the same goals as (1) above. After serious consideration it was determined that although the information gathered from these efforts could prove interesting, given the time available, resources would be more profitably utilized for other activities.

6.4 What strategies were effective in improving data collection? How did they make a difference (e.g., increasing response rates)?

The original sample size for the UIC population survey sample was 19,089 random digit dial numbers. As the random digit dial survey progressed it was determined that an additional sample of cases would enhance confidence intervals around expected outcomes. An additional sample of 8,383 cases was purchased. It was also determined that the addition of several extra focus groups in the Chicago, metro-Chicago, and collar counties would strengthen the qualitative research so such groups were added. Both these activities were done for the sole purpose of improving the strength of the final outcomes.

6.5 What additional data collection activities are needed and why? What questions of significant policy relevance were left unanswered by the research conducted under HRSA grant? Does the State have plans to conduct that research?

Additional data collection activities that would be useful include:

? Our data collection activities were a one-time project, it would be most helpful to be able to gather this data routinely

? Standardized comparative state data on the demographics of the uninsured

? A website that includes regularly scheduled updates on significant legislation dealing with policy issues concerning the uninsured

Policy areas that have not been addressed, or fully addressed, included:

? Consideration of the issues and circumstances surrounding insurance and medical care needs of undocumented aliens

? Development of strategies directed toward uninsured pre-Medicare individuals and families

? Coordination of insurance coverage with availability of health care providers

? Continuation of data collection and maintenance of bibliography and literature review

6.6 What organizational or operational lessons were learned during the course of the grant? Has the State proposed changes in the structure of health care programs or their coordination as a result of the HRSA planning effort?

There are no proposed changes in the structure of health care programs or their coordination contemplated as a result of the HRSA planning effort. The goal of the Illinois State Planning Grant is to develop strategies to provide affordable health insurance coverage to all Illinoisans. The structure and coordination of health care programs will at some time call for careful examination and consideration of the relationships and interactions between the institution of insurance and the health care community but such an activity is beyond the scope of this grant.

6.7 What key lessons about your insurance market and employer community resulted from the HRSA planning effort? How have the health plans responded to the proposed expansion mechanisms? What were your key lessons in how to work most effectively with the employer community in your State?

The Insurance Market: The private health insurance market in Illinois appears to be quite competitive (see Section 3. Summary of Findings: Health Care Market Place and Appendix I: Baseline Information). This contributes to the well being of residents in the state by assisting in keeping the cost of products lower than it might be without the amount of competition that currently exists. The insurance industry, while supportive of the planning process, is concerned that failure to implement the right kind of strategy to increase the number of those insured will result in injury to the market. They expressed these concerns in a letter which is contained in the Report of the Illinois Assembly.

The presence of the Illinois Comprehensive Health Insurance Plan (ICHIP) has contributed to maintaining an environment consistent with the high level of competition. By making insurance available to federally eligible individuals through this high risk pool, individual health insurance premiums across the state have been lower, and the number of health insurance providers has been higher, than would have been the case in the absence of ICHIP.

The Employer Community: The employer community has serious concerns about costs and legislative mandates imposed on insurance policies. Although employers are not required to provide health insurance, if they decide to do so they are mandated to provide costly benefits. It is important to recognize these basic concerns. The employer community expressed concerns about the Illinois Assembly process and its final report.

Health Care Plans and Providers: Representatives of health care plans and health care providers have been involved in the planning process. They are supportive of the general options we have identified. There have been no expansion plans identified at this time that would cause changes in health plans.

The dynamics of the planning grant on the insurance market, employer community and health care community is not yet clear. The process is not complete. What seems patently apparent is that there is renewed interest and excitement among many groups and individuals to discuss solutions to common needs in pursuit of a common goal. The activities of the grant have been responsible for much of the enhanced understanding between constituents.

6.8 What are the key recommendations that your State can provide other States regarding the policy planning process?

Involvement of a Large Variety of Stakeholders: The greater the variety of stakeholders involved in the problem solving exercise the higher the probability of success of reaching agreement on policy, strategy, and implementation processes. Empowering stakeholders seems to bring greater cooperation among competing interests. Stakeholders identify points of similarity among and between groups and are able to identify and work on compromise positions where differences exist. Recognition of similarities and resolvable differences encourage cooperative efforts across other boundaries and a generally more collaborative legislative environment. This also allows for identification of major differences while there is an opportunity to attempt to resolve them.

Interaction of Opinion Leaders and Stakeholders: Cross-sectional involvement of identified opinion leaders together with broad based representation of stakeholders can assist in linking aspirations with practical, workable solutions. One valuable part of informing the process can be bringing decision makers, opinion leaders and stakeholders together to provide an opportunity for more open communication.

SECTION 7: RECOMMENDATIONS TO THE FEDERAL GOVERNMENT

7.1 What coverage expansion options selected require Federal waiver authority or other changes in Federal law (e.g., SCHIP regulations, ERISA)?

The Family Care legislation (Illinois HB 23) would require an 1115 waiver. Beyond that, no strategies that require changes in federal law or waiver requests have been identified. It is possible as the state moves further along the planning process that other waivers or legislative changes might be deemed necessary.

7.2 What coverage expansion options not selected require changes in Federal law? What specific Federal actions would be required to implement those options, and why should the Federal government make those changes?

The Illinois Assembly process generated a much richer and more expansive set of policy recommendations than was ever anticipated by the facilitators or the Steering Committee. Over 100 potential policy options were suggested and voted on by Illinois Assembly participants. We have not had the opportunity to determine which of these would require changes in federal law.

7.3 What additional support should the Federal government provide in terms of surveys or other efforts to identify the uninsured in States?

Several times during the Illinois Assembly process it was noted that a need exists to have some facility institutionalized nationally where data can be collected, maintained, and accessed, by interested parties. Data needs to be consistent in definition and vocabulary, methodology, and presentation. It has been stated repeatedly by almost every organization or agency that researches insurance or health topics that data generated by agency X will not be consistent with that developed by organization Y. For data to be truly useful it needs to be codified. Now data exists in disaggregated form as generated by individual states and the federal government, and in limited aggregated form for national data.

If data were codified it could be disseminated and accessed through a special Health Topics Clearinghouse. The Clearinghouse would include health, insurance, and combined issues similar to those delineated in the Kaiser Family Foundation State Health Facts site at http://www.statehealthfacts.kff.org/. The U.S. Census is the natural organization to look to for data collection. Another organization that has been suggested for consideration could be the Internal Revenue Service (IRS).

Areas that need additional support include methodological problems such as:

Consistency of Data: Data need to be codified. In the 1930s there were no pensions, unemployment insurance, public assistance, health insurance, medical assistance, or disability insurance. It was left to the federal government to solve the problems of an economy in deep

recession and high levels of unemployment through the enactment of major social legislation. In the early 1960s there were difficulties surrounding the enactment of public policy because the definition, and thus the level, of unemployment was problematic. In the 1970s similar policy issues existed because of limited codification or availability of information surrounding the demographics of race/ethnicity. The way out of those dilemmas was legislated definitions and centralization of data collection allowing efficient social legislation to move the country forward toward certain specific predetermined goals.

Occasionally it becomes necessary for the federal government to impose, or regulate, a methodology or approach on an issue of current relevance. It would appear that the time has come for insurance and health to take their place in the forefront of domestic issues. In Illinois there has been much discussion in support of creating and maintaining a state database. There is also a desire for comparative data analysis, which requires consistent data among and between states. If the federal government could provide research assistance in the following three ways the accuracy, viability, and efficiency of comparative state and national analysis would be significantly enhanced:

Develop Consistent Definitions and a Common Vocabulary: Two examples of needed definitions would be "a minimal coverage package" and "underinsurance." (Note: there are two definitions of the Federal Poverty Level used by the same agency for slightly different needs.)

Common, and Current, Data Collection Mechanism: Data collection is inordinately expensive for each state. Two obvious federal agencies exist that already have national data collection capabilities: the Internal Revenue Service and the U.S. Census Bureau.

Data Maintenance and Access: Development of a central data clearinghouse for health and insurance related topics that would assist legislators, researchers, and all stakeholders interested in obtaining consistent, current data with common meanings and definitions, and would allow for comparative analysis across states.

7.4 What additional research should be conducted (either by the federal government, foundations, or other organizations) to assist in identifying the uninsured or developing coverage expansion programs?

The scope of needed research is large. In the area of health insurance there is substantial need for additional information on the marketplace, the number and nature of competitors, number of employers by industry groups, number of employers by industry group providing insurance, information on self-insured firms, types of employer-sponsored insurance coverage offered across firm size by number of employees and salary levels. Studies need to be done on the effect of universal coverage in a variety of economic conditions across an array of health care plans with special consideration to health care delivery, effects on health providers, and the insurance industry, etc.

There is also a deficit in data relating to employer-sponsored insurance. The Medical Expenditure Survey (MEPS)[6] could be an excellent resource. However, while the data is helpful,

in some ways utilization is difficult for the average user. There have been some excellent attempts made to make the data more user friendly but there is still much to be done. Additionally, much of the data is based on very small samples, and/or aggregated to the degree that it is not particularly useful for state policy decisions. For example, insurance coverage by industry type by state by employer size might be aggregated across 10 industries in 5 states. With no meaningful way to disaggregate the data (because of small sample size) to a single state the MEPS data provides little insight into unique state problems. Data needs of this type and nature would include, but not be limited to, number and size of employers (sorted by number of employees) and self-insured firms cross-tabulated over industry groups or types, employee income levels, part-time and seasonal employees, type of health plan(s), and nature of employee contributions (salary deductions, co-payments, deductibles, etc.).

APPENDIX I. BASELINE INFORMATION

Please provide the following baseline information about your state (if possible). Also include any additional baseline information especially relevant to your coverage expansion strategies:

I. Population: 12,419,293

Source: U.S. Census Bureau – Census 2000
http://quickfacts.census.gov/qfd/states/17000.html

II. Number and percentage of uninsured (current and trend):

Current:	1,664,185	(13.4%)	[U.S. Census Bureau]
	1,204,671	(9.7%)	[UIC Random Digit Dial Report]
Trend:	1998 = 15%, 2000 = 13.4%		[U.S. Census Bureau]
3 Year Average:	13.3%		

Source: U.S. Census Bureau, Current Population Survey, March 2000,
As reported in Current Population Reports, September 2000
http://www.census.gov/hhes/www/hlthin99.html

III. Average age of population: 34.7 years

Source: U.S. Census Bureau
http://www.factfinder.census.gov/bf/_lang=en_vt_name=DEC_2000_SF1_U_DP1_geo_id=04000US17.html

IV. Percent of population living in poverty (<100% of the FPL):

10.4%

Source: U.S. Census Bureau,
Table C, Percent of People in Poverty by State: 1997, 1998, and 1999
http://www.census.gov/prod/2000pubs/p60-210.pdf

V. Primary industries:

Agriculture plays an important role in Illinois in terms of employment and total sales. Because of the diversity of services in the market place, agriculture is difficult to measure since it is classified and measured in several different segments of the Illinois economy. For example; crops, livestock, animal specialties, other services. The industries listed below represent the best

response to the question based on information provided by the U.S. Census Bureau and the Illinois Department of Commerce and Community Affairs.

Top five by number of paid employees: Manufacturing; Retail; Accommodation and Food Services; Administrative; Health Care and Social Services

Source: U.S. Census Bureau, 1997 Economic Census: Summary Statistics for Illinois 1997 NAICS Basis
http://www.census.gov/epcd/ec97/il/IL000.HTM

Mr. Ed Taft, Coordinator, Business and Industry Data Center,
Illinois Department of Commerce and Community Affairs

VI. Number and percent of employers offering coverage: Information not available

VII. Number and percent of self-insured firms: Information not available

VIII. Payer mix: Information not available

IX. Provider competition: Information not available

X. Insurance market reforms: Small employer health insurance rating act. 215ILCS93/1-40

XI. Eligibility for existing coverage programs (Medicaid/SCHIP/other):

MEDICAID:

Enrolled: 1.4 Million

Cost of Program: $7.4 Billion

Children (0-18) up to 133% of the FPL

Pregnant Moms up to 200% of the FPL

Parents/Caregivers up to 100% of the FPL

Assistance for Aged

Blind and Disabled

(AABD)/Other up to 85% of the FPL

KIDCARE (ILLINOIS' SCHIP PROGRAM):

Enrolled: 160,000

Cost of Program: $178 Million

Children (0-18) up to 185% of the FPL

ILLINOIS COMPREHENSIVE HEALTH INSURANCE PLAN (ICHIP), high risk pool:

Enrolled: 12,000

General Revenue Fund Appropriation: $32 Million

HIPAA Pool Insurance Industry Assessment: $18.5 Million

PROPOSED PROGRAM: FAMILY CARE BILL*:

Estimated Eligible (assumes 100% enrollment):

Adults 200,000

Children 12,000

Estimated Total Cost: $396 Million

Adults up to 185% of the FPL

Children up to 200% of the FPL

** Note: As of July 2001 the Family Care Bill had not been passed by the Illinois General Assembly.*

XII. Use of Federal waivers:

Proposed Use: Family Care Bill*

**Illinois will apply for a Title XXI waiver should the Family Care Bill Pass the Illinois General Assembly.*

Source: Illinois Department of Public Aid

APPENDIX 2 LINKS TO RESEARCH FINDINGS AND METHODOLOGY

Indicate the website addresses for any additional sources of information regarding your state's research work, including detailed data spreadsheets, cross-tabs, focus group and key informant interview summary reports, survey instruments, and summaries of research methodology.

The Illinois State Planning Grant website is located at **http://www.ins.state.il.us/spg/**. This website contains all the items in Appendix 3 and all other data gathered.

APPENDIX 3 ILLINOIS REPORTS

Report of the Illinois Assembly, October 2001

The Illinois Population Survey of the Uninsured and Newly Insured (IPSUNI)

Health Insurance Coverage of Illinoisans: An Analysis of the Current Situation, Trends, and Correlated Health Behaviors Using BRFSS Data

Opinions Concerning Access to Health Insurance in Illinois: A Report of Focus group and Key Informant Interviews

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[1] Rucinski, D. (2001, September) The Illinois Population Survey of the Uninsured and Newly Insured (IPSUNI). Chicago, IL: University of Illinois-Chicago.

[2] Sarvela, P., *et al*, (2001) Focus Group and Nominal Resource Guide Overview. Carbondale, IL: Southern Illinois University.

[3] McNamara, P. (2001, October) Health Insurance Coverage of Illinoisans: An Analysis of the Current Situation, Trends, and Correlated Health Behaviors Using BRFSS Data. Urbana-Champaign, IL: University of Illinois at Urbana-Champaign.

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[5] Dr. Dianne Rucinski, University of Illinois-Chicago, Mr. Bruce Steiner, Illinois Department of Public Health, Dr. Paul McNamara, Department of Agriculture and Consumer Economics, University of Illinois Urbana-Champaign, Dr. Paul Sarvela, Health Care Management, Southern Illinois University at Carbondale, Dr. Peggy Stockdale, Department of Psychology, Southern Illinois University at Carbondale, Dr. Caryl Cox, Program Evaluation for Education and Communities, Southern Illinois University at Carbondale, Dr. Jane Swanson, Department of Psychology, Southern Illinois University at Carbondale

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REPORT OF THE ILLINOIS ASSEMBLY
October, 2001

I. Introduction

In September 2000, the State of Illinois received a $1.2 million State Planning Grant from the Health Research and Services Administration of the U.S. Department of Health & Human Services. The purpose of the grant is to develop a plan to assure access to health insurance for all Illinoisans. The grant funded two components of this planning: research on the characteristics of the uninsured in Illinois and a participatory process among diverse stakeholders to move toward consensus strategies to reduce the number of uninsureds in Illinois.

The grant gave Illinois the opportunity to gather state specific data which had not been available before. Several types of research were conducted, including a random digit dial survey, focus groups and key informant interviews, and an expansion of the Behavioral Risk Factor Surveillance System (BRFSS). Also, a website was created, information was gathered on a variety of potential strategies which have been used in other states, a literature review was undertaken, and a large bibliography was developed. The new data, as well as existing national data, served as a bridge between researchers and stakeholders during the participatory process of developing strategies to provide coverage to all uninsured persons in the State. The research results, as well as the results of the Illinois Assembly process are to be included in the Report to the Secretary of the Department of Health & Human Services which is due October 29, 2001.

The Illinois Department of Insurance is the lead agency for the State Planning Grant. Assistant Director Madelynne L. Brown serves as Project Director. A steering committee composed of representatives of State agencies and universities[1] and the Office of the Governor has guided the direction of the project.

II. The Illinois Assembly on the Uninsured Process

The Illinois Assembly on the Uninsured (the Assembly) was developed as a modified version of the American Assembly Model. Dwight D. Eisenhower pioneered the American Assembly process while President of Columbia University. It was chosen for its characteristics of engaging stakeholders in dialogue and encouraging a consensus building process among the stakeholders who take part

[1] Departments of Public Health, Public Aid, Commerce and Community Affairs, Human Services, Illinois Comprehensive Health Insurance Plan, Southern Illinois University at Carbondale and the University of Illinois at Chicago.

in the participatory process. It has since been used successfully at the local, national, and international levels to develop policy on a variety of issues.

The Assembly was designed to allow stakeholders to move toward consensus on ways to initiate the process of reducing the number of uninsured to zero. Employers, labor unions, social service advocates, commercial insurers, insurance agents, medical practitioners and others share a fair amount of common ground on this issue, but rarely have had a chance to work cooperatively. The Assembly was an organized, interactive process where all of these entities could meet and work together to discuss ways to provide access to health insurance. The process has had covert and overt benefits beyond the specific work product that was created.

The Assembly convened in January 2001 to review the project and be introduced to the Assembly process. The major meeting of the Illinois Assembly on the Uninsured was convened for three days in Springfield, Illinois in July 2001. Former U.S. Senator Paul Simon, Director of the Public Policy Institute and Professor at Southern Illinois University Carbondale delivered remarks via videotape. Mike Lawrence, Public Policy Institute Associate Director helped guide the Assembly activity.

The July session consisted of three components:

1. Reports on research[2] results from the random digit dial survey of uninsured households; stakeholder focus groups and key informant interviews; the expanded Behavioral Risk Factor Surveillance System (BRFSS); and a review of programs currently in use in Illinois and highlights of strategies in use in other states were presented.

2. Participants were then divided into eight small heterogeneous groups to discuss strategies to provide coverage to the uninsured. The group make-up was designed to reflect balance between the organizations represented by the participants.

[2] Dr. Dianne Rucinski, University of Illinois Chicago, Mr. Bruce Steiner, Illinois Department of Public Health, Dr. Paul McNamara, Department of Agriculture and Consumer Economics, University of Illinois Urbana-Champaign, Dr. Paul Sarvela, Health Care Management, Southern Illinois University Carbondale, Dr. Peggy Stockdale, Southern Illinois University Carbondale, Dr. Caryl Cox, Program Evaluation for Education and Communities, Southern Illinois University Carbondale, Dr. Jane Swanson, Department of Psychology, Southern Illinois University Carbondale

3. Guided by trained facilitators[3] each group met for five sessions. Each session focused on separate target populations: small employers, children, young adults, working uninsured, and Hispanics and other minorities. Each group produced strategies for all target populations. These reports were compiled and distributed to caucus groups for review.

Originally, the Assembly was to have prioritized the results of the small group deliberations during the July meeting. Due to the volume of strategies produced and a desire by members to consult with their constituencies, Assembly participants requested that the group be given time to digest the material prior to setting priorities. Subsequently a ballot was prepared and distributed to each participant. Participants selected their first, second and third choice of strategies for each target population and in an overall category. The ballot tabulation process is described in detail in the Appendix. The ballots were tabulated and the results distributed for comment to all those on the Illinois Assembly distribution list. The results for each ballot category are summarized in the Appendix.

Representatives of the insurance industry submitted a paper describing the industry's position on providing coverage to the uninsured that was distributed to all participants along with the ballot results. The insurance industry paper is in the Appendix to this report. Employers submitted a letter in October which is also in the Appendix.

A final plenary session of the Assembly was held September 10, 2001. During this one day session presentations were made by former Senator Paul Simon, Eric Brenner, Senior Policy Advisor to the Governor and Dr. John Lumpkin, Director of the Illinois Department of Public Health. The Assembly participants were given an opportunity to review and comment upon a draft of this report. In addition representatives of activists, employers, providers and insurers provided feedback on next steps.[4] The September 10 discussion reinforced the general results of the balloting. A number of participants recommended that the Governor appoint a small group to determine which strategies should receive closer examination. It was also suggested that we establish pilots at the local level to test strategies. Strategies that are based on better consumer communication to increase uptake of available benefits, and incentives to attract employers to offer health benefits can be tested by coalitions and leading employers in Illinois.

[3] Ms. Debbie Potts, *et al*, Illinois Office of Educational Services, Southern Illinois University Carbondale, Springfield, IL

[4] Pamela Mitroff, Pamela D. Mitroff, Consulting; Howard Peters, Illinois Hospital Association; Robyn Gabel, Illinois Maternal and Child Health Coalition; Jim Mortimer, Midwest Business Group on Health

III. Summary of Assembly Results

The balloting reflected three general, but important, areas of agreement. Review of the top four strategies by category and review of the Chart of Strategies shows the degree of consensus in each of these areas. It is important to note that specific methods of funding each strategy were not voted upon. Also it is recognized that in some cases the funding method selected could impact support for a strategy.

The Illinois Assembly process resulted in three general areas being identified, out of the many areas proposed, for priority consideration in specific strategy development. To date we have neither selected, nor failed to select for implementation, any of the policy options developed through the consensus building process of the Assembly. Our next step is to develop specific models in the framework of these options. The following are the three options that received the greatest degree strong support from stakeholders during the participatory process and appear to be the most compelling for priority consideration:

1. There is strong support for provision of coverage to parents with children in KidCare (SCHIP), the proposed Family Care legislation. There was also support for expansion of both KidCare and Medicaid to undocumented immigrant children. There is substantial agreement on the need for additional options for covering entire families. Options for increasing family care range from increasing qualifying income percentages for eligibility for public programs to allowing opportunity to buy-in to existing public programs such as the state employee health insurance plan. These Assembly results mirror the shift in emphasis in the literature on providing health coverage for uninsured children, from children only to children as a part of the family group.

2. The Assembly reflected clear interest in providing support to the employer-based system. There was clear support for a strategy to implement incentives to employers that cut across all target populations. There was less consensus on exactly what techniques to use to do this. Specific strategies suggested include reinsurance schemes such as an expansion of ICHIP, the creation of purchasing pools, tax breaks, employer subsidies and the development of new insurance products. Such new products may require legislation to allow for flexibility and to reduce mandates. These strategies have had varying degrees of success when implemented in other states. Therefore as we continue the planning process we will have to look carefully at these ideas to assure long-term viability.

3. Considerable agreement exists in the Assembly that outreach, education and marketing activities need to be undertaken. Education strategies were proposed for several target populations. There is support for educating the uninsured population as well as small employers on the importance of health insurance coverage and how it works. Specifically there is consensus that these initiatives should concentrate on identifying and pursuing unique activities consistent with the socio-cultural or ethnic group(s) being targeted.

Cost is an issue in all the proposed strategies. During the July meeting of the Illinois Assembly each breakout group was charged with developing, for each strategy recommended, considerations for implementation, possible funding sources, and the type of assessment that might be needed.

Each strategy that was recommended had a plethora of suggested funding sources that could be considered to support that particular strategy. For example, in the broad strategy of "Develop Purchasing Pools for Small Businesses," the suggested funding sources from the break-out groups included: state seed money for start-up; state provided/established stabilization fund; self-funded or self sufficient; employer cost sharing; employee funding; state funding; foundation funds; federal reallocation of existing resources and tapping into new funds; and finally, a mix of state, federal, employer, employee and insurance company money to fund creation of plan, tobacco settlement funds and tax credits to employees as well as employers. It became clear that in order to reach agreement on broad strategies details on funding options would have to be deferred.

Until the specific strategies for implementation are identified, it would be premature to attempt to develop a cost structure and amount associated with each of the strategies presented. When specific strategies are identified as practical for potential policy implementation the funding sources suggested by the Illinois Assembly participants will be given serious consideration. At that time the cost structure and level should be determined consistent with standard actuarial methods used in public insurance/health efforts. The Assembly recognizes that costs are a major issue and must be given consideration prior to any final decision being made regarding policy implementation.

The Illinois Assembly process produced very good ideas that should receive continued scrutiny. The next steps in this project involve making determinations as to the specific steps Illinois should pursue. We have received additional funding from HRSA to continue the effort.

IV. Appendix

A. Detailed Ballot Results – Top Four Strategies

Participants in the July session voted in six categories. The categories consisted of the five target populations and a category of strategies that cut across populations. The target populations selected for consideration have a high population of uninsured individuals or families. They are: Young Adults; Working Uninsured; Children; Small Employers; and Hispanics and Other Minorities. This section reports on the top four strategies per category that resulted from the ballots. The top strategy in each category received significantly more votes than the next three strategies. The language in this section is the language that is on the ballots. It is somewhat difficult to read but we have chosen not to edit it. It also contains a brief description of each target population. It should be noted that in some cases several similar options are grouped together in one strategy number.

Young Adults

A young adult is defined to be between ages 19-29. Approximately one-third of the 18 million young adults of college age attend college full time and are very likely covered under their parent's health insurance policies or through their college or university. Approximately 1.3 million (19%) college age young adults are uninsured. There is a strong direct relationship between young adults from higher-income families, college or university attendance, and insurance coverage. Twelve million young adults age 19-23 are not in school and 5 million are not insured (38%). Males are less likely to be covered than females and minorities are less likely to be covered than whites. Of young adult workers (19-29), 42% are covered by their employer's insurance. Only 61% of employers of young adults offer employer sponsored insurance and 35% of young workers are not eligible for their employer's sponsored plan (look back provisions, part time or temporary positions or waiting time effect eligibility). Thirty percent (30%) of young adults (12 million or ¼ of the total 44 million uninsured) were without insurance in 1999.

The top four strategies for young adults are:

1. Create new incentives for employers to provide coverage.
   Change state law.
   Provide employer incentive for part time workers.

2. Expand family plan eligibility.
   Extend dependent coverage insurance options.
   Extend dependent coverage by X years (based on data) for single young adults.

3. Educate young adults on social responsibility of health insurance and costs of not having health insurance.
   Communicate the value of being insured and the options available.
   Educate individuals on the cost of health care.
   Educate young adults on the need for health insurance and the possible medical financial risks.
   Educate the young adult of the need, importance, and cost effectiveness of health insurance.
   Market the cost of not being insured.

4. Expand the current public insurance programs to include young adults.
   Extend public insurance to young adults.

Children

Hispanic and other minority or ethnic group children are more likely to be uninsured and more likely to come from low-income families than white non-Hispanic children. Twenty three percent (23%) of poor children are uninsured. Almost 14% of children less than 6 years old are uninsured, with uninsured rates being 13.3% and 14.4% respectively for children 6-11 and 12-17 years old. There are about 1.3 million families in which children are insured but parent(s) are uninsured. Most are low-income families with children eligible, and parents ineligible for Medicaid/SCHIP. The rate of uninsured children is decreasing and the rate of uninsured parents is increasing. In states where public insurance programs have been expanded to include the parents of eligible children, there are 40% lower rates of uninsured children.

The top four strategies for children are:

1. Expand KidCare eligibility.
   Expand income eligibility levels for KidCare.
   Expand KidCare income eligibility to greater than 185%.

Raise KidCare eligibility to 200% Federal Poverty Level (FPL) and apply for federal waiver to go higher.
Expand KidCare to family care.
Extend KidCare to all children – no categorical exclusions.

2. Improve outreach, enrollment and access to Medicaid/KidCare.
   Reach single parent and hard-to-reach families with Medicaid/KidCare eligibility.
   Use non-traditional marketing strategies.
   Simplify KidCare/Medicaid enrollment.
   Validate insured status of all children in Illinois.

3. Develop state program that allows all uninsured children enrollment regardless of income/citizenship.

4. Make dependent coverage affordable to employers and employees.
   Provide low-income employees with a choice of having KidCare/Medicaid or the employer based program rebate.

Hispanics and Other Minority Groups

Data on insurance coverage shows that the rate of uninsurance among racial/ethnic minorities is high, but that Hispanics have the highest rates among minority groups. Therefore, the Assembly considered the issue of racial/ethnic disparities in insurance coverage with an emphasis on Hispanics.

Hispanics are among the poorest segment of minority groups, with 59% having family incomes below 200% of the FPL as compared to whites at 23%. While 87% of uninsured Hispanics are from working families, they have access to Employer Sponsored Insurance (ESI) only two-thirds as often as whites (58% as compared to 85%). They also have the highest rate of uninsurance for children compared to other minority groups. Young adult Hispanics (18-29) are 50% less likely to be insured than any other group with the male Hispanic population uninsurance rate at 56% as compared to 42% for females. Undocumented immigrants have no access to Medicaid or job-based coverage while documented but non-citizen immigrants have reduced access to Medicaid.

The top four strategies for Hispanics and other minority groups are:

1. Eliminate immigration status as a barrier.
   Support the undocumented population.
   Open up Medicaid for undocumented immigrants using state dollars.
   Get undocumented kids into KidCare/Medicaid.

2. Design special Outreach programs (information and referral).
   Market available insurance to the population to increase uptake levels using health care clinics.
   Market/educate/outreach through ethnic associations/churches or chambers of commerce in ethnic neighborhoods, etc.
   Design and market insurance to cultural groups.

3. Support and encourage more community health centers with high minority populations tailored to the specific minority needs. Increase in preventive care, job access, and insurance access.

4. Educate Hispanics and other minority groups in health insurance products.
   Offer culturally competent education regarding accessing and use of health insurance.
   Develop educational program regarding what is already available – keeping in mind changing cultural and family norms.
   Develop awareness and intake program that lets people know what is available through services and agencies that they use and trust. (Churches, ESL, CBOs, free clinics, schools, etc.)
   Develop KidCare outreach enrollment programs for Hispanic and other minority groups.

Small Employer

Nearly half of all uninsured workers are either self-employed or work for firms with fewer than 25 employees. Another 14% are in firms with 25-99 workers. Firm size is a factor for those employers who do offer health coverage, with 60% of businesses with 3-9 workers offering health coverage in 2000, versus 97% of firms with 50 or more workers. Two-thirds of small firms offering insurance provide coverage through a managed care plan with 10% of small firms offering a choice of plans compared to 84% of large firms. Of those firms that do not offer health coverage 69% stated they could not afford coverage and 56% stated that their revenues were too uncertain to commit to health insurance. Other reasons given by small employers who do not provide health coverage are: 61% -

employees get coverage elsewhere and 54% - employees cannot afford their premium contribution. Small employers did offer suggestions as to what incentives they would respond to in order to provide health coverage to their employees. Sixty four percent (64%) stated they would seriously consider offering insurance if government subsidized their premiums. Eighty six percent (86%) favored tax breaks to help low-wage workers obtain coverage. Premiums are more volatile because small-group coverage generally involves medical underwriting, so workers with pre-existing medical conditions affect premiums. Very small firms (fewer than 5 employees) find that insurers do not market to them because they are viewed as too risky.

The top four strategies for small employers are:

1. Develop statewide purchasing cooperative. (Look at California plan.)
   Develop a group purchasing pool by geographical region.
   Create large risk pool for small businesses.
   Create 3rd party administrative pools.

2. Reduce/stabilize costs for small employers.
   Offer a small incentive (business voucher) to partially offset costs.
   Subsidize price of insurance to low wage employees.

3. Revise government regulations to encourage flexibility/creativity in the development of affordable health plans.
   Make Illinois insurance laws/regulations more flexible for competition.

4. Capitalize on CMS Health Insurance buying leverage for small employers.

Working Uninsured

The working uninsured are defined as working individuals ranging in age from 19–64. They are individuals who are single, or a single head of household, married with children or are married without children. The working uninsured are poor or near-poor, change jobs frequently, hold more than one job, have low wages, work part time and work for small companies. In 1998 over 45% of low-income workers were uninsured. Their wage earnings are above the eligibility requirements for public programs (e.g., Medicaid, SCHIP). Over 42.6 million workers (the majority of the uninsured population) and their families do not have

access to affordable insurance through their employer (even though they may have technical access because their employer offers coverage with relatively expensive premiums). Eighty percent (80%) of uninsured Americans live in households where at least one member of the household is employed. In more than three-quarters of families all members have health coverage, however in one of seven families only some members are insured. About 9 million parents are uninsured.

The top four strategies for the working uninsured are:

1. Expand family care for families that qualify for KidCare/Medicaid.
   Create family care with expanded buy-in options.
   Expand SCHIP (KidCare) programs with state and federal matched dollars. Bring parents of KidCare children in by expanding eligibility to allow parents. Increase the income levels to include low and moderate-income families.
   Expand KidCare to families.
   Employers promote KidCare and family care to employees.
   Increase family care through KidCare (SCHIP) expansion and employee subsidy for employer sponsored plans.
   Increase state flexibility for KidCare.
   Expand Medicaid to households to a significantly higher level. Include public/private subsidies to 200% of the federal poverty level.
   Outsource marketing of KidCare Rebate.
   Outsource administration of KidCare/Family Care plans like Illinois Comprehensive Health Insurance Plan (ICHIP).
   Increase family care.
   Expand Medicaid option – medical sliding scale, premium subsidy, increase income eligibility.

2. Create employer incentives to offer health insurance.
   Assist employers with finding affordable health insurance products for their employees.
   Design portable mandatory employer-based insurance.
   Encourage employer sponsored minimum benefits package.
   Assist employee with finding affordable health insurance products.
   Explore feasibility to offer voluntary ESI program on income-based premiums sharing.

3. Develop a small business purchasing pool.
   Combine purchasing pool with reinsurance.

Create community-based networks encompassing community hospitals and individual providers.
Develop group purchasing pool on a geographical basis.
Encourage private purchasing pools.

4. Carry out multi-pronged strategy including developing a new affordable product, family care expansion, affordable products, preventative services, CHC expansion, pre-payment through savings (IRAs), low end preventative and high end catastrophic products, reinsurance, review of "no frills" insurance requirements, risk pooling, and buying into state employee plan.

Summary of Strategies (Cross Population)

In addition to voting on the strategies by target populations that resulted from the small group sessions, participants voted on a listing of strategies that appeared in more than one target population strategy list. The cross population summary of strategies was developed after evaluation of the target population strategies. Voting results for the top priority approached consensus, however there was a drop off in the numbers for the next three strategies.

The top four cross population strategies are:

1. Expand family care for families that qualify for KidCare (SCHIP)/Medicaid.

2. Carry out multi-pronged strategies including: develop a new affordable product, family care expansion, preventive services, Community Health Care (CHC) expansion, pre-payment through savings (IRA), catastrophic coverage and reinsurance.

3. Create employer incentives to offer health insurance to full time and part time employees. (Portable mandatory employer-based insurance.)

   (Note: Formatting problems in preparation of the ballot resulted in the portable mandatory language being attached to the employer incentive language. There was considerable discussion of this at the final Assembly meeting with some thinking it should be deleted and others wanting to retain the language. Based on the conversation it

appears that most of those who voted for this ballot item were only voting for incentives while others were voting for both concepts. We consider creating employer incentives as the strategy on which there was consensus, not portable mandatory employer-based insurance.)

4.* Provide for a single payer that preserves private sector involvement. Not single provider.

4.* Develop statewide (or regional) purchasing cooperative.

* The last two strategies are tied.

B. Chart of Strategies by Topic

The Chart of Strategies by Topic considers the top four solutions across the six categories in topical order. Strategies have been categorized by topics that appeared across categories most regularly. Those topics are: family care options; expansion of coverage for children; outreach/education/marketing activities; employer options; legislative activities; preventive services and new product development; and community-based alternatives. Reading down the columns the general topics are highlighted in gray, and beneath each broad heading are the choices that reflect that topic. Each topic may have strategies from any, or all, of the target population categories. Across the top of the chart are the target population categories. Check marks (X's) reflect the option under any given broad category which was selected by a specific target population. For example, the first line under Family Care Options is *Include parents of eligible children in KidCare/Medicaid.* Reading across the line there is a check under *Working Uninsured* and another check under *Summary of Strategies*. This indicates that the strategy *Include parents of eligible children in KidCare/Medicaid* was prioritized in the first four choices of <u>both</u> target populations. As can be noted there are a number of strategies that overlap more than one target population. (For more detailed information on each of the target groups *Fact Sheets* have been placed in the Appendix.)

Chart of Strategies by Topic	Working Uninsured	Children	Small Employers	Hispanics & Other Minorities	Young Adults	Summary of Strategies
Family Care Options						
Include parents of eligible children in Kid-Care/Medicaid	X					X

Expand Kid-Care to family care	X	X				
Increase qualifying income percentages to include moderate income families	X					
Expand family plan eligibility, extend dependent coverage	X				X	
Increase family care	X					X
Extend public insurance					X	
Expand Medicaid at a significantly higher level (public/private subsidies to 200% of FPL)	X					
Expand Medicaid option - medical sliding scale, premium subsidy, increase income eligibility	X					
Create family care with extended buy-in options	X					
Subsidize price of insurance to low wage employees			X			
Reach single parent and hard-to-reach families with Medicaid/Kid-Care eligibility	X					
Eliminate immigration status as a barrier				X		
Support undocumented population				X		
Buy-in to state employee plan	X					
Expand Coverage for Children						
Extend Kid-Care to all children - no categorical exceptions (include undocumented children)		X		X		
Expand Kid-Care eligibility to 200% of more of the FPL	X	X				
Expand SCHIP (Kid-Care) programs with state and federal matched dollars	X					

Simplify public program enrollment		X				
Validate insured status of all children in Illinois				X		
Develop state program that allows all uninsured children enrollment regardless of income/citizenship		X		X		
Open up Medicaid for undocumented immigrants using state dollars				X		
Get undocumented kids into Kid-Care				X		
Outreach/Education/Marketing Activities						
Educate all groups on the cost of health care, need for insurance and financial risk	X			X	X	
Communicate the value and need for health insurance	X				X	
Improve marketing techniques through expansion, creative activities, and ethnic groups		X			X	
Outsource marketing of Kid-Care rebate and administration	X					
Design special outreach programs (information and referral)				X		
Market/educate/outreach through ethnic associations/churches or chambers of commerce in ethnic neighborhoods, etc.				X		
Design and market insurance to cultural groups				X		
Develop awareness and intake program that lets people know what is available through services and agencies that they use				X		

and trust (churches, ESL, CBOs, free clinics, schools, etc.)						
Improve outreach, enrollment and access to Medicaid/Kid-Care						
Employer Options						
Develop regional, or statewide, purchasing cooperatives/pools	X					X
Combine purchasing pool with reinsurance	X					
Encourage private purchasing pools	X					
Stabilize or reduce costs for small employers						
Subsidize employer sponsored insurance (ESI)			X			
Capitalize on CMS Health Insurance buying power leverage for small employers						
Make dependent coverage affordable to employers/employees		X				
Create new incentives for employers to provide coverage	X		X		X	
Provide incentives for employers to cover full-time and part-time workers			X		X	X
Assist employers in finding affordable health insurance products for employees	X					
Design portable mandatory employer-based insurance	X					
Encourage employer sponsored minimum benefits package	X					
Explore feasibility to offer voluntary ESI program on income-based premium	X					

sharing						
Extend dependant coverage by X years (based on data) for single young adults					X	
Employers promote Kid-Care and family care to employees	X					
Legislation Activities						
Make government regulations and legal environment more flexible to health insurance environment			X			
Make Illinois insurance laws/regulation more flexible for competition			X			
Eliminate immigration status as a barrier					X	
Extend public insurance to young adults	X				X	
Increase state flexibility for Kid-Care	X					
Pre-payment through savings (IRAs)	X					X
Preventative Services and New Product Development						
Develop new affordable products	X					X
Low end preventative and high end catastrophic products	X					X
Reinsurance	X					
Review of “no frills” insurance requirements	X					
Provide for a single payor that preserves private sector involvement. Not a single provider						X
Community-based Alternatives						

Create community-based networks encompassing community hospitals and individual providers	X					
CHC expansion	X					X
Preventative services	X					X
Support and encourage more community health centers with high minority populations tailored to the specific minority needs. Increase in preventive care, job access, and insurance access				X		

C. Details on Tabulation Process

Balloting Procedure Used by the Illinois Assembly

In order to rank strategies previously identified in small group break out sessions a ballot was developed listing all previously identified options. Strategy options were categorized according to each targeted population group, e.g., all policy options that were generated under the "Young Adult" category were grouped under that category while those identified under "Working Uninsured" were grouped under the Working Uninsured category, etc. There were six (6) categories: the Working Uninsured; Young Adults; Children; Small Employers; Hispanics and Other Minorities; and an artificially generated category titled Summary of Strategies, which was a combination of all of the strategies identified in all of the break-out groups that appeared in more than one category.

Ballots were distributed to the registrants of the Illinois Assembly July meeting. Each registrant received three votes per category for each of the 6 categories. Registrants were allowed to cast all three votes for one strategy or one vote each for three different strategies within a category.

Voters cast their votes using one (1) as the most preferred, two (2) as the second choice, and three (3) as the third choice. When tallying votes each number one choice received a three, each number two choice received a two, and each number three choice received a one, as follows:

First Preference: Vote = 1 Weight = 3

Second Preference: Vote = 2 Weight = 2
Third Preference: Vote = 3 Weight = 1

This was done in order to allow individuals to cast votes in a 1, 2, 3 priority order (hoping to reduce any confusion among voters). Note: This is the same effect as having voters use three for the first choice, two for the second choice and 1 for the third choice. When counting the votes the numbers were reversed in order to allow the first preferred vote to have the highest weight, the next preference the middle weight, and the third preference the lowest weight. In some cases participants chose not to vote.

After votes were weighted as stated above they were counted, and the strategies were ranked from highest to lowest numbers of votes. The top four strategies were than identified in each category. All strategies were listed in the order of ranking, with the first listed being the highest ranked, and the last listed being the lowest rank. This list was then reported to Assembly participants.

It should also be noted that first choices in each of these categories were first with huge margins while in almost all cases 2nd, 3rd, and 4th choices were substantially lower. The following charts give more detail on the results.

RESULTS OF VOTE (1st CHOICE ONLY EACH CATEGORY) INCLUDES SUMMARY OF STRATEGIES

Group	Weighted Vote Count	% of Total Vote	Total Votes Received in Category
Working Uninsured	89 points	39%	196
Small Employers	76 points	34%	225
Hispanics	66 points	30%	216
Children	82 points	38%	215
Young Adults	58 points	22%	244
Summary of Strategies	66 points	31%	210

WORKING UNINSURED*

Weighted Vote Count of Top 4	% of Total Votes Cast
1. 89 points	**1.** 39%
6. 31 points	**6.** 14%
4. 30 points	**4.** 13%
7. 10 points	**7.** 4%

Ballot Number:

1. Expand family care for families that quality for Kid-Care/Medicaid.
Create family care with expanded buy-in options.
Expand SCHIP (Kid-Care) programs with state and federal matched dollars.
Bring parents of Kid-Care children in by expanding eligibility to allow parents. Increase the income levels to include low and moderate-income families.
Expand Kid-Care to families.
Employers promote Kid-Care and family care to employees.
Increase family care through S-CHIP – Kid-Care expansion and employee subsidy for employer-sponsored plans.
Increase state flexibility for Kid-Care.
Expand Medicaid to households to a significantly higher level. Include public/ private subsidies to 200% of the federal poverty level.
Outsource marketing of Kid-Care Rebate.
Outsource administration of Kid-Care/Family Care plans like I-CHIP.
Increase family care.
Expand Medicaid option – medical sliding scale, premium subsidy, increase income eligibility.

6. Create employer incentives to offer health insurance.
Assist employers with finding affordable health insurance products for their employees.
Design portable mandatory employer-based insurance.
Encourage employer sponsored minimum benefits package.
Assist employee with finding affordable health insurance products.
Explore feasibility to offer voluntary ESI program on income-based premiums sharing.

4. Develop a small business purchasing pool.
   Combine purchasing pool with reinsurance.
   Create community-based networks encompassing community hospitals and individual providers.
   Develop group-purchasing pool on a geographical basis.
   Encourage private purchasing pools.

7. Carry out multi-pronged strategy including developing a new affordable product, family care expansion, affordable products, preventative services, CHC expansion, pre-payment through savings (IRAs), low end preventative and high end catastrophic products, reinsurance, review of “no frills” insurance requirements, risk pooling, and buying into state employee plan.

* Note: Total votes cast in this category - 196

SMALL EMPLOYER*

Weighted Vote Count of Top 4	% of Total Votes Cast
1. 76 points	**1.** 34%
5. 24 points	**5.** 11%
2. 19 points	**2.** 8%
10. 16 points	**10.** 7%

Ballot Number:

1. Develop statewide purchasing cooperative. (Look at California plan.)
   Develop a group purchasing pool by geographical region.
   Create large risk pool for small businesses.
   Create 3rd party administrative pools.

5. Reduce/stabilize costs for small employers.
   Offer a small incentive (business voucher) to partially offset costs.
   Subsidize price of insurance to low wage employees.

2. Revise government regulations to encourage flexibility/creativity in the development of affordable health plans.
   Make Illinois insurance laws/ regulations more flexible for competition.

10. Capitalize on CMS Health Insurance buying leverage for small employers.

* Note: Total votes cast in this category - 225

CHILDREN*

Weighted Vote Count of Top 4	% of Total Votes Cast
1. 82 points	**1.** 38%
3. 33 points	**3.** 15%
2. 29 points	**2.** 13%
4. 25 points	**4.** 12%

Ballot Number:

1. Expand Kid-Care eligibility.
   Expand income eligibility levels for Kid-Care.
   Expand Kid-Care income eligibility to greater than 185%.
   Raise Kid-Care eligibility to 200% poverty and apply for federal waiver to go higher.
   Expand Kid-Care to family care.
   Extend Kid-Care to all children – no categorical exclusions.

3. Improve outreach, enrollment and access to Medicaid/Kid-Care.
   Reach single parent and hard-to-reach families with Medicaid/Kid-Care eligibility.
   Use non-traditional marketing strategies.
   Simplify Kid-Care/Medicaid enrollment.
   Validate insured status of all children in Illinois.

2. Develop state program that allows all uninsured children enrollment regardless of income/citizenship.

4. Make dependent coverage affordable to employers and employees.
   Provide low-income employees with a choice of having Kid-Care/Medicaid or the employer based program rebate.

* Note: Total votes cast in this category - 215

YOUNG ADULTS*

Weighted Vote Count of Top 4	% of Total Votes Cast
8. 58 points	**8.** 22%
4. 40 points	**4.** 15%
1. 35 points	**1.** 14%
2. 34 points	**2.** 13%

Ballot Number:

8. Create new incentives for employers to provide coverage.
   Change state law.
   Provide employer incentive for part-time workers.

4. Expand family plan eligibility.
   Extend dependant coverage insurance options.
   Extend dependant coverage by X years (based on data) for single young adults.

1. Educate young adults on social responsibility of health insurance and costs of not having health insurance.
   Communicate the value of being insured and the options available.
   Educate individuals on the cost of health care.
   Educate young adults on the need for health insurance and the possible medical financial risks.
   Educate the young adult of the need, importance, and cost effectiveness of health insurance.
   Market the cost of not being insured.

2. Expand the current public insurance programs to include young adults.
   Extend public insurance to young adults.

* Note: Total votes cast in this category - 244

HISPANICS*

Weighted Vote Count of Top 4	% of Total Votes Cast
4. 66 points	**4.** 30%
1. 31 points	**1.** 14%
6. 30 points	**6.** 14%
7. 24 points	**7.** 11%

Ballot Number:

4. Eliminate immigration status as a barrier. Support undocumented population.
   Support the undocumented population.
   Open up Medicaid for undocumented immigrants using state dollars.
   Get undocumented kids into Kid-Care/Medicaid.

1. Design special Outreach programs (information and referral).
   Market available insurance to the population to increase uptake levels using health care clinics.
   Market/educate/outreach through ethnic associations/churches or chambers of commerce in ethnic neighborhoods, etc.
   Design and market insurance to cultural groups.

6. Support and encourage more community health centers with high minority populations tailored to the specific minority needs. Increase in preventive care, job access, and insurance access.

7. Educate Hispanics and other minority groups in health insurance products.
   Offer culturally competent education regarding accessing and use of health insurance.
   Develop educational program regarding what is already available – keeping in mind changing cultural and family norms.
   Develop awareness and intake program that lets people know what is available through services and agencies that they use and trust. (Churches, ESL, CBOs, free clinics, schools, etc.)
   Develop Kid-Care outreach enrollment programs for Hispanic and other minority groups.

* Note: Total votes cast in this category - 216

SUMMARY OF STRATEGIES*

Weighted Vote Count of Top 4	% of Total Votes Cast
1. 66 points	**1.** 31%
5. 24 points	**5.** 11%
4. 20 points	**4.** 10%
2. & 7. 16 points	**2. & 7.** 8%

Ballot Number:

1. Expand family care for families that quality for Kid-Care/Medicaid (SCHIP).

5. Carry out multi-pronged strategy including develop a new affordable product, family care expansion, preventive services, CHC expansion, pre-payment through savings (IRA), catastrophic coverage and reinsurance.

4. Create employer incentives to offer health insurance full time and part time. (Portable mandatory employer-based insurance.)

   (Note: Formatting problems in preparation of the ballot resulted in the portable mandatory language being attached to the employer incentive language. There was considerable discussion of this at the final Assembly meeting with some thinking it should be deleted and others wanting to retain the language. Based on the conversation it appears that most of those who voted for this ballot item were only voting for incentives while others were voting for both concepts. We consider creating employer incentives as the strategy on which there was consensus, not portable mandatory employer-based insurance.)

2. Provide for a single payor that preserves private sector involvement. Not single provider.

7. Develop statewide (or regional) purchasing cooperative.

* Note: Total votes cast in this category - 210

D. Letter from the Insurance Industry

August 7, 2001

Madelynne L. Brown
Assistant Director
Illinois Department of Insurance
100 West Randolph, Suite 15-100
Chicago, IL 60601

Dear Ms. Brown:

The members of the "Insurance Caucus" that took part in the Illinois Assembly meetings July 10 – 12, 2001 addressing the issue of covering the uninsured citizens of Illinois submit the following response paper for consideration.

The deliberations of the Illinois Assembly provided the promise of bringing the issue of the uninsured into the spotlight. As representatives of the insurance industry and the agents and brokers who market and sell its products, we have long struggled with this issue. Given this, we believe that our contribution to the Illinois Assembly at this point is a thoughtful response paper. We believe that a vote to prioritize the strategies would mean far less than a discussion of the issues and possible solutions.

The representatives of the Illinois insurance industry and insurance agents and brokers believe that the answer to solving the plight of the uninsured in Illinois is found in a strong, competitive private health insurance market fostered by government cooperation. The current system is employer-based. Since nine in ten insured Americans receive health insurance benefits through their employer, according to the Health Insurance Association of America, any reform of the market to increase access should preserve and build upon the current employer-based delivery system where possible.

Solutions that hold promise are those that promote a competitive market and foster development of new affordable health insurance products. We support private insurance market solutions for more affordable products where feasible and believe in lessening regulations proven to provide little value to the consumer, providing financial incentives for employers and individuals, and molding incentives for insurers and provider groups to work together in certain areas will prove more viable in both the near and long term future. Through a healthy,

competitive market, consumers are able to access efficient and responsive products and mechanisms at affordable rates.

Recommendation: Overall we support efforts that encourage health insurance carriers to bring new innovative products to the marketplace. By streamlining current legislative and regulatory and approval requirements for insurance products, carriers would have an incentive to develop a new generation of products to meet the unique needs of this population. For example, we need to look at a "fast-track" approval mechanism, offering options to differentiate employers with 10 or less employees, etc. Our caucus agrees this will provide assistance to the target populations discussed at the Illinois Assembly.

Comments: We want to take this opportunity to present some research on how our recommendation will affect certain target populations. According to research conducted by The Commonwealth Fund, "About 24 million U.S. workers, often employees of small firms, have no health insurance. Together with their families, these "working uninsured" comprise the vast majority of all uninsured people in this country." [5] According to the 1997 CPS, about a quarter of the uninsured are self-employed or work in firms with 10 or fewer employees. Therefore, it makes sense to understand the reasons they lack insurance coverage and concentrate our efforts on addressing those specific obstacles.

The Kaiser Family Foundation/Health Research and Educational Trust *2000 Annual Employer Health Benefits Survey* found that three-quarters of small employers (3-199) do not offer coverage due to high premiums. Studies indicate that small businesses are least likely to offer health insurance to their employees, often due to costs. Even when employers do offer coverage, many employees decline it because they cannot afford the premiums or they are young and healthy and do not feel it is necessary. Nationally, around 2.5 million individuals turned down coverage offered by their employers in 1997.[6] The Kaiser survey found that the take-up rate for employees offered insurance by their employer ranges from 76% to 83%. The take-up rate increases as the size of the firm increases. The sole exception to this statement is among jumbo firms (1,000-4,999 workers) where the rate drops from 83% to 79%. Sadly, the Midwest lags behind the rest of the country on take-up rates. Even in the government sector, take-up rates are not 100%. State and local government workers cover about 84% of their workers. The government sector employees take-up rate is 94%.

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[5] Silow-Carroll, S., Waldman, K., & Meyer J (2001, February). "Expanding Employment-Based Health Coverage: Lessons From Six State and Local Programs. The Commonwealth Fund.

[6] See Footnote 1.

The insurance market has the potential to affect change by developing new and distinct products that reach out to employers and their employees. More flexible plan designs with varying cost sharing schemes (i.e., high deductibles, etc.) could provide more affordable and attractive options that better meet their unique health care needs. Digital health plans that bring more choice and flexibility and less costs to consumers are also beginning to be offered in the market place and "dependent-only" or other target population products would fill many holes. As these types of innovative products come to market and are made available to consumers, we believe they could help minimize some of the barriers facing the working uninsured today.

Recommendation: We also support limited State incentives to employers and individuals to target certain populations.

Comments: We support a limited tax credit assistance program to encourage employers to offer health insurance benefits to individuals to take part in group health plans and creating a premium assistance program for low –income working adults and young adults who meet financial requirements. By enrolling employees in private sector programs through their employers, the employees become more knowledgeable about private sector insurance system and stronger ties are developed linking them into the world of work. Every effort that can be made to equate work with a better lifestyle and better economic outcomes through wages and benefits achieves broader societal goals than a government health program can achieve.

Tax credits could improve affordability and increase access to private group health insurance in three key groups: 1) small businesses with high risk individuals; 2) start-up businesses; and 3) low income employees. Under such a tax credit program small businesses offering group benefit plans to their employees would be protected from rising health coverage costs due to catastrophic illnesses by some tax offset. Additionally, start-up businesses would see less initial capital depleted by health benefit plan establishment and can begin to attract potential employees. Finally, the low-income employees would have a financial incentive to participate in employer offered group health plans through a return in taxes.

Offering premium assistance for working young adults who meet a certain financial threshold to assist them in paying their employee contributions would provide greater access to private health insurance coverage with less cost to the government and taxpayers. It would also minimize any incentives for individuals who are currently enrolled in employer-sponsored coverage to decline that coverage and enroll in a state-subsidized program.

In reviewing some of the literature the Department made available on its website, it appears that when young adults are offered health insurance coverage, they are only *slightly* less likely to enroll in coverage than their older counterparts, meaning they would like coverage.[7] This study, *"Health Insurance: On their own: Young adults living without health insurance",* goes on to state that 17 percent, or close to one-fifth of uninsured young workers are offered coverage, but decline it, the most common reason given is money. Further, low-wage employers who offer coverage tend to require employees to make larger dollar contributions.[8] These findings suggest that more, not less, emphasis on the value of work place benefits should be considered. Young adults who see a job as merely a paycheck are less likely to view their job as a stepping-stone to financial independence and personal growth.

A premium assistance program for low-income individuals in the workplace could considerably improve their ability to purchase coverage. If coverage is available to them through their employer, it makes more sense to maintain employer-based coverage rather than enrolling them in a state-run program. This was an important consideration in the KidCare Rebate program. That program recognized that providing assistance to families to pay for their employer-based insurance provided families an opportunity to maintain continuity of care among a network of medical providers. Also, it bypassed the stigma discussed in the Assembly's focus groups of a public assistance program. If you consider the average monthly premiums compared with current employee contribution levels, there are potentially significant savings to the state if it adopts a premium assistance program as opposed to a total buy-in program for all young adults. For example, according to the Medical Expenditure Panel Survey (MEPS) -- IC Employer Survey for 1998, the average monthly premium for a typical Illinois employee in a firm of any size is $463.91 for family coverage and $181.65 for

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[7] Quinn, K., Schoen, C. & Buatti, L. (2000, May). Health Insurance: On their own: Young adults living without health insurance. The Commonwealth Fund. [On-Line]. Available HTTP: http://www.cmwf.org/programs/insurance/quinn_ya_391.asp [2001, June 8]

[8] Quinn, K., Schoen, C. & Buatti, L. (2000, May). Health Insurance: On their own: Young adults living without health insurance. The Commonwealth Fund. [On-Line]. Available HTTP: http://www.cmwf.org/programs/insurance/quinn_ya_391.asp [2001, June 8]

single coverage. The monthly premiums for firms with 0 to 50 employees are greater at $484.28 for family coverage and $198.85 for single coverage. The average monthly employee contribution is higher for firms with 50 and fewer employees, ranging from $35.80 for single coverage to $148.21 for family coverage. The survey also indicates that lower wage employees tend to have higher contribution levels.[9]

Using these averages as an illustration, the state would only pay $35.80 a month for a single employee of a small employer with 50 or fewer employees (the employee's contribution level) as opposed to $198.85 per month to fully subsidize the entire premium through a state-run program. The table below illustrates the potential annual savings to the state for one person with single coverage or family coverage employed by a small employer, using the premium estimates provided in the MEPS survey.

Type of Coverage	Avg. annual premium	Estimated annual state costs for premium assistance	Estimated annual state costs for full subsidy	Estimated annual savings to the state
Single Coverage	$2,386.20	$429.60	$2,386.20	$1,956.60
Family Coverage	$5,811.36	$1,778.52	$5,811.36	$4,032.84

As illustrated, providing premium assistance to working uninsured individuals would require the state to pay only a portion of the premium, rather than fully subsidizing the cost of an entire premium. This appears to be a more cost-effective and practical approach to reaching this population of the uninsured.

Conclusion

In addition to the above recommendations, we wish to make three important points as you consider the State's options.

First, we strongly caution against a State government buy-in approach or creating more "low-cost" risk pools. This approach has the threat of attracting individuals already participating in private group insurance or encouraging them to turn down coverage by their employer. This could place a particular burden on small employers. If small employer groups lose young and healthy members from their plans to a state subsidized program, it will be more difficult for carriers to balance the costs of unhealthy risks in these groups and ultimately cause an increase in

[9] Wicks, E. (2000, June). Health Purchasing Coalitions Struggle to Gain Bargaining Clout: Small Size and Lack of Support from Health Plans are Factors. Health Care Financing & Organization Brief.

their insurance rates. In a voluntary market when the cost of health care is increasing rapidly across the country, a proportional distribution of low-risk groups helps stabilize the rates for the block as a whole. When the pool of low-risk groups shrinks, the cost for the remaining groups escalate at a faster rate than if the low-risk groups were in the pool. If this occurs, affordable health insurance will be even further out of reach for small employers and their employees in the state.

According to a recent study on the experience of the Health Insurance Plan of California (HIPC), the country's first state-run health insurance purchasing alliance for small firms, "pooled purchasing alone cannot sustainably lower the cost of health insurance enough to increase coverage among small business employees."[10] The study further states "…an examination of the HIPC's experience also raises doubts as to whether pooled purchasing has yielded significant savings relative to options available in the small-group market. It has been reported that the HIPC's initial premiums were lower than those outside the HIPC. More recent data, however, provide no evidence that HIPC rates are still lower."[11]

A recent General Accounting Office (GAO) study of small group purchasing cooperatives found that these arrangements have not been able to enroll sufficient numbers to provide bargaining leverage. Even the Pacific Health Advantage with 144,000 covered lives accounts for only 2% of the small group health insurance market in California. In general, all coops reviewed had less than 5% of the state's market.

Another study on health purchasing cooperatives (HPCs) found that "Virtually all HPCs have lost PPOs, in part because of adverse selection. Not having a PPO option has exacerbated HPCs' problems competing in the small-group market."[12] The study, which evaluated several HPCs around the county, found that when PPOs were sold through HPCs, they only attracted unhealthy or high-risk individuals. Even enrollment in the largest HPCs in California and Florida accounted for only 5 percent of small group enrollment.[13]

The population groups discussed at the Assembly are too large to sustain in a HPC or risk pool setting without moving towards a "single payor system," which we do

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[10] Yegian, J., Buchmueller, T., Smith, M., & Monroe, A (2000, September/October). The Health Insurance Plan of California: The First Five Years. Health Affairs.

[11] See Footnote 3.

[12] Wicks, E (2000, June). Health Purchasing Coalitions Struggle to Gain Bargaining Clout: Small Size and Lack of Support from Health Plans are Factors. Health Care Financing & Organization Brief.

[13] See Footnote 5.

not support.

Second, any state reforms should be carefully considered so that we do not exacerbate the uninsured population. A study of the uninsured conducted by The Employee Benefit Research Institute (EBRI), also provides insight on state initiatives and their affect on the uninsured. The study used the U.S. Census Bureau's March 1998 Current Population Survey as its basis. The study found that state reform efforts could add to the problem of the uninsured:

- The sole effort among states to decrease the number of uninsured was the establishment of high-risk pools, resulted in only a 1.5% decrease.

- Small group community rating in conjunction with a guaranteed issue requirement increased the probability that an individual will be uninsured by 28.5%.

- Small group rating bands coupled with guaranteed issue increased the probability that an individual will be uninsured by 15.8%.

- Community rating and guaranteed issue requirements in the individual health insurance marketplace increased the probability that an individual will be uninsured by 11.3%.

- Rating bands with guaranteed issue requirements in the individual health insurance market increased the probability that an individual will be uninsured by 5.1%.

- A mandate that insurance plans cover mental health increased the probability that an individual will be uninsured by 5.8%.

This analysis does much to explain how the numbers of uninsured can vary from state to state.

Third, we are aware of the President's initiative to make the Medicaid program more accessible to uninsured low income Americans. We would caution that any expansion of public programs such as Medicaid, should only be addressed in conjunction with reforming the benefit package provided recipients. Specifically, the State employee, Medicaid and Federal Employee Health Benefit Program (FEHB) benefits do not resemble the private market. As such, in order to expand any public program to cover more people there must be a resource shift away from overly rich benefits to what the market currently provides most employees.

While we believe the private market recommendations discussed previously will provide access to health insurance for most Illinois citizens, we acknowledge the federal administration's Medicaid revisions.

In closing, we hope that the Illinois Assembly will advance proposals predicated on promoting innovative free-market initiatives and cost-effective improvements to current government programs. The Insurance Caucus, comprised of the insurance trade associations, insurers, brokers, agents, etc., wants to be a part of this solution and will look forward to continuing our dialogue on these important issues in the future.

Thank you for your careful consideration of our comments.

Sincerely,

Larry Barry, Illinois Life Insurance Council
Elena Butkus & Matthew Napierkowski, Illinois Association of Health Plans
Gary Fitzgerald, Harmony Health Plan of Illinois
Brian Glassman, Health Care Service Corporation
Sharon Heaton, Heaton Agency Inc.
Paul Hilling, Near North Insurance Brokerage, Inc.
Phil Lackman, Professional Independent Insurance Agents of Illinois
Pamela Mitroff, Mitroff Consulting
Michael Murphy, Humana Health Care Plans, Inc.

cc: Eric Brenner, Governor's Office
Michael Lawrence, SIU
Director Nat Shapo, Illinois Department of Insurance

E. Employer Letter

October 16, 2001

Ms. Madelynne Brown
Assistant Director
Illinois Department of Insurance
320 West Washington
Springfield, IL 62767

Dear Ms. Brown:

The goal of the Illinois Assembly to provide solutions to the ongoing problem of uninsured in our State is one the employer community wholeheartedly embraces. Employers have been struggling for years to provide high quality, affordable health care benefits to their employees. Unfortunately, many cost-related factors have led employers to either reduce or eliminate health care insurance as a benefit leading to a rise in working uninsured.

As initially outlined by the Department, the Illinois Assembly process seemed to be one of consensus building. A diverse group was brought together and representatives of the employer community attended the Assembly in good faith hoping to find solutions. A lot of differing views were discussed during the Assembly, some were agreed upon but many were not.

The problem is the draft report seems to indicate a consensus where there is none. Under the heading of "cross population strategies" the report lists the supposed top 4 strategies that are meant to cut across all populations. One of the strategies is the notion of developing a single payor health care system. We are perplexed and dismayed as to how this strategy made it into the top 4 when it is not listed as a strategy under any of the single population targets. Furthermore the discussion of a single payor system, while brought up in passing, was not seriously considered as a solution by anyone in the business community. We believe it is deceiving to list this "strategy" as one of consensus when it was clearly supported by a minute segment of those attending the Assembly.

Also disturbing is the fact that a strategy with clear support under all populations - creating employer incentives to provide health insurance - was diminished in its importance due to "formatting" mistakes. There is great discomfort by us to sign off on any concept that includes the idea of "portable mandatory employer-based insurance." The fact that the report ties employer incentives to portable mandatory employer-based insurance severely misrepresents what we feel was consensus by the Assembly.

We also believe that since most Illinoisans obtain their insurance through employment, we should look at ways to lower insurance costs so that more employers can offer insurance to their employees. Your own research has shown that 64 percent of employers would consider offering insurance if there was some type of premium assistance and 86 percent favored tax breaks to offset the cost of coverage. Those opinions should not be ignored since employers are likely to remain the "consumers" of health insurance coverage for their employees.

For these reasons, we are unable to fully embrace the contents of this report and would like this letter to be included with the report. It must be stated emphatically that we in no way would support any solution that contained a provision for a single payor health care system or any type of mandatory employer-based insurance plan.

Sincerely,

Kim Clarke Maisch
NFIB

Jay Dee Shattuck
Employment Law Council

Todd Maisch
Illinois Chamber of Commerce

Rob Karr
Illinois Retail Merchants Association

Boro Reljic
Illinois Manufacturers Association

Larry Barry
Illinois Life Insurance Council

Elena Butkus
Illinois Association of Health Plans

James Stutz
St. Louis Area Business Health Coalition

Jim Mortimer
Midwest Business Group on Health

F. January Assembly Registrants

First Name	Last Name	Organization
Larry	Barry	Illinois Life Insurance Council
Matt	Baughman	Southern Illinois University - Public Policy Institute
Lucinda	Beier	Illinois State University - Applies Social
Gayle	Blair	Illinois Department of Public Health
Eric	Brenner	Office of Governor
Madelynne	Brown	Illinois Dept. of Insurance
Chuck	Budinger	Illinois Dept. of Insurance
Elena	Butkus	Illinois Association of Health Plans
Rick	Carlson	Illinois Comprehensive Health Ins. Plan
Steve	Carlson	Illinois Rural Health Association
Greg	Carney	Illinois Farm Bureau
David	Citron	Illinois Dept. of Public Aid
Gerri	Clark	Division of Specialized Care for Children
Sue	Clark	Illinois Nurse's Association
Yvonne	Clearwater	Illinois Department of Insurance
Ray	Cooke	Springfield Department of Public Health
Caryl	Cox	Program Evaluation for Education and Communities
Maria	de Guzman	Chicago Health Outreach

Steve	Derks	Advocate Health Care
Francisco	d'Escoto	United Neighborhood Organization
Jim	Duffett	Campaign for Better Health Care
Pat	Eckert	Southern Illinois University - Division of Continuing Education
Joe	Feinglass	Northwestern University - Preventative Medicine
Dan	Fulwiler	Access Community Health Network
Paul	Galligos	Rural Partners
Vickie	Gates	Academy for Health Services Research & Health Policy
Michelle	Gentry-	Illinois Dept. of Public Health
Joy	Getzenberg	Chicago Dept. of Public Health
Lisa	Gregory	Illinois Primary Health Care Association
Dale	Griffin	Health Care Service Corporation
Robert	Haight	United Way of IL
Joseph	Harrington	Rush Medical Center
Sharon	Heaton	Heaton Agency Inc.
Aaron	Hernandez	United Power for Action and Justice - United Neighborhood
Jerry	Hickam	Southern Illinois Healthcare
Paul	Hilling	Near North Insurance Brokerage, Inc.
D.G.	Huelskoetter	
Mike	Jones	Illinois Dept. of Public Health
Julie	Kaiser	Southern Illinois University - Public Policy Institute
Fred	Kalsbeek	St. Francis Medical Center
Rob	Karr	Illinois Retail Merchants Association
Peg	Keeley	AARP of Illinois - Legislative Office
Katy	Khayyat	Dept. of Commerce and Community Affairs
Patti	Kimmel	Illinois Department of Public Health
Jan	Kirby	Illinois Comprehensive Health Ins. Plan
Mike	Koetting	University of Chicago Hospitals
Frank	Kopel	Illinois Department of Public Aid
Richard	Kotz	Consultant
Gordana	Krkic	Illinois Academy of Family Physicians
Laura	Landrum	Illinois Department of Public Health
Philippe	Largent	Illinois Primary Health Care Association
Mike	Lawrence	Southern Illinois University - Public Policy Institute
Diane	Lindblom	State Planning Grant
Debbie	Lounsberry	Senate Republican Staff
Johanna	Lund	Health Care Consultants
Kim	Maisch	National Federation of Independent Businesses
Todd	Maisch	Illinois Chamber of Commerce
Dennis	Matheis	CIGNA Healthcare of Illinois, Inc.
Bill	McAndrew	Illinois Dept. of Insurance
Holly	McCaffrey	National Alliance for the Mentally Ill
Terri	McEntaffer	Illinois Pharmacists Association
C.J.	Metcalf	Illinois Department of Insurance
Pam	Mitroff	Pamela D. Mitroff, Consulting
Shannon	Moorer	Senate Democrat Staff
Marty	Morris	Illinois Comprehensive Health Insurance Plan

Saul	Morse	Illinois State Medical Society
Jim	Mortimer	Midwest Business Group on Health
Sharon	Mumford	Department of Human Services
Mike	Murphy	Humana, Inc.
Matt	Napierkowski	Illinois Association of Health Plans
Merwyn	Nelson	Illinois Department of Public Health
Ray	Passeri	Illinois Department of Public Health
Howard	Peters	Illinois Hospital Association
Mark	Peters	Illinois Public Health Association
Georgeen	Polyak	Oak Park Department of Public Health
Matt	Powers	Illinois Department of Public Aid
Boro	Reljic	Illinois Manufacturer's Association
Sinead	Rice	Illinois Department of Insurance
Mary	Ring	Illinois Department of Public Health
Ken	Robbins	Illinois Hospital & Health Systems Association
Dick	Rogers	Illinois Association of Health Plans
Dianne	Rucinski	University of Illinois at Chicago
Paul	Sarvela	Southern Illinois University - Health Care Professions
Steve	Saunders	Department of Human Services
Robert	Schaaf	IMS Inc.
Hank	Scheff	AFSCME Council 31
Laura	Schneider	Lake County Health Department
Ralph	Schubert	Department of Human Services
Nat	Shapo	Illinois Department of Insurance
Jay	Shattuck	Employment Law Council
Ross	Silverman	SIU School of Medicine - Department of Medical Humanities
Greg	Smith	PIIAI, IAIFA, ISAHU
Susie	Smith	Illinois Department of Insurance
Jason	Speaks	Attorney General
Zack	Stamp	Zack Stamp, Ltd.
Bruce	Steiner	Illinois Department of Public Health
Jerry	Stermer	Voices for Illinois Children
Ashley	Stiller	State Planning Grant
Peggy	Stockdale	Southern Illinois University - Psychology Department
Connie	Sullinger	Illinois EPA
Bryan	Swank	Swank Insurance Agency, Inc.
Jane	Swanson	Southern Illinois University - Psychology Department
Kathryn	Taylor	Illinois Department of Public Health
Bob	Wagner	Illinois Department of Insurance
Sally Jo	Wright	State Planning Grant
Quentin	Young	Health & Medicine Policy Research Group

G. July Assembly Registrants

First Name	Last Name	Organization
Larry	Barry	Illinois Life Insurance Council

Elissa	Bassler	Public Health Futures Illinois - Illinois Department of Public Health
Matt	Baughman	Southern Illinois University - Public Policy Institute
Kim	Beggs	Community Health Initiative
Gayle	Blair	Illinois Department of Public Health
James	Bloyd	Cook County Department of Public Health
Sylvie	Bouriaux	Illinois State University - Finance, Insurance and Law
Eric	Brenner	Office of Governor
Madelynne	Brown	Illinois Dept. of Insurance
Chuck	Budinger	Illinois Dept. of Insurance
Elena	Butkus	Illinois Association of Health Plans
Rick	Carlson	Illinois Comprehensive Health Ins. Plan
Rob	Carney	Illinois Chamber of Commerce
Sue	Clark	Illinois Nurse's Association
Yvonne	Clearwater	Illinois Department of Insurance
Debra	Cole	Illinois Retail Merchants Association
Ray	Cooke	Springfield Department of Public Health
Caryl	Cox	Program Evaluation for Education and Communities
Maria	de Guzman	Chicago Health Outreach
Steve	Derks	Advocate Health Care
Brian	DeRue	House Republican Staff
Francisco	d'Escoto	United Neighborhood Organization
Kurt	DeWeese	House Democratic Staff
Mary	Dobbins	Illinois Chapter, American Academy of Pediatrics
David	Dring	Illinois Association of Health Plans
Jim	Duffett	Campaign for Better Health Care
Jim	Durkan	Community Memorial Foundation
Pat	Eckert	Southern Illinois University - Division of Continuing Education
Ray	Empereur	Rockford Health Council
Richard	Endress	Access DuPage
Gary	Fitzgerald	Harmony Health Plan
John	Frana	Community Health Initiative
Dan	Fulwiler	Access Community Health Network
Robyn	Gabel	Illinois Maternal and Child Health Coalition
Paul	Galligos	Rural Partners
Donna	Ginther	AARP of Illinois
Brian	Glassman	Blue Cross/Blue Shield of Illinois
Tiffany	Grant	
Lisa	Gregory	Illinois Primary Health Care Association
Dale	Griffin	Health Care Service Corporation
Lori	Hafel	
Robert	Haight	United Way of IL
Joseph	Harrington	Rush Medical Center
Sharon	Heaton	Heaton Agency Inc.
Jerry	Hickam	Southern Illinois Healthcare
Paul	Hilling	Near North Insurance Brokerage, Inc.
Karen	Hoffert	
Barbara	Holmes	United Healthcare

Josh	Hoyt	United Power for Action and Justice
D.G.	Huelskoetter	
Kevin	Jarvis	Illinois Public Health Association
Iris	Johnson	Illinois Health Care Cost Containment Council
Mike	Jones	Illinois Dept. of Public Health
Fred	Kalsbeek	St. Francis Medical Center
Rob	Karr	Illinois Retail Merchants Association
Joleen	Katula	United HealthCare
Vincent	Keenan	Illinois Academy of Family Physicians
Katy	Khayyat	Dept. of Commerce and Community Affairs
Patti	Kimmel	Illinois Department of Public Health
Mike	Koetting	University of Chicago Hospitals
Frank	Kopel	Illinois Department of Public Aid
Richard	Kotz	Consultant
Gordana	Krkic	Illinois Academy of Family Physicians
Phil	Lackman	Professional Independent Insurance Agents of Illinois
Laura	Landrum	Illinois Department of Public Health
Philippe	Largent	Illinois Primary Health Care Association
Kathy	LaSpina	Harmony Health Plan
Mike	Lawrence	Southern Illinois University - Public Policy Institute
Amy	Lay	Illinois Department of Public Health - Division of Health Policy
Kate	Leinweber	Governor Ryan's Office
Patrick	Lenihan	Chicago Dept. of Public Health
Diane	Lindblom	State Planning Grant
Ancelmo	Lopes	Harmony Health Plan of Illinois, Inc.
Debbie	Lounsberry	Senate Republican Staff
John	Lumpkin	IDPH
Johanna	Lund	Health Care Consultants
Kim	Maisch	National Federation of Independent Businesses
Todd	Maisch	Illinois Chamber of Commerce
Bill	McAndrew	Illinois Dept. of Insurance
Paul	McNamara	Department of Agriculture and Consumer Economics
Andrew	Melczer	Illinois State Medical Society - Health Policy Research
Pat	Merryweather	Illinois Hospital and Health Systems Association
C.J.	Metcalf	Illinois Department of Insurance
Pam	Mitroff	Pamela D. Mitroff, Consulting
John	Monahan	Annie E. Casey Foundation
Emily	Mondschein	Voices for Illinois Children - State Fiscal Analysis Project
Shannon	Moorer	Senate Democrat Staff
Marty	Morris	Illinois Comprehensive Health Insurance Plan
Jim	Mortimer	Midwest Business Group on Health
Mike	Murphy	Humana, Inc.
Matt	Napierkowski	Illinois Association of Health Plans
Merwyn	Nelson	Illinois Department of Public Health
Tim	Olmsted	State Planning Grant
Charles	Onufer	UIC-DSCC
Ray	Passeri	Illinois Department of Public Health

Steve	Perlin	Illinois Hospital & Health Systems Association
Georgeen	Polyak	Oak Park Department of Public Health
Debbie	Potts	Illinois of Educational Services
Linda	Potts	Community Health Initiative
Matt	Powers	Illinois Department of Public Aid
Boro	Reljic	Illinois Manufacturer's Association
Rachel	Reutter	Southern Illinois University
Susan	Reyman	Reyman Associates
Sinead	Rice	Illinois Department of Insurance
Margaret	Richards	Illinois Department of Public Health
Mary	Ring	Illinois Department of Public Health
Julio	Rodriguez	Illinois Department of Human Services
Dianne	Rucinski	University of Illinois at Chicago
Paul	Sarvela	Southern Illinois University - Health Care Professions
Steve	Saunders	Department of Human Services
Robert	Schaaf	IMS Inc.
Margie	Schaps	Health & Medicine Policy Research Group
Hank	Scheff	AFSCME Council 31
Laura	Schneider	Lake County Health Department
Ralph	Schubert	Department of Human Services
Dan	Shannon	Southern Illinois University - Ctr. For Rural Health & Social Service
Jay	Shattuck	Employment Law Council
Ross	Silverman	SIU School of Medicine - Department of Medical Humanities
Susie	Smith	Illinois Department of Insurance
Jason	Speaks	Attorney General
Zack	Stamp	Zack Stamp, Ltd.
Margaret	Stapleton	National Center on Poverty Law
Bruce	Steiner	Illinois Department of Public Health
Ashley	Stiller	State Planning Grant
Peggy	Stockdale	Southern Illinois University - Psychology Department
Jane	Swanson	Southern Illinois University - Psychology Department
Jeffrey	Todd	Stephenson County Health Department
Bob	Wagner	Illinois Department of Insurance
Zachary	Wichmann	Attorney General
Julie	Williamson	Southern Illinois University - Division of Continuing Education
Neil	Winston	Illinois State Medical Society
Kate	Woods	Southern Illinois University - Division of Continuing Education
Sally Jo	Wright	State Planning Grant
Theresa	Wyatt	Illinois Department of Public Aid

H. September Assembly Registrants

First Name	Last Name	Organization
Larry	Barry	Illinois Life Insurance Council
Elissa	Bassler	Public Health Futures Illinois - Illinois Department of Public Health
Matt	Baughman	Southern Illinois University - Public Policy Institute

Kim	Beggs	Community Health Initiative
James	Bloyd	Cook County Department of Public Health
Eric	Brenner	Office of Governor
Madelynne	Brown	Illinois Dept. of Insurance
Chuck	Budinger	Illinois Dept. of Insurance
Elena	Butkus	Illinois Association of Health Plans
Rick	Carlson	Illinois Comprehensive Health Ins. Plan
Greg	Carney	Illinois Farm Bureau
Gerri	Clark	Division of Specialized Care for Children
Yvonne	Clearwater	Illinois Department of Insurance
Ray	Cooke	Springfield Department of Public Health
Steve	Derks	Advocate Health Care
Brian	DeRue	House Republican Staff
Pat	Eckert	Southern Illinois University - Division of Continuing Education
Ray	Empereur	Rockford Health Council
Richard	Endress	Access DuPage
Gary	Fitzgerald	Harmony Health Plan
Robyn	Gabel	Illinois Maternal and Child Health Coalition
Paul	Galligos	Rural Partners
Joy	Getzenberg	Chicago Dept. of Public Health
Greg	Glahn	Office of the Auditor General
Brian	Glassman	Blue Cross/Blue Shield of Illinois
Dale	Griffin	Health Care Service Corporation
Robert	Haight	United Way of IL
Jerry	Hickam	Southern Illinois Healthcare
Barbara	Holmes	United Healthcare
Josh	Hoyt	United Power for Action and Justice
Kevin	Jarvis	Illinois Public Health Association
Iris	Johnson	Illinois Health Care Cost Containment Council
Mike	Jones	Illinois Dept. of Public Health
Fred	Kalsbeek	St. Francis Medical Center
Rob	Karr	Illinois Retail Merchants Association
Joleen	Katula	United HealthCare
Katy	Khayyat	Dept. of Commerce and Community Affairs
Patti	Kimmel	Illinois Department of Public Health
Candace	King	DuPage Federation on Human Services Reform
Richard	Kotz	Consultant
Gordana	Krkic	Illinois Academy of Family Physicians
Amiad	Kushner	Northwestern University
Phil	Lackman	Professional Independent Insurance Agents of Illinois
Laura	Landrum	Illinois Department of Public Health
Mike	Lawrence	Southern Illinois University - Public Policy Institute
Amy	Lay	Illinois Department of Public Health - Division of Health Policy
Diane	Lindblom	State Planning Grant
John	Lumpkin	IDPH
Johanna	Lund	Health Care Consultants
Kim	Maisch	National Federation of Independent Businesses

Barbara	Mason	SIU School of Medicine
Bill	McAndrew	Illinois Dept. of Insurance
Paul	McNamara	Department of Agriculture and Consumer Economics
Pat	Merryweather	Illinois Hospital and Health Systems Association
C.J.	Metcalf	Illinois Department of Insurance
Pam	Mitroff	Pamela D. Mitroff, Consulting
Emily	Mondschein	Voices for Illinois Children - State Fiscal Analysis Project
Saul	Morse	Illinois State Medical Society
Jim	Mortimer	Midwest Business Group on Health
Merwyn	Nelson	Illinois Department of Public Health
Tim	Olmsted	State Planning Grant
Steve	Perlin	Illinois Hospital & Health Systems Association
Howard	Peters	Illinois Hospital Association
Debbie	Potts	Illinois of Educational Services
Boro	Reljic	Illinois Manufacturer's Association
Susan	Reyman	Reyman Associates
Sinead	Rice	Illinois Department of Insurance
Dianne	Rucinski	University of Illinois at Chicago
Paul	Sarvela	Southern Illinois University - Health Care Professions
Steve	Saunders	Department of Human Services
Margie	Schaps	Health & Medicine Policy Research Group
Hank	Scheff	AFSCME Council 31
Jay	Shattuck	Employment Law Council
Paul	Simon	Southern Illinois University - Public Policy Institute
Susie	Smith	Illinois Department of Insurance
Jason	Speaks	Attorney General
Margaret	Stapleton	National Center on Poverty Law
Bruce	Steiner	Illinois Department of Public Health
Ashley	Stiller	State Planning Grant
James	Stutz	St. Louis Area Business Health Coalition
Jane	Swanson	Southern Illinois University - Psychology Department
Bob	Wagner	Illinois Department of Insurance
Angie	White	Senate Republican Staff
Blair	Whitney	Community Health Initiative
Kate	Woods	Southern Illinois University - Division of Continuing Education
Sally Jo	Wright	State Planning Grant
Theresa	Wyatt	Illinois Department of Public Aid

The following Appendices are available on the Website: www.ins.state.il.us/spg

I. Ballot Tabulations

J. Report of Small Group Deliberations (July 10-12)

K. Fact Sheet - Young Adults

L. Fact Sheet - Children

M. Fact Sheet - Minority Groups

N. Fact Sheet - Small Employers

O. Fact Sheet - Working Uninsured

P. UIC PowerPoint Slides – Report to the Illinois Assembly on the Uninsured

Q. SIUC PowerPoint Slides – Focus Groups and Interviews: Preliminary Findings

R. BRFSS PowerPoint Slides – Trends in Health Insurance Coverage in Illinois

Report to the Illinois Assembly on the Uninsured:
Illinois Population Survey of Uninsured and Newly Insured

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1. Executive Summary

The Illinois Population Survey of the Uninsured and Newly Insured (IPSUNI) was conducted as part of the research effort for the Illinois State Planning Grant to assist in formulating policies to address the problem of the lack of health insurance. The project was supported by the U.S. Department of Health and Human Services Health Resource and Services Administration.

The IPSUNI was designed to provide current, accurate and reliable data about Illinois residents who were currently uninsured or recently uninsured but were insured at the time of the survey to get a clearer understanding of the usual paths of coverage and the dynamics of insurance coverage. The survey was conducted using telephone interviews with computer-assisted interviewing techniques. Interviews were conducted in English and in Spanish from January, 2001 to May, 2001. The final response rate was 52%.

A. Major Results

1. **Uninsured in Illinois at 9.7%.** There appear to be fewer uninsured persons in the State of Illinois than what would be expected based on other estimates from the Current Population Survey or the Behavioral Risk Factor Surveillance System. In light of similar findings from other states, the estimates presented in this report ought to be considered reliable and valid estimates of the uninsured.
2. **Uninsured disproportionately Latino, African American, and of lower socio-economic status.**
3. **The uninsured and newly uninsured disproportionately reside in Cook county. Southern Illinois residents are significantly unrepresented among the uninsured and newly uninsured.**
4. **Many uninsured people are working but do not have insurance available from their employers.** A large percentage–nearly half–of Illinois' working uninsured do not have insurance available through their employers. Many of these workers are employed in smaller business, which tend to be less likely to offer coverage to their workers. The working uninsured in Illinois are more likely to work in the service industries and in service occupations.
5. **Cost is a significant and onerous barrier to coverage for most uninsured people, and most would not or could not pay the premiums that many plans require.** Most uninsured workers with coverage available through their employers cite cost/values issues as a barrier to coverage. Respondents indicate they would pay about $78 a month for individual coverage and $100 for family coverage.
6. **"Lifestyle choice" is not a salient factor for most uninsured people.** Very few respondents report lifestyle issues–that they do not think they need insurance at this time in their lives.
7. **Awareness continues to be a major challenge for government-sponsored programs.** In addition to more aggressive and innovative outreach, For KidCare, Illinois' S-CHIP program,

the state of Illinois may wish to consider further streamlining of application processes by reducing the amount documentation needed. Apart from lack of awareness, cost was cited as a barrier to I-CHIP.

B. **Conclusions**

Economics explains why most uninsured Illinois residents lack of health insurance. While most uninsured residents work, most are more likely to work for small businesses, or in occupations or industries which do not provide group-based insurance. Perhaps in some industries and occupations, the labor market is not tight enough to induce employers to offer health insurance as a benefit. Because health insurance tends to be more expensive for smaller businesses, many employers of respondents to our survey reported that employer-based coverage was simply not available. In addition, many working uninsured people are low-wage workers and are highly unlikely to have the disposable income to purchase a policy directly through an insurance company.

Based on the results of this population survey, we must acknowledge that the direct purchase of health insurance or relying exclusively on greater participation in an employment-based insurance plan are highly unlikely to have a significant impact on the rate of uninsured in Illinois. The most efficient and effective strategies will be those that first build on the existing government-sponsored infrastructure to attend to those least likely to be served through private employers and then focus on expanding coverage options for targeted employers and industries.

II. Introduction

To assist in the formulation policies to cover all Illinois residents, the Steering Committee decided that current, focused Illinois data were needed. The project described here, the Illinois Population Survey of Uninsured and Newly Insured (IPSUNI), was one of several research projects associated with the Illinois State Planning Grant. The IPSUNI was designed to provide current, accurate and reliable data about Illinois residents who were currently uninsured or recently uninsured but were insured at the time of the survey to get a clearer understanding of the usual paths of coverage and the dynamics of insurance coverage. The project involved the collection and analysis of demographic data, and study the duration of noncoverage; employment status; group-based insurance availability; reason(s) for declining employment based-coverage if available; awareness of alternative sources of health insurance (privately and publicly-sponsored) and attempts to secure such coverage. The IPSUNI was conducted using computer-assisted telephone interviewing techniques and a randomly selected sample.

This report represents preliminary results that needed for the Illinois Assembly on the Uninsured. The PSINI is a rich data source and analysis continues.

A. Research Objectives

The objectives of the PSINI were three-fold. First, to develop reliable and accurate estimates of the number of uninsured persons in the State of Illinois Second, to define the demographic, economic, and health related characteristics of the uninsured in Illinois. Third, to collect sufficient information to facilitate the design of an effective communication plan to inform the insured of the availability of any programs emerging from this planning grant, and to encourage them to find out more about the plans. This information should allow us the answer to following general questions about our uninsured population:

1. What are the demographic characteristics (race, gender, age, ethnicity, education, employment status, type of employment, size of employer, income level, family composition, immigrant status, etc.) of the uninsured?
2. Are uninsured individuals unable to obtain or afford health insurance due to "preexisting conditions"?
3. Have uninsured individuals ever had health insurance? If so, what type?
    - --Employer-provided commercial insurance
    - --Personally purchased coverage
    - --Medicare
    - --Medicaid
4. How long have these individuals been intermittently or continuously uninsured?
5. What factors have caused them to be currently uninsured?
    - --Loss of job
    - --Lack of employer-provided insurance/wages too low to purchase individually

--Welfare-to-work-transition
--School-to-work transition
--Preexisting conditions
--Amount of employee share of employer's coverage

6. What are the main barriers to obtaining health insurance coverage?
7. What amount would uninsured individuals be willing to pay for individual coverage or family coverage?
8. What are the awareness and information levels of KidCare, Medicaid, ICHIP and other insurance coverage among the uninsured? What do they think about those programs? How does this impact enrollment decisions?
9. What channels or mechanisms might be used to reach uninsured groups with targeted messages to inform them of the existence of programs and plans? What are the points of contact through interpersonal, organizational, and mass media channels to facilitate information dissemination?

2. Methods

1. Research Design

To meet the objectives, the study was designed to allow estimates of the number and distribution of households with at least one person uninsured or newly insured at the time of the interview. Therefore, the study was composed of two instruments: a screening instrument and a main instrument. A screening instrument was used with all contacted households to determine if an eligible person lives in the household. If an eligible person was found in a household, the main instrument was conducted. The screening and main instruments would address the issues listed below:

- Estimated distribution of uninsured and newly insured persons in Illinois statewide and regionally.

- Estimated distribution (numbers and percentages) of uninsured persons residing in households according to percentages above and below the Federal Poverty Levels for family size.

- Demographic and socioeconomic characteristics of households with at least one member without health insurance including:

Age
Family composition
Race
Ethnic background
Citizenship status
Geographic Region
Employment status of adults
Employment sector of working adults

Occupation of working adults
Size of organization employing working adults

- Availability of insurance coverage through employment or other group-based plan.

- Reasons for lack of coverage if employer or union-based coverage is or has been available to employee or by family members of an insured employee.

- Amount uninsured individuals would pay for quality health insurance coverage.

- Continuity of insurance coverage

- Was private individual insurance applied for? Results?

- Medicaid application, where application was taken, and outcome of application.

- Reasons for not using Medicaid or Kidcare if children are eligible.

- Awareness of KidCare, Medicaid, and ICHIP.

2. Sample

Sample design was a disproportionate stratified sample with 5 strata: Northwestern, Central, Southern, Cook County, and the Collar Counties of Cook County (Appendix A lists the counties in each region). Interviews were conducted by telephone throughout the state.

Sample

Sample design was a disproportionate stratified sample with 5 strata: Northwestern, Central, Southern, Cook County, and the Collar Counties of Cook County (Appendix lists the counties in each region). Interviews were conducted by telephone throughout the state.

A sample of 19,089 random digit dial numbers was purchased from Genesys Sampling Systems on November 14, 2000. An additional sample of 8,383 cases was purchased from Survey Sampling, Inc. on March 6, 2001. The sample was released in 17 replicates over a period of about three months, from mid-January through mid-April, 2001.

Table A shows the final disposition for the total sample. Appendix B contains a description of the disposition codes.

Table A. Final Disposition of Sample, State of Illinois

Code	Disposition	Number	Percent
01	Completed interview (English)	759	2.95
02	Completed interview (Spanish)	86	0.33
03	Partial Complete Interview (English)	69	0.27
04	Partial Complete Interview (Spanish)	18	0.07
30	No answer	2784	10.82
31	Answering machine/answering service	937	3.64
32	Eligible R not available	22	0.09
33	Unscreened R not available	1034	4.02
40	Final refusal to screener	4203	16.33
41	Final refusal after screening	38	0.15
42	Final Spanish refusal	19	0.07
47	Final refusal, unscreened – PM	68	0.26
55	Not able to interview during survey period	81	0.31
56	Never able to interview	205	0.80
70	Inelig, R under 18	58	0.23
71	Inelig, R is insured	9599	37.30
85	Deceased	2	0.01
86	Nonworking	3291	12.79
87	Non-residential	2348	9.12
88	Ineligible foreign language	114	0.44
	Total	**25,735**	**100.00**

Table B shows the completion rates for the sample. Appendix C contains a description of the completion rate categories. The response rate is the number of completed interviews divided by the total number of eligible respondents. The response rate is the proportion of the eligible respondents who completed the interview. There were 6,547 cases for which we could not conduct a screener. We assumed that 9.2% of those would have been eligible. In another 2,784 cases the phone rang continuously and was never answered at any contact attempt. We assumed that 87.2% of those were working numbers, 89.5% were residential, and 9.2% were eligible. Consequently, the total number of cases with assumed eligibility is estimated as 9.2% of 6,547 (602) plus 7.2% of 2,784 (200). Thus, the response rate is computed as the ratio of 932 completed interviews to the sum of the cases known to be eligible (992) plus the estimated number of eligible cases among the cases for which eligibility was unknown (802). Thus, the final response rate is 51.9%.

The refusal rate is the number of refusals (to both the screener and the interview) divided by the eligible sample. The cooperation rate is the number of completed interviews divided by the number of completed interviews plus the number of refusals.

Table B. Final Sample Rates, Illinois

Total sample	25,735	
Non duplicates	25,735	100.0%
Working #s	22,444	87.2%
Residential	20,096	89.5%

Contact to Screener	16,375	81.5%
Cooperation to Screener	10,765	65.7%
Eligible	992	9.2%
Contact to Final	970	97.8%
Cooperation to Final	932	96.1%
Response rate		**51.9%**
Refusal rate		24.0%
Cooperation rate		67.9%

Weights

The study design was a disproportionate stratified sample. The strata consisted of regions of the state of Illinois. Rather than sample from those regions proportionate to their share of the state population, we sampled roughly equal numbers of households from each region. As a result of the disproportionate sampling, the probability of a household being sampled varied from region to region. Therefore, it was necessary to calculate weights for the sample.

The weights are the inverse of the probability of selection and include three separate components: the probability the telephone number was sampled, the probability the respondent was selected from all adults in the household, and an adjustment for non-response.

The probability the telephone number was sampled is equal to the ratio of the total number of telephone numbers sampled to the total number of working, residential numbers in the region. The household selection weight is the inverse of the probability of selection.

The probability the respondent was sampled out of all adults in the household is equal to 1 divided by the total number of adults in the household. In about 10 percent of the cases, the respondent refused to answer the question about the number of adults. In those cases, we assumed there was one adult and the respondent refused to answer the question for safety reasons. The respondent selection weight is the inverse of the probability of selection.

The overall probability of selection is the probability the household was selected multiplied by the probability the respondent was selected. The overall selection weight is the inverse of this probability. However, this weight had to be adjusted for non-response. The non-response adjustment is simply the inverse of the response rate.

The final dataset contains two weights: *popwgt* and *smpwgt*. *Popwgt* weights the sample to population estimates. *Smpwgt* ratio adjusts the population weights so they sum to the sample size. The limitation of the population weights is that it is not clear exactly what population is represented by the sample. Each respondent is an uninsured adult in Illinois, however, the sample does not represent all uninsured adults in Illinois because of the way the screener was designed. The screener asked to speak

to the person most knowledgeable about health care in the household. If that person was uninsured, the interview continued. If that person was insured, the interview was terminated, without discovering whether or not there were other uninsured adults in the household. As a consequence, uninsured adults who are not knowledgeable about household healthcare, yet who live with another insured adult will be seriously under-represented by this study.

3. Instrumentation

The data collection instrument was programmed using CASES software for the computer-assisted data collection system. The instrument was pretested with a randomly selected sample of respondents, and minor programming changes were made to the data collection instrument to reflect the correct flow and skip pattern of the questionnaire. The instrument was then translated into Spanish. A copy of the questionnaire and interviewer directions appears in Appendix D.

4. Data Collection Procedures

Under the direction of Dr. Dianne Rucinski, the University of Illinois Survey Research Lab (SRL) conducted the field work for the study of uninsured and newly insured in the State of Illinois. Dr. Rucinski designed the survey, provided oversight to the Survey Lab for the pretest and main data collection, and worked closely with the sampling statistician for the assignment of weights.

All interviewers were recruited and trained by the Survey Research Laboratory staff. Interviews trained for eight hours on general interviewing procedures, and eight hours on project specific protocols. All interviewers were required to complete mock interviews with Survey Research Laboratory supervisors or the Principal Investigator before beginning interviews with members of the population. Ten percent or more of all interviewers calls were monitored for quality control purposes throughout the field period.

Interviews were conducted beginning in January 15, 2001 and ended on May 6, 2001.

All members of the project team, including those at the Survey Research Laboratory and at the Health Research and Policy Centers, received extensive training in human subjects protection and confidentiality procedures. This project was reviewed by the University of Illinois at Chicago Institutional Review Board and found to contain the proper protections for human subjects.

5. Data Analysis Procedures

After the data were cleaned and responses to open-ended were coded, the data sets were transmitted from the Survey Research Laboratory to the Health Research and Policy Centers. Additional data cleaning and missing data imputation was performed by Shasha Gao, M.S., a statistician at the Health Research and Policy Centers.

Because the findings were to be presented to an audience of little or unknown statistical expertise, it was decided to keep the analysis simple and descriptive. Thus, the majority of presented analyses consisted of univariate and bivariate tables.

IV Results & Discussion

A. Estimate of the Uninsured Population

We used a combination of CPS and BRFSS health insurance items were used to screen for insurance status. For the first 5 of 17 replicates, respondents were randomly assigned to the CPS or to the BRFSS health insurance series. The two series did not produce differences in eligibility estimates, and subsequent replicates used only the BRFSS version to reduce respondent burden. Based on the survey, we estimate that 8.9% to 15.7% of Illinois residents were uninsured or newly insured at the time the survey was conducted. At the time of the survey 61.3% were uninsured and 38.7%were newly insured.

If we assume that all of the numbers for which we could not complete a screening interview contained insured respondents (ineligible for the main instrument), then about 8.9% of Illinois residents are estimated to be uninsured. However, as discussed in III.B. (Sample), if we assumed that some portion of those numbers for which a completed screener could not be conducted were eligible, then the percentage of uninsured and newly insured increases to 15.7%. Specifically, if we assume that 9.2% of 6,547 cases for which a screening interview could not be completed were eligible for the main instrument (newly insured or uninsured), an additional 602 cases would be eligible. Further, if we assume that of 2,784 cases in which the phone rang continuously and was never answered at any contact attempt, that 87.2% of those were working numbers, 89.5% were residential, and 9.2% were eligible, and additional 200 cases would have been eligible for the main instrument. Finally, if we assume that these uninterviewed but presumptively eligible respondents were uninsured or newly insured in rates similar to those found in completed interviews, then we estimate that approximately 9.7% of Illinois residents are uninsured. Although these estimates are the best estimates that can be produced from the PSINI, the usual cautions associated with any survey should be exercised in reading these results.

The most striking result of the project is the difference between the estimate of uninsured in the state of Illinois according to the PSINI (about 9.7%) compared to that produced by the March Supplement of the Current Population Survey for Illinois (14.1% in 1999). This result has been found in many other states[1] and is thought to occur for several reasons. First, the primary purpose of the CPS is to provide labor statistics, not health insurance estimates, and as such, design decisions and interviewer training may reflect those priorities. Second, until recently, the estimates of uninsured were derived from residual responses and not verified through an additional question confirming uninsured status. This question format has been altered in the past year and has resulted in a downward revision in estimates of

the uninsured.[2] Finally, as many as 24% of responses to the health insurance series are imputed due to non-response, and may not accurately reflect the insurance status of respondents. These factors, singly or in combination, may have resulted in differences in estimates. It is also possible, although highly unlikely, that insurance coverage increased sharply between 1999 and 2001.

B. Insurance status by poverty status

To reduce respondent burden a single income item was asked of each respondent. Where applicable, respondents were asked to report income for the entire family. Respondents were asked an income question that expressed income as a percentage of the Federal Poverty Level for a family of the size of the respondent. Results are presented in Table 1 in Appendix E.

Compared to the newly insured, uninsured had lower incomes. About one in five uninsured respondents had incomes below the poverty level, compared to one in ten newly insured respondents. Approximately 12% of uninsured respondents had incomes over 250% of the FPL, compared with 23% of newly insured.

C. Demographic and socioeconomic characteristics

Age. In most age categories there were no significant differences between the newly insured and uninsured. The exception was for adults between 45-64–who are more likely to be uninsured than newly insured. (See Table 2 in Appendix E). In addition, in comparison to their representation in the general population, Latinos and African Americans are over represented among the uninsured.

Gender. Men and women were no more likely to be newly insured or uninsured .(See Table 3 in Appendix E).

Family Composition. The newly insured and the uninsured were no more likely to be members of single-person households. (See Table 4 in Appendix E). In addition, in comparison to their representation in the general population, Latinos and African Americans are over represented among the uninsured.

Race and Latino Ethnicity. Compared to the newly insured, the uninsured were more likely to be Latino and African American than non-Hispanic white (See Table 5 in Appendix E). In addition, in comparison to their representation in the general population, Latinos and African Americans are over represented among the uninsured.

Citizenship Status. Contrary to popular conceptions, compared to the newly insured, the uninsured were no more likely to non-citizens. (See Table 6 in Appendix E).

Geographic Region. There were no significant regional differences between the newly insured

and uninsured. (See Table 7 in Appendix E). However, Cook County shoulders a disproportionate burden of uninsured and newly insured while Southern Illinois has relatively fewer uninsured and newly insured. Specifically, Cook county accounts for 43.3% of Illinois' population but roughly half of the uninsured and newly insured. Conversely, Southern Illinois accounts for 16.1% of the state's population but only about 10-12% of the state's newly insured and uninsured.

Employment. The majority of newly insured and uninsured respondents were working at the time of the survey (see Table 8 in Appendix E). Newly insured were more likely to be employed than uninsured respondents (75.5% vs. 64.3%, respectively), but were less likely to have been working for the same employer for over a year than uninsured (46.7% vs. 62.2%, respectively).

More than half (52.7%) of the uninsured employed adults did not have health insurance offered to them or to employees in the same position as them (data not shown in tables). Uninsured workers are more likely to work in smaller companies (those employing fewer than 50 workers) than in larger companies than are the newly insured. (See Table 9 in Appendix E).

Among working adults, there were fewer industry differences between newly insured and uninsured adults compared with occupational differences (see Tables 10 and 11 in Appendix E). Both the newly insured and uninsured were most likely to work in the service sectors than in any other sector. About twice as many newly insured adults (34.9%) were employed as managers, professionals, and technicians than uninsured (17.4%). More uninsured adults were employed in service occupations (26.4%) compared to newly insured (20.3%).

Reasons for declining Employee Sponsored Insurance coverage.

Working respondents who had health insurance employment-sponsored insurance were asked a series of questions about why they did not take employment-based coverage. Respondents could agree to as many or as few items as were applicable. An open-ended question was also asked to capture reasons that respondents did not feel were captured by any of the close-ended questions. When appropriate, responses to open-ended were recoded in categories if they were judged to be identical or similar to closed-ended items. Results are presented in Table 12 in Appendix E.

Among the employed uninsured working in a firm in which coverage was available, cost was the most important reasons for declining coverage (55.3.%). The second most common reason was the belief that premiums were not worth the cost and co-pays (30.7%). Many workers reported that they had not worked for their employer long enough (29.3%). Just under one in five reported that their employer did not offer a high quality plan (18.8%), and 16.8% reported that they could not use their doctor through the employer's plan. Just over one in ten reported that they did not need health insurance at that time in their life (11.2%).

Amount uninsured individuals would pay for quality health insurance coverage.

While behavioral intentions do always correspond closely to future behavior, the amount of money uninsured people might pay for coverage for themselves and their families was of substantial interest to those involved with the planning grant. Depending on their family situation (i.e., respondents with spouses/children–defined as "families", or respondents without spouses/children–defined as single persons), respondents were asked whether they would spend one of four dollar amounts for a quality health insurance plan. The dollar amount specified in a question was determined by random assignment and guided by the typical costs of a group-based plan for families and individuals (estimated by the Department of Insurance to be $4000-6000 a year). The amounts ranged from $100 to $250 a month for individuals and $250 to $400 for family coverage. Specifically, those respondents with families were asked:

"Suppose you had a chance to purchase a high quality health insurance plan that includes prevention care and care for serious illness, mental health coverage, dental coverage, and eye care for you and your family. Would you spend [RANDOMLY SELECTED AMOUNT FROM $250-$400) a month for this coverage?"

There is a negative, linear relationship between the cost of coverage and a willingness to pay, ranging from 66% of those asked about the $100 level (individual) and 43% at the $250 and $300 amount (family) to only 34% at the $250 (individual) and 31% (family). (See Table 12 in Appendix E).

For those respondents who indicated they were unwilling to pay the amount specified in the experimental condition, a follow-up question was asked to assess how much respondents would be willing to spend. The median response for individuals was $77.50 (mean = $93) and $100 for families (mean = $131).

Continuity of insurance coverage over the last 12 months.

Those without health insurance and those newly insured were asked how long they had been without coverage. Those currently without coverage tended to be without coverage for a longer period of time than those newly insured (see Table 13 in Appendix E).

Nearly one-third of those without health insurance at the time of the survey had been without health insurance for five or more years, and just under half (49%) had been without health insurance for more than two years.

Among those newly insured, half had been without health insurance coverage for less than six months.

Private direct purchase health insurance

Very few respondents with or without health insurance at the time of the survey had ever applied for a health insurance policy directly with an insurance company. About 8% of those without insurance at the time of the survey had applied directly to an insurance company, and only one respondent was able to secure coverage through a direct purchase policy.

Among newly insured, the figures are relatively higher but low in absolute terms. Less than 17% of those newly insured had applied for coverage directly with an insurance company and less than a third of those who had applied were able to secure coverage. (See Table 14 in Appendix E).

Awareness of I-CHIP and KidCare

All respondents were asked if they had ever heard or read anything about I-CHIP, Illinois' Comprehensive Health Insurance Plan (Illinois' health insurance program for those with medical conditions who cannot be insured through private plans). About 11% of respondents said they had heard about I-CHIP. Among those who had heard of I-CHIP, about one in three reported that they did not think that they were eligible for I-CHIP coverage. About one in four reported that they could not afford the premium. Just over 10% reported that the coverage was not sufficient for their medical needs. (Data not shown in Appendix E).

Parents with uninsured children whose self-reported income was less than 185% of the Federal Poverty Level were asked if they had ever heard or read any about KidCare. About 38% of parents with eligible children reported having read or heard something about KidCare. Those who reported being aware of KidCare were asked a series of questions about why they were not using Medicaid or KidCare for their children. About 45% of respondents reported wanting to enroll in Kidcare but being told they would have to enroll children in Medicaid instead and declined this coverage. About 43% reported that they did not know where to apply, and about 30% reported that they did not have the necessary documents for making an application. Less than 10% reported that the following were reasons they did not use KidCare or Medicaid:

- Could not get to the office
- Could not get appointments scheduled quicky enough
- Could not find a provider who accepted KidCare or Medicaid
- Family doctor would not take KidCare or Medicaid
- Can't afford KidCare premiums and copays
- Health care provided under KidCare and Medicaid is not very good
- Child is pretty healthy and insurance is not needed
- They did not think their child was eligible

IV Conclusions

Based on the results of this population survey, the following tentative conclusions are offered:

8. There appear to be fewer uninsured persons in the State of Illinois (estimated at about 9.7% of the population) than what would be expected based on estimates from the Current Population Survey or the Behavioral Risk Factor Surveillance System. The discrepancies between noncoverage estimates produced in this survey and the CPS and the BRFSS deserve further investigation to which the Principal Investigator is committed. In light of similar findings from other states, the estimates presented in this report ought to be considered reliable and valid estimates of the uninsured.
9. The uninsured in Illinois are disproportionately Latino and African-American.
10. The uninsured and newly uninsured disproportionately reside in Cook county. Southern Illinois residents are significantly unrepresented among the uninsured and newly uninsured.
11. The uninsured in Illinois are disproportionately low and very low income, which underscores the importance of the cost of coverage to creating policy solutions. Because low and very low-income persons are less likely to owe income taxes and many uninsured people do not even file income taxes, it is unlikely that tax credits would be effective in reducing the uninsured rate in Illinois.
12. A large percentage–nearly half–of Illinois' working uninsured do not have insurance available through their employers. Many of these workers are employed in smaller business, which tend to be less likely to offer coverage to their workers. The working uninsured in Illinois are more likely to work in the service industries and in service occupations.
13. Most uninsured respondents report that they would not pay premium amounts that reflect low to moderate group-based premiums for individuals ($100 to $250) and families ($250 to $400).
14. Most uninsured workers with coverage available through their employers cite cost/values issues as a barrier to coverage. Very few respondents report lifestyle issues–that they o not think they need insurance at this time in their lives. That so many uninsured respondents wanted to buy their employer's coverage but could not afford it and so few respondents reported that they did not need coverage should disabuse policymakers of the belief that many uninsured people just don't want health insurance.
15. The direct purchase of private policies through insurance companies does not appear to be a viable approach to reducing the uninsured in Illinois.
16. Awareness continues to be a major challenge for government-sponsored programs. For KidCare, in addition to more aggressive and innovative outreach, the state of Illinois may wish to consider further streamlining of application processes by reducing the amount documentation needed.
17. Apart from lack of awareness, cost was cited as a barrier to I-CHIP.

Appendix A - Counties per Regions

Northwestern Region 1	Central Region 2	Southern Region 3	Cook County Region 4	Collar Counties Region 5
Boone	Adams	Alexander	Cook	DuPage
Bureau	Brown	Bond		Grundy
Carroll	Calhoun	Clay		Kane
DeKalb	Cass	Clinton		Kankakee
Fulton	Champaign	Crawford		Kendall
Henderson	Christian	Edwards		Lake
Henry	Clark	Effingham		McHenry
JoDaviess	Coles	Fayette		Will
Knox	Cumberland	Franklin		
LaSalle	DeWitt	Gallatin		
Lee	Douglas	Hamilton		
Marshall	Edgar	Hardin		
Mercer	Ford	Jackson		
Ogle	Greene	Jasper		
Peoria	Hancock	Jefferson		
Putnam	Iroquois	Johnson		
Rock Island	Jersey	Lawrence		
Stark	Livingston	Madison		
Stephenson	Logan	Marion		
Tazewell	Macon	Massac		
Warren	Macoupin	Monroe		
Whiteside	Mason	Perry		
Winnebago	McDonough	Pope		
Woodford	McLean	Pulaski		
	Menard	Randolph		
	Montgomery	Richland		
	Morgan	Saline		
	Moultrie	St. Clair		
	Piatt	Union		
	Pike	Wabash		
	Sangamon	Washington		
	Schuyler	Wayne		
	Scott	White		
	Shelby	Williamson		

Vermillion

Appendix B - Disposition Codes

(01) Completed interview (English)	Complete phone interview with eligible English-speaking respondent.
(02) Completed interview (Spanish)	Complete phone interview with eligible Spanish-speaking respondent.
(03) Partial Complete Interview (English)	Partially completed interview in English.
(04) Partial Complete Interview (Spanish)	Partially completed interview in Spanish.
(30) No answer	Used for telephone numbers that have never answered or that always ring busy. This disposition is not used once someone has answered the phone, or an answering device has been reached.
(31) Answering machine/answering service	Used for answering devices or answering services.
(32) Eligible R not available	Used once the respondent has been screened.
(33) Unscreened R not available	Used when someone has answered the telephone, but screening to ascertain the eligible or appropriate respondent has not yet been completed.
(40) Final refusal to screener	Respondent refused to complete the screener.
(41) Final refused interview: English	The eligible English-speaking respondent refused to be interviewed or to complete interview.
(42) Final refused interview: Spanish	The eligible Spanish-speaking respondent refused to be interviewed or to complete interview.
(47) Final refusal, unscreened – PM	Household had a telephone Privacy Manager service and it requested that we remove the number from our list. We consider these households unscreened.
(55) Not able to interview during survey period	Used when there is a clear indication that the respondent cannot participate within the time confines of the study/wave.
(56) Never able to interview	Used when there is a clear indication that the respondent cannot participate in the study. It is not related to the time frame of the data collection effort.
(70) Ineligible, no one 18 or older	There is no one currently living in the household who is 18 years or older.
(71) Ineligible, respondent is insured	The respondent is ineligible because s/he is insured.

(85) Deceased	The respondent selected after screening died by the time we called back to complete the interview.
(86) Non-working	The phone number given is a non-working number.
(87) Nonresidential	Phone number reached was a nonresidence.
(88) Ineligible foreign language	Used if the respondent speaks a language other than English or Spanish.

Appendix C - Completion Rates

Total Sample - the total number of phone numbers called for the study

Non-duplicate numbers – the total number of phone numbers that are not duplicated in the sample

Working numbers - the number of phone numbers that were working phone numbers

Residential - the number of phone numbers that were households, not businesses

Contact to screener - the total number of respondents who were contacted for the screener

Cooperation to screener - the total number of respondents who completed the screener

Eligible - the number of respondents who fit the eligibility criteria

Contact to final - the total number of respondents who were contacted for an interview

Cooperation to final - the total number of respondents who completed an interview

Appendix E

TABLES

Table 1. Insurance Status by Income as Expressed as a percentage of the Federal Poverty Level (Population Weighted)

Poverty Level	Newly Insured		Uninsured	
	Number (95% CI)	percentage	Number (95% CI)	percentage
< 45%	4993 (2784, 7201)	11.30%	14915 (11009, 18820)	20.10%
Between 45% and 100%	9440 (6846, 12035)	21.37%	23650 (19163, 28138)	31.87%
Between 100% and 185%	12097 (8672, 15521)	27.38%	18538 (14496, 22580)	24.98%
Between 185% and 250%	7718 (5184, 10252)	17.47%	8781 (5355, 12206)	11.83%
Between 250% and 300%	2758 (1026, 4490)	6.24%	1329 (435, 2224)	1.79%
Between 300% and 350%	2043 (519, 3567)	4.63%	1989 (412, 3565)	2.68%
Between 350% and 400%	1829 (249, 3409)	4.14%	130 (0, 385)	0.18%
> 400%	3299 (1401, 5198)	7.47%	4870 (1994, 7747)	6.56%

Table 2. Insurance Status by Age (Population Weighted)

Age group	Newly Insured		Uninsured	
	Number (95% CI)	Percentage	Number (95% CI)	Percentage
18-24	6450 (3964, 8935)	13.11%	6525 (4244, 8807)	8.43%
25-34	14143 (10390, 17896)	28.75%	22441 (17688, 27194)	28.99%
35-44	11795 (8898, 14692)	23.98%	18067 (13929, 22204)	23.34%
45-64	12811 (9315, 16307)	26.04%	27947 (22682, 33212)	36.10%
65 and older	3990 (1668, 6313)	8.11%	2442 (558, 4325)	3.15%

Table 3. Insurance Status by Gender (Population Weighted)

Gender	Newly Insured		Uninsured	
	Number (95% CI)	Percentage	Number (95% CI)	Percentage
Male	22217 (17525, 26908)	36.90%	34101 (28523, 39678)	35.70%
Female	37983 (31753, 44213)	63.10%	61421 (53538, 69304)	64.30%

Table 4. Insurance Status by Family Composition: Single-Person vs. Multi-person family (Population Weighted)

Family Composition	Newly Insured		Uninsured	
	Number (95% CI)	**Percentage**	**Number (95% CI)**	**Percentage**
Single person household	15716 (11097, 20335)	31.87%	27045 (20938, 33153)	34.68%
Multiple member household	33600 (28990, 38211)	68.13%	50947 (45308, 56587)	65.32%

Table 5. Insurance Status by Race and Ethnicity (Population Weighted)

Race/Ethnicity	Newly Insured		Uninsured	
	Number (95% CI)	percentage	Number (95% CI)	percentage
Latino/Hispanic	8165 (5191, 11139)	18.68%	15459 (11502, 19416)	21.17%
Non-Hispanic White	28838 (24500, 33176)	65.97%	41416 (36600, 46232)	56.71%
African American	6711 (3659, 9763)	15.35%	16160 (10816, 21504)	22.12%

Table 6. Insurance Status by Citizenship Status (Population Weighted)

Citizenship	Newly Insured		Uninsured	
	Number (95% CI)	Percentage	Number (95% CI)	Percentage
Citizen	44810 (38830, 50789)	90.03%	67113 (59887, 74339)	85.87%
Non-citizen	4965 (2692, 7237)	9.97%	11042 (7723, 14361)	14.13%

Table 7. Insurance Status by Geographic Region (Population Weighted)

Region	Newly Insured		Uninsured	
	Number (95% CI)	Percentage	Number (95% CI)	Percentage
Northwest	6562 (4863, 8262)	10.90%	12255 (10021, 14490)	12.83%
Central	6035 (4563, 7505)	10.03%	10492 (8607, 12376)	10.98%
Southern	6014 (4549, 7480)	9.99%	11647 (9566, 13728)	12.19%
Cook	30369 (23430, 37307)	50.45%	46754 (37843, 55666)	48.95%
Collar	11219 (8273, 14166)	18.64%	14373 (11233, 17513)	15.05%

Table 8. Insurance Status by Employment Status and Tenure (Population Weighted)

Employment Status & Tenure	Newly Insured		Uninsured	
	Number (95% CI)	percentage	Number (95% CI)	percentage
Currently employed	45337 (38791, 51884)	75.48%	61235 (53593, 68877)	64.32%
Same Employer over one year	18532 (14391, 22673)	46.69%	30661 (25183, 36139)	62.18%

Table 9. Insurance Status by Employer Size (Population Weighted)

Employer's size	Newly Insured		Uninsured	
	Number (95% CI)	percentage	Number (95% CI)	percentage
1-50	19455 (14388, 22522)	46.42%	28927 (23509, 34345)	60.89%
Over 50	21298 (16618, 25979)	53.58%	18579 (13998, 23160)	39.11%

Table 10. Insurance Status by Industry (Population Weighted)

Industry	Newly Insured		Uninsured	
	Number (95% CI)	Percentage	Number (95% CI)	percentage
Agriculture	488 (0, 983)	0.81%	525 (37, 1014)	0.55%
Construction	1190 (244, 2136)	1.98%	2614 (1453, 3774)	2.74%
Manufacturing	5478 (3169, 7788)	9.10%	6261 (3546, 8975)	6.55%
Trade	5746 (3465, 8027)	9.55%	18134 (13493, 22775)	18.98%
Services	36634 (30603, 42664)	60.85%	59634 (52143, 67124)	62.43%
Other	10664 (6855, 14474)	17.72%	8354 (5111, 11597)	8.75%

Table 11. Insurance Status by Occupation (Population Weighted)

Occupation	Newly Insured		Uninsured	
	Number (95% CI)	percentage	Number (95% CI)	percentage
Managers, Professionals, Technical	15714 (11576, 19851)	34.87%	10462 (6833, 14092)	17.43%
Sales	4372 (2144, 6600)	9.70%	7609 (4631, 10587)	12.67%
Administrative support	7073 (4108, 10038)	15.70%	10538 (6587, 14490)	17.55%
Services	9166 (5955, 12376)	20.34%	15842 (11855, 19829)	26.39%
Farmers, Fishermen	358 (0, 783)	0.79%	996 (315, 1678)	1.66%
Precision products, Operators, Transportation	8379 (5717, 11040)	18.59%	14586 (10743, 18429)	24.30%

Table 12. Reasons for declining Employment Sponsored Coverage (Population Weighted)

Reasons people don't have employer's plan	Uninsured	
	Number (95% CI)	percentage
Not worth the cost of the premium and co-pay	7880 (5613, 10147)	30.71%
Can not find a good doctor who accepts the plan	2843 (885, 4801)	11.10%
Have a pre-exist illness or disability	1625 (539, 2710)	6.41%
Employer does not offer high quality plan	4620 (2168, 7071)	18.76%
Can not use the doctor through the plan	4070 (1894, 6245)	16.78%
Do not need health insurance	2847 (903, 4791)	11.20%
Have not worked long enough to get coverage	7304 (4501, 10106)	29.23%
Can not afford the premium	13658 (10655, 16630)	55.31%
Other reasons	7264 (4319, 10210)	30.85%

Table 13. Percent Willing to Pay for Coverage by Amount and Type of Coverage (Uninsured Only)

Amount	Individual	Family
$100	66%	NA
$150	54%	NA
$200	43%	NA
$250	34%	43%
$300	NA	43%
$350	NA	36%
$400	NA	31%

Table 14. Insurance Status by Time without Coverage (Population Weighted)

Time without coverage	Newly Insured		Uninsured	
	Number (95% CI)	percentage	Number (95% CI)	percentage
Less than 6 months	28827 (23453, 34202)	49.34%	24231 (18825, 29638)	25.65%
6 - 12 months	611 (0, 1809)	1.05%	10482 (6678, 14286)	11.10%
12 - 24 months	12483 (8988, 15978)	21.37%	13971 (9833, 18109)	14.79%
24 - 60 months	6908 (3998, 9819)	11.82%	14974 (11157, 18791)	15.85%
Over 60 months	9595 (6272, 12918	16.42%	25455 936182)	32.62%

Table 15. Application and Outcome for Direct Purchase of Private Health Insurance (Population Weighted)

Direct Purchase	Newly Insured		Uninsured	
	Number (95% CI)	percentage	Number (95% CI)	percentage
Ever applied for health insurance directly	5081 (3235, 6927)	16.59%	4317 (2105, 6530)	7.25%
Were able to get coverage (among those who applied)	1888 (865, 2912)	28.95%	108 (0, 268)	7.14%

APPENDIX E. Endnotes

1.State Health Access Data Assistance Center (June, 2001). State Health Insurance Coverage Estimates: Why State-Survey Estimates Differ from CPS. State Health Access Data Assistance Center Issue Briefs. URL: http://www.shadac.org/publications/pubs.htm.

2.Nelson, C.T., and Mills, R.J. (2001). The March CPS health insurance verification question and its effect on estimates of the uninsured. U.S. Bureau of the Census. URL: http://www.census.gov/hhes/hlthins/verif.html.

Health Insurance Coverage of Illinoisans: An Analysis of the Current Situation, Trends, and Correlated Health Behaviors Using BRFSS Data

A Report Submitted to the Illinois Department of Public Health

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I. Introduction

As public leaders and representatives of interested groups develop strategies for reducing the number of uninsured Illinoisans, the information system that monitors the extent of health insurance coverage in Illinois and the ways health insurance coverage influences health behaviors can play an important role. Up to date state-level information can assist policy makers in targeting initiatives and in evaluating initiatives. The Illinois Department of Public Health, through its Illinois Center for Health Statistics possesses a unique resource in Illinois for monitoring health insurance coverage and examining its impacts on utilization and health behaviors. Its Behavioral Risk Factor Surveillance System (BRFSS) fields a comprehensive survey of Illinois individuals to learn about health behaviors (including health insurance coverage) of Illinoisans. The Illinois BRFSS operates with the combined support of both the Federal and State governments. Using the BRFSS data, this report addresses the questions of the number of uninsured Illinoisans currently, as well as the changes in health insurance coverage over the past decade.

The Health Resources and Services Administration (HRSA) State Planning Grant in support of the Illinois Assembly process has allowed for the expansion of the BRFSS and the development of a trend analysis and a report on the current level of health care coverage in Illinois. To that end, additional questions regarding a person's industry of employment were posed to respondents beginning in December 2000. While the focus of the BRFSS is on individuals and their health behaviors related to major causes of disease and death, the introduction of the industry of employment question begins to allow the consideration of health insurance coverage in terms of a system and as part of a labor market process. This is critical if the information is to

be used to assist in policy development, since health insurance coverage in the United States is directly related to employment for working-age people.

This report uses the following outline. Section II gives an overview of the BRFSS data and variables employed in this analysis. In addition, the analytic methods are described. Next is an analysis of the trends in health insurance coverage over the period 1991 through 2000. Section IV reports on the current level of the lack of health care coverage in Illinois along with an analysis of variables related to being uninsured. It also describes the differences between people without health insurance and people with health insurance. Section V lays out recommendations for variables to be included in future BRFSS efforts, and it suggests strategies for public health leaders in Illinois to further the development and dissemination of information related to health insurance coverage.

II. Data and Methods

The BRFSS provides Illinois public health officials and public policy makers with an ongoing source of monitoring information about health insurance coverage of Illinois residents and related demographic and health variables. The BRFSS is a telephone survey of adults (non-institutionalized) and it relies on self-reported answers to questions such as "Do you have a health plan?" As observers and users of such public health survey research should note, estimates of health insurance coverage differ across surveys (such as the BRFSS and the Current Population Survey) for a number of reasons, including slightly different wording of survey questions, slightly different sampling frames, different follow-up questions and probes, and in some cases, the use of imputation methods. While differences between estimates of the BRFSS

and other surveys should be noted, the BRFSS has a number of advantages for state-level monitoring of health insurance coverage. Those advantages include its design as a state-level public health monitoring tool, its ongoing nature and ability to produce trend data for the state, its ability to gather information not only about health insurance coverage, but also some measures of health care utilization and measures of many health behaviors. While the BRFSS cannot answer every question about health insurance coverage in Illinois that analysts may think of, it does address the primary monitoring issues very well and, through the HRSA Planning Grant has been enhanced to add more detail on the employment and occupations of individuals.

II.A Overview of the Data

In all, there are 22,054 observations for the *Health Plan* variable from adults ages 18-64 over the time period 1991 through 2000. The number of observations per year has increased as the Illinois BRFSS increased its scope. For 1991, 1554 observations on *Health Plan* are available for adults in the 18 to 64 year age range. By 1995 the number of observations had increased to 2337, and, in the year 2000, the number of observations increased to 3411. These differences in sample size necessarily mean that the precision of estimates for the earlier part of the decade is less than the precision of estimates from the later part of the decade.

To measure whether or not changes in health screening behaviors occurred over the 1991 through 2000 period, the variable *Mammogram, Clinical Breast Exam, Pap Smear*, and *Cholesterol* are examined. *Mammogram* (asked to women 40 years and older) is a dichotomous variable that indicates if a woman has had a mammogram or not. Similarly, *Clinical Breast Exam* indicates whether or not a woman has had a clinical breast exam. *Pap Smear* shows

whether or not a woman has had a pap smear taken. The screening variable *Cholesterol* indicates whether or not a person has had their cholesterol level checked.

Along with the link between an individual's health insurance coverage and health screening exams, another relationship of interest is that of health care utilization and health insurance coverage. To measure health care utilization, two BRFSS variables are examined. *Medcost* tells whether or not an individual avoided seeing the doctor because of cost. *Checkup* indicates when a person's last routine checkup was, with a range of answers possible (eg. within the past year, within two years, etc.).

The Enhanced BRFSS that began to gather information in December of 2000 included two additional variables related to health insurance coverage. The first, *Employer*, indicates the type of employer a person has if they are currently employed. The categories for this variable are: Federal Government, State Government, Local Government, Private Sector, Not-for-Profit, and Other. The second new variable is *Occupation*, which has the following thirteen categories: Management, Business, and Finance; Technical, Computer, Engineering and Social Science; Social Service, Legal, and Education; Health Care Support and Personal Care; Construction, Maintenance, Production, and Transport; Arts, Design, Media, and Sports; Healthcare Practitioners; Protective Service; Food Service; Building Maintenance and Cleaning; Sales; Office Support; and, Agriculture, Fishing, and Forestry. These two new variables expand the BRFSS's capability to help target program and policies (including experimental initiatives) that are aimed at reducing the levels of uninsuredness in Illinois. In addition, these new variables should prove useful for program and policy evaluation in the future.

II.B Methods

Since the purpose of the BRFSS is to monitor behavioral health measures at the state level, a sampling strategy that employs stratification and weighting is employed. Therefore, to produce unbiased estimates of health insurance coverage for the Illinois population, the analysis must take into account the weighting structure and the survey structure. For this analysis, Stata software was used. Stata's survey estimation routines account for the differential weighting of observations and the survey design found in the BRFSS data.

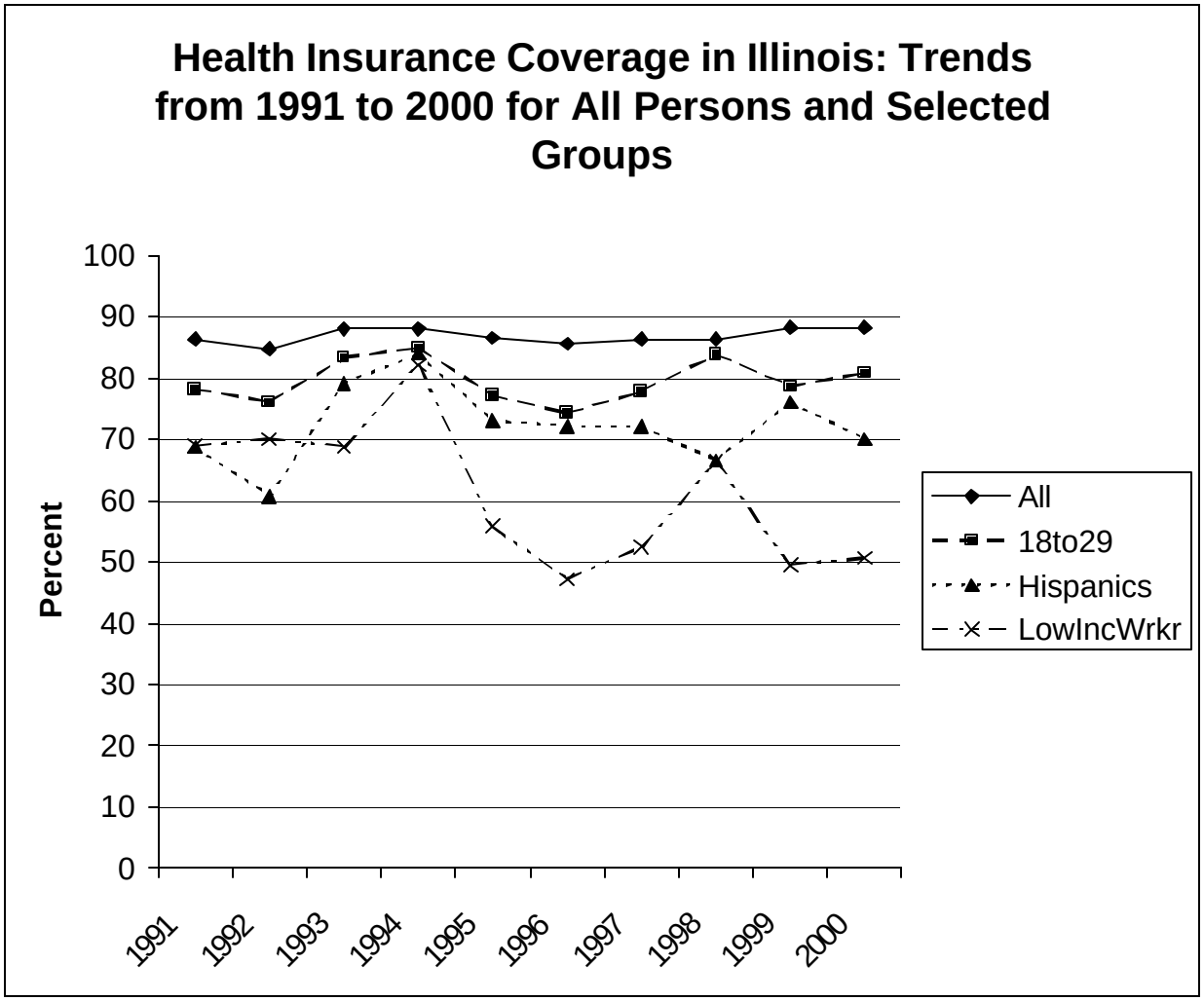
Descriptive statistics are used to answer most of the questions that are the focus of this report. Estimates of the proportion of Illinoisans with (or without) health insurance coverage of different population subgroups are the primary example of this sort of descriptive statistic. To look at changes in health insurance coverage trends, a breakpoint analysis is employed. This divides the decade into two parts (1991-1995 and 1996-2000) and descriptive statistics are estimated for each half of the decade. Then tests to determine whether or not the estimated statistics are significantly different at the 95 percent confidence level are performed. A third type of analysis is employed in the study to account for potential confounding variables that make descriptive statistics less useful as measures of association. To account for multiple confounding variables (such as income, sex, age, race, ethnicity, and urban or rural residence) a regression analysis approach is used (a probit regression estimated with survey weights). This allows the determination of the distinct contribution of a particular demographic variable, such as a low-income level, to the probability that a given Illinois resident would be without health insurance coverage.

III.Trend Analysis: 1991 Through 2000

III.A Graphical Analysis of Trends

Health insurance coverage for all persons (ages 18-64) changed little over the period 1991 through 2000. As Figure 1 shows, the level of health insurance coverage for Illinoisans over that period varied between a low of 84.7 percent in 1992 to a high of 88.6 percent in 2000.

Figure 1



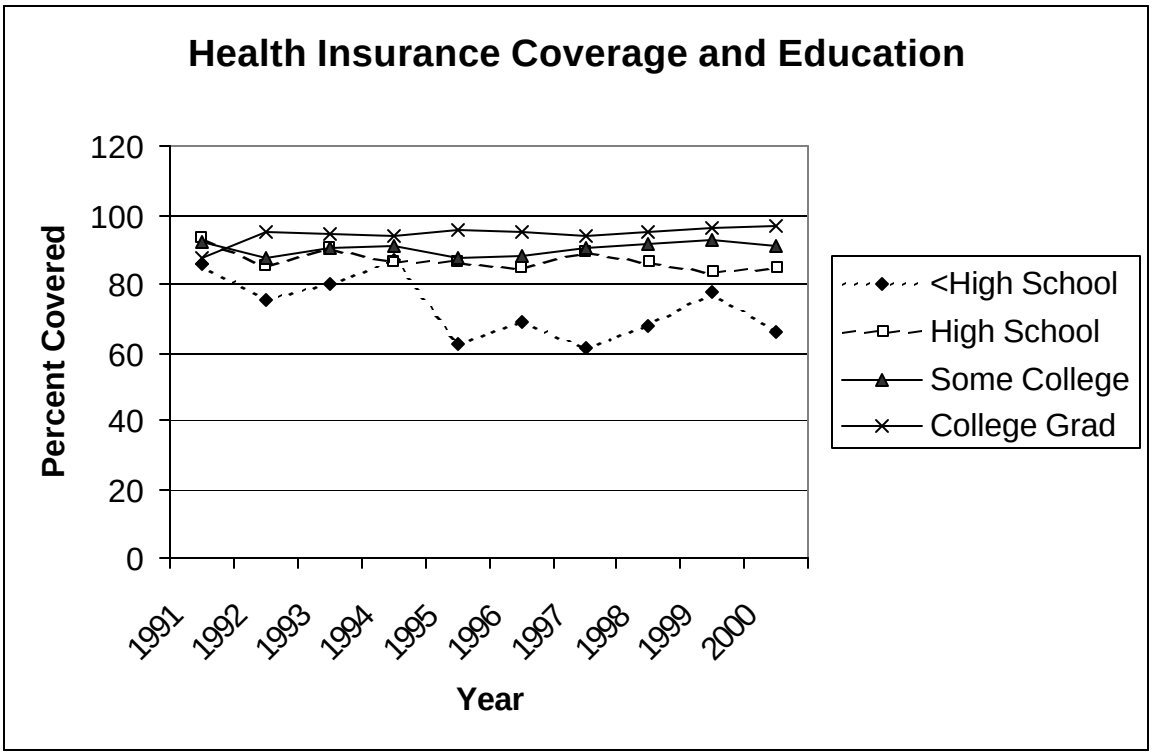
From the point of view of uninsured people, the levels of uninsuredness varied between a high of 15.3 percent in 1992 to a low of 11.4 percent in the year 2000.

The Illinois Assembly identified a number of groups of special interest, and trends for three of these groups are shown in Figure 1. The three groups are Young Adults (18-29 years old), Hispanics, and Low-Income Workers. From the graph it is apparent that a general ordering exists across the three groups that holds fairly constant across the decade. (In comparing these groups, readers should remember that the groups are not mutually exclusive.) A general pattern of health insurance coverage, from highest to lowest holds, with 18 to 29 year olds holding the highest place, and low-income workers having the lowest level. For all of the decade, 18 to 29 year olds have the highest level of health insurance coverage of the three groups. The high for the young adults was in 1994 when 85 percent were covered with health insurance at a given point in time. The lowest level of coverage for 18 to 29 years old during the 1991 to 2000 period came in 1996 when 74.3 percent had coverage.

Health insurance coverage for Hispanics is estimated to range from a low of 60.8 percent in 1992 to a high of 84.0 percent in 1994. However, with the smaller sample sizes in the early 1990s, the estimated standard errors (and resulting confidence intervals around the estimates) are relatively large. Therefore, some of the extreme variation seen before 1995 in the annual estimates of the proportion of Illinois Hispanics having health insurance coverage may be due to chance and small numbers. After 1995 the number of Hispanics surveyed annually increased to between 200 and 300 per year. This increases the precision of estimates of health insurance coverage of Hispanics in the later part of the decade.

Of the three groups considered here, low-income workers (defined as those people in a household with an income below $15,000 per year and working) had the lowest estimated levels of health insurance coverage over the decade. The year with the lowest level of coverage is observed in 1996 (see Figure 1) when 47.2 percent of low-income workers held health insurance coverage. The highest level seen for the low-income workers was in 1994, when 82.1 percent of low-income workers were covered. An issue arises in the statistical analysis of these data over time with respect to the income variable, since income is reported in the BRFSS categorically, meaning that adjustments for changes in purchasing power cannot be undertaken. This categorical income variable leads to several statistical issues, including a reduction in sample size for this group in the later part of the decade (and lowered precision in estimates) and an

Figure 2. Health Insurance Coverage for Employed Persons By Education Level, 1991 to 2000



upward bias in the estimate of the proportion of low-income workers without health insurance coverage at the end of the decade relative to what the estimate would be if income were kept constant (adjusted for changes in the Consumer Price Index) over time.

While it may not be possible to ascertain with absolute certainty whether or not health insurance coverage declined for low-income workers, another piece of evidence related to this question comes from the change in coverage for workers with less than a high school education. The trend lines for health insurance coverage over the period 1991 to 2000 for working people by education level are shown in Figure 2. As might be expected, an ordering of health insurance coverage levels according to educational attainment holds in this graph. Workers with the least education have the lowest levels of health insurance coverage. On the other hand, workers with a college education or beyond have the highest levels of health insurance coverage. By visual inspection, it appears that workers with less than a high school education (the most likely workers to be low-wage earners) experienced a decline in health insurance coverage. This lends further support to the idea that low-income workers saw declines in their health insurance coverage over the decade of the 1990s in Illinois.

Overall, the trend graphs displayed in Figures 1 and 2 portray a picture of health insurance coverage remaining fairly constant for most people considered, but with evidence of declines for low-income workers and working people with less than a high school education. It is important to keep in mind that this relative constancy in health insurance coverage occurred over a period of robust economic activity and a very strong labor market. In the later half of the 1990s, Illinois experienced historically low levels of unemployment. If some groups experienced declines in

health insurance coverage during such good economic times, what slippage in coverage might be observed if the labor market and economy weakens significantly?

III.B Breakpoint Analysis of Changes in Coverage by Demographic Characteristics

Along with graphical analysis of trends, statistical tests can be employed to measure whether or not changes measured with survey data are, in fact, statistically significant. To test the significance of change in health insurance coverage associated with different demographic characteristics, observations were grouped by year into two sets (sub-samples), and summary statistics (proportion of a group insured, for example) are calculated. Data were grouped into a 1991-1995 set and a 1996-2000 set. Then hypothesis tests were constructed using the statistic and the estimate of the standard error or standard deviation. This method was employed to determine whether or not changes occurred and whether or not the observed changes were statistically significant at the 95 percent confidence level.

Table 1 provides estimates of the proportion of people covered across the two time periods (1991-1995 and 1996-2000) for groups based on age and income. The estimate of health insurance coverage for all adults shows a very slight decline over the period, but this decline is not statistically significant. Young adults (18-29 year olds) also experienced a decline in coverage over the period, and this decline was fairly large (about 5.5 percentage points). However, it too was not statistically significant at the 95 percent confidence level.

Working adults in households with incomes below $35,000 did experience a decline in health insurance coverage over the decade. In the 1991-1995 period 85.56 percent of these adults had

Table 1 Changes in Health Insurance Coverage Over the Periods 1991-1995 and 1996-2000 by Young Adult Status, Low-Income Working Person Status, Education, Geographic Region, and Race and Ethnicity Groups

Demographic Group	% Covered		Diff. Significant?
	91-95	96-00	
All Adults 18-64 Years of Age	87.96	87.02	No
18 to 29 Years of Age	84.79	79.26	No
Working Adults			
HH Income<$35,000	85.56	75.57	Yes
HH Income<$15,000	81.95	53.89	Yes
Working Adults, by Education			
Less than High School	86.87	67.69	Yes
High School	86.11	85.76	No
Some College or Tech. School	91.05	90.91	No
College Graduate	94.12	95.36	No
Geographic Region			
Chicago	81.72	79.79	No
Other Metropolitan Area	91.28	90.57	No
Rural Illinois	84.51	85.90	No
Race/Ethnicity (not mutually exclusive)			
White	89.41	88.12	No
Black	79.88	79.94	No
Hispanic	83.45	70.80	No

health insurance coverage, and that level declined to 75.57 percent in the later half of the decade. Similarly, working people in households with incomes less than $15,000 experienced a sharp decline in the proportion with health insurance over the decade. In the first half of the decade, 81.95 percent of these workers had health insurance coverage, but in the later half of the decade just 53.89 percent of these workers had health insurance coverage. The declines for both of these groups of low-income workers are statistically significant with 95 percent confidence. The only other group found with a statistically significant change in health insurance coverage over the sub-periods of the decade was working people with less than a high school education.

Trends for other groups, including working adults with at least a high school education, adults by geographic region of the state, and adults by Black and White race and Hispanic ethnicity are also reported in Table 1. Most of these groups experience very little change in their rates of health insurance coverage over the two periods. However, Hispanic Illinoisans did experience a decline in health insurance coverage from 83.45 percent in 1991-1995 to 70.80 percent in 1996-2000. However, this drop in coverage was not statistically significant.

Table 2 reports changes in coverage over the period by sex and marital status. Females experienced a decline in coverage over the period from 89.95 percent to 86.82 percent. On the other hand, males experienced a small increase in coverage from 85.93 percent to 87.29 percent. With respect to marital status, most categories experienced small changes but persons with an unmarried couple saw a sharp drop in their health insurance coverage, but with fairly large estimated standard errors, the drop is not statistically significant at conventional levels of significance.

Table 2 Change in Coverage by Sex and Marital Status

Demographic Group	% Covered		Diff. Significant?
	91-95	96-00	
Sex			
Female	89.95	86.82	No
Male	85.93	87.29	No
Marital Status			
Married	93.42	91.73	No
Divorced	81.46	80.97	No
Widowed	87.37	78.25	No
Separated	82.02	78.91	No
Never Married	78.97	80.19	No
Unmarried Couple	89.79	75.49	No

In summary, in this section of the report changes in health insurance coverage were reviewed for different demographic groups in Illinois over the period 1991 to 2000. For most demographic groups small changes in the level of health insurance coverage were observed. However, for low-income workers and workers with less than a high school education, the proportion of people in these groups with health insurance coverage declined over the decade. These declines are not only significant in a statistical sense, but they also are large in magnitude.

III.C Changes in health screening behaviors among uninsured Illinois residents

Figure 3. Mammogram Screening Exam Use and Health Insurance Coverage

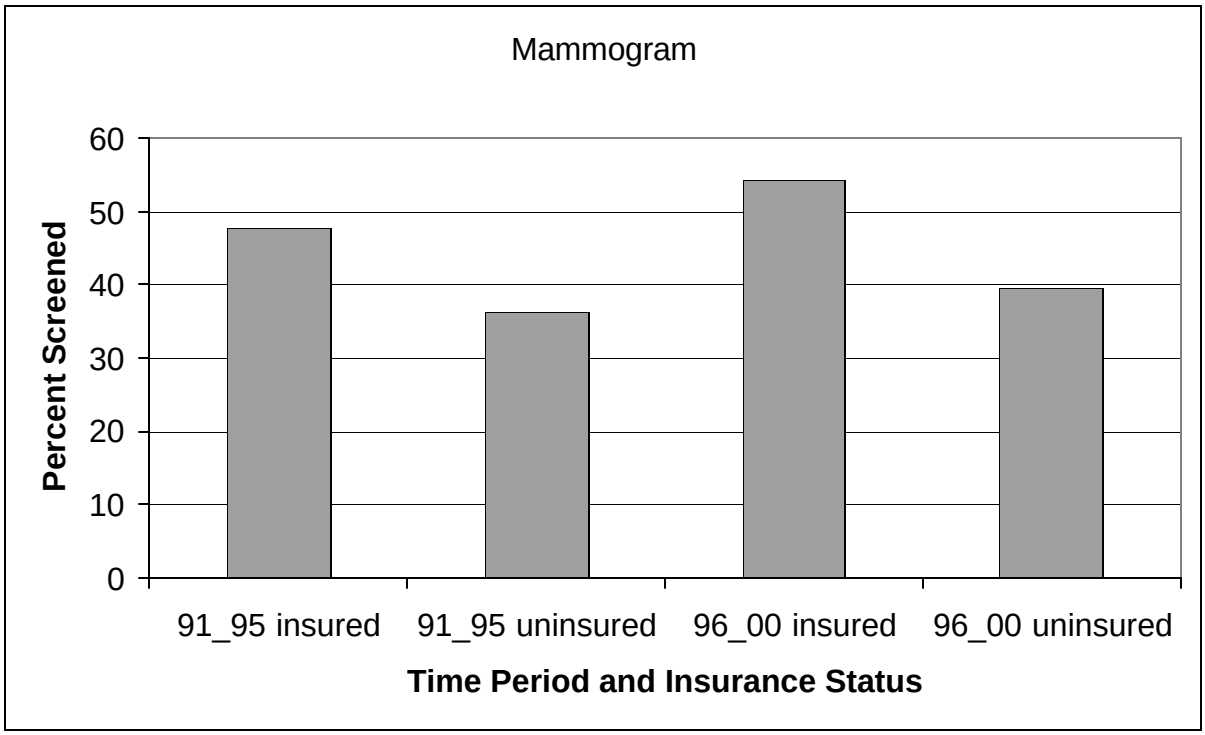


Figure 4. Clinical Breast Exam Use and Health Insurance Coverage Overtime

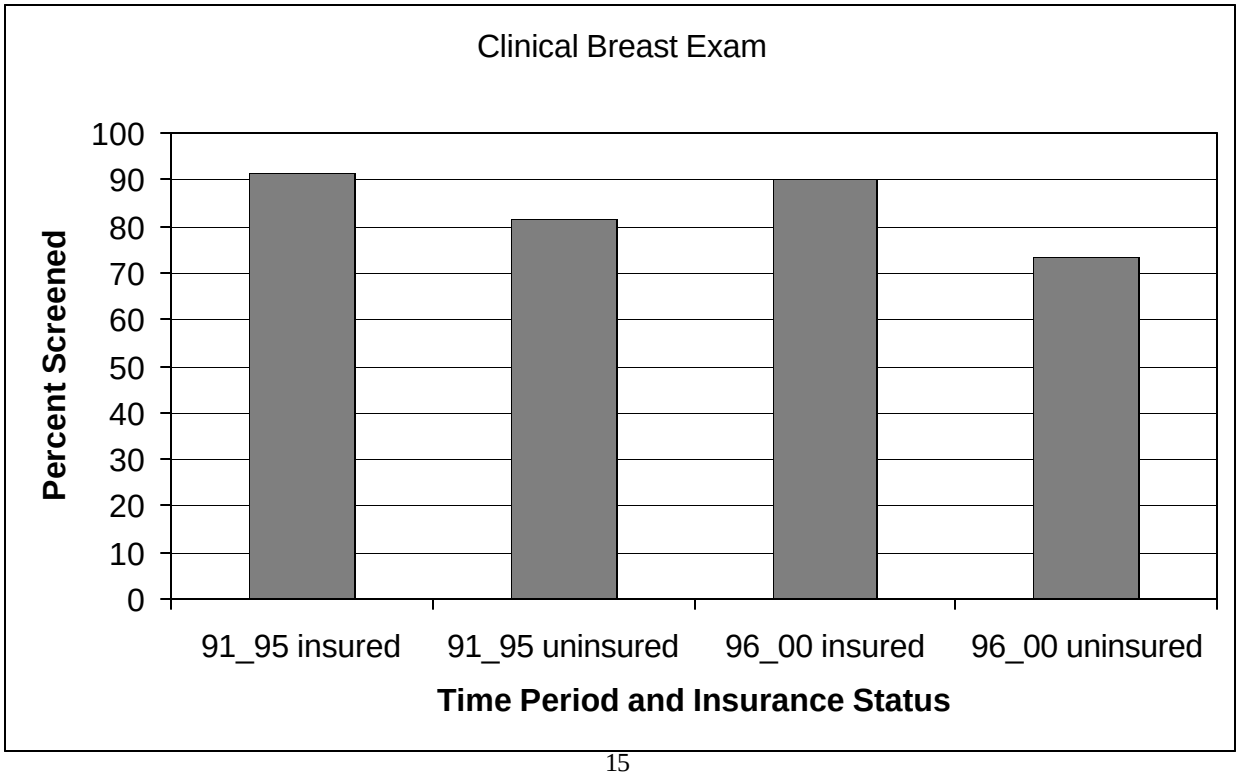


Figure 5 Pap Smear Exam Use and Health Insurance Coverage

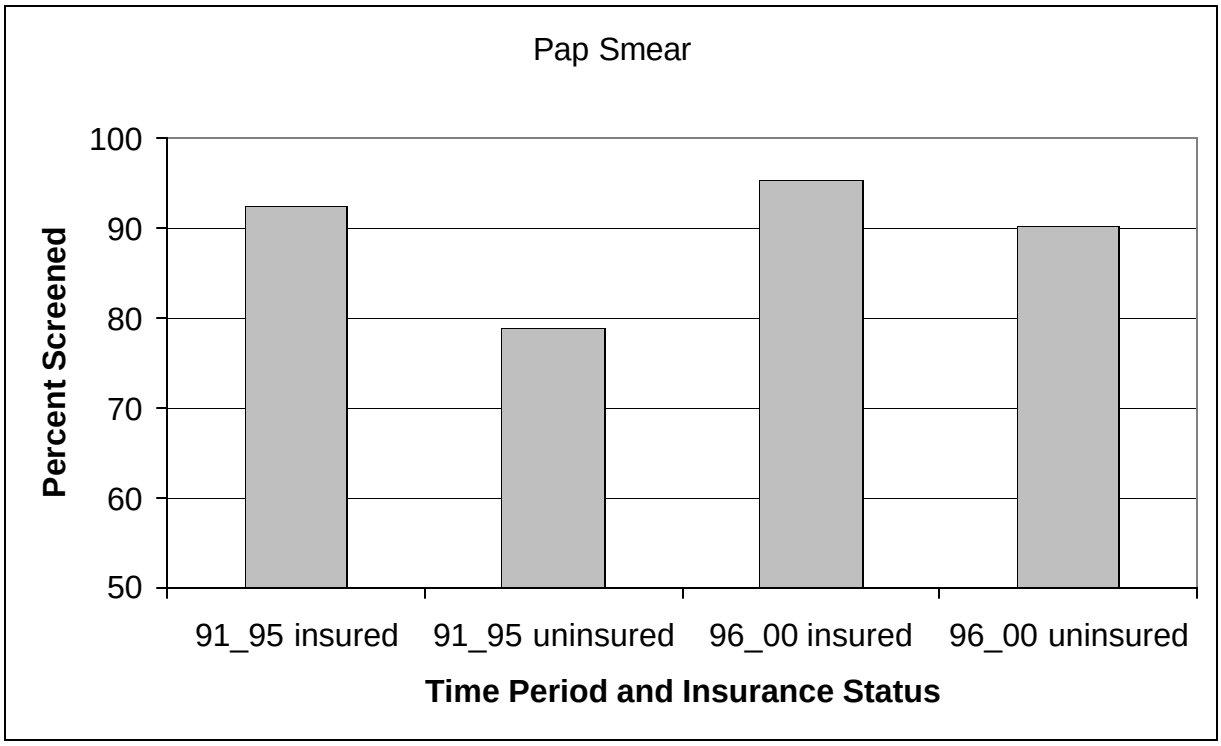
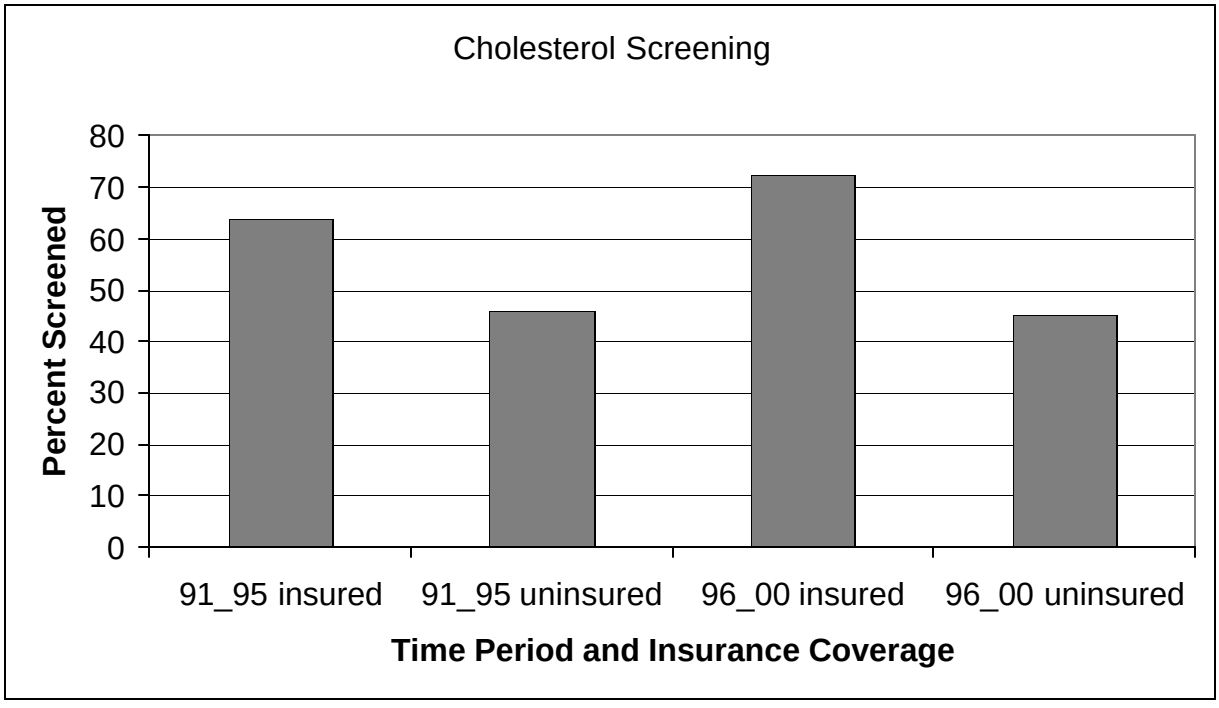


Figure 6 Cholesterol Screening and Health Insurance Coverage



Health insurance coverage is of concern to public health policy makers and advocates because having health insurance is a critical factor in whether or not a person has access to high quality health care. To examine the link between insurance coverage and screening exams, Figures 3 through 6 present graphs depicting the use of screening exams by uninsured people and insured people over the periods 1991-1995 and 1996-2000. Along with documenting the connection between health insurance coverage and screening exam use, these figures allow us to examine whether the connection between health insurance coverage and screening use has changed over the past decade.

Taking the screening exam use graphs as a group, it is readily apparent that uninsured people are less likely to have had any one of the four screening exams when compared with people with health insurance. The difference ranges between from around 10 percentage points to more than 25 percentage points (cholesterol screening exams in the 1996-2000 time period). In addition, there also appears to be an increase in the overall level of use of screening exams, with use increasing for each exam whether or not a person is uninsured. The exceptions to that trend are the clinical breast exam for both insured and uninsured people (a decline in use among uninsured persons) and cholesterol screening exams for uninsured people. However, while increases occurred for screening exams, the size of the increase differed across insured people and uninsured people. In the case of mammogram screening exams (women aged 40 and older), insured women increased their use rate from about 47 percent to about 54 percent. Uninsured women on the other hand, only increased their use rate from about 36 percent to almost 40 percent. In contrast, the increase in pap smear exam use was dramatic for uninsured women across the two time periods. The increase for these women was from below 80 percent having

had a pap smear exam in the first half of the decade to over 90 percent having had an exam by the later half of the decade. This slightly mixed picture makes conclusions about changes in the use of screening exams by uninsured people over the past decade include difficult to make. However, it appears to be the case that in the face of overall increases in the level of screening exam use (mammograms and cholesterol screening exams, for example) uninsured people are less likely to respond to the same degree to whatever public health and medical messages insured people are hearing.

III.D Utilization and Access to Care for the Uninsured

To examine whether changes occurred over the past decade in the relationship between uninsuredness and the use of health care services, the role of medical care costs and visits to a primary care physician were examined. *MEDCOST* is a BRFSS variable that measures if a person avoided seeing a doctor because of the cost. *CHECKUP* asks an individual when he or she last had a routine checkup.

The BRFSS data from the period show a strong association between having health insurance coverage and utilization of primary care services, as measured by *CHECKUP* and *MEDCOST*. In the first half of the decade (1991-1995), 35.5% of uninsured people stated that they avoided the doctor because of cost. Only 6.9% of insured people reported avoiding the physician because of cost during the same time period. Based on these frequencies, uninsured people are about five times more likely than insured people to report cost as a barrier to seeking primary care services. In the second half of the decade, 32.3% of uninsured people reported avoiding the doctor because of costs. However, this percentage is not statistically different from the percentage in

the first half of the decade. Therefore, evidence exists that over the 1990s a slight decrease in cost as an access barrier for uninsured Illinoisans occurred, but the decrease is not statistically significant with 95% confidence.

Similarly, in the case of a person's last routine checkup the data show a large difference between the proportion of insured people having a checkup in the past year (70.1% over 1991 to 2000) and the proportion of uninsured (51.0% over 1991 to 2000) who report a checkup in the past year. While this difference between the insured and uninsured and the timing of last routine checkup exists, no evidence exists that the percentage of uninsured people putting off obtaining a routine checkup has increased. In the first half of the decade 50.9% of uninsured people reported having a routine checkup within the past year. In the later half of the decade that percentage was virtually unchanged at 51.8%. To sum up, the evidence from the BRFSS variable *MEDCOST* and *CHECKUP* show that while significant differences in utilization for insured and uninsured Illinoisans exist, there is no statistically significant evidence from this data demonstrating a decrease in utilization for uninsured people.

This section has reviewed trends in health care insurance coverage for people in Illinois, and it has examined changes in health screening exam use and changes in utilization for uninsured people over the past decade. The main findings are that, while most groups did not experience significant changes in their rates of health insurance coverage over the period, low-income working people (including working people with less than a high school education) experienced significant declines in the proportion of people in the group with health insurance.

IV. Analysis of Enhanced BRFSS data

The Enhanced BRFSS data was collected over the period December 1, 2000 through May 30, 2001. The Enhancement refers to additional questions that were posed to respondents about their industry of employment and job type. The Enhanced BRFSS data analyzed here covers 1602 complete responses by adults (aged 18 through 64) to the question on coverage of a health plan. Overall, the Illinois BRFSS data show that an estimated 9.8% of adults aged 18 to 64 years of age were without health insurance coverage in the December 2000 through May 2001 time period.

IV.A Demographic Differences Between Insured and Uninsured Illinoisans

As Table 3 illustrates, people with health insurance differ markedly from people without health insurance at the current time in Illinois. Table 3 reports the composition of two groups, people with health insurance and people without health insurance, by a variety of demographic characteristics. Strong differences in the composition of the two groups appear immediately from an examination of Table 3. First, the uninsured are more likely to be young adults, with 39.4 percent of the uninsured falling in the 18 to 29 year age group. The insured group is more heavily weighted with adults aged 30 to 64 years (74.2 percent), compared to 60.6 percent of people in the uninsured group. Second, the uninsured are much more likely to be in a low-income household. More than 75 percent of uninsured Illinoisans live in households with an annual income below $35,000, while only about 23.4 percent of insured people live in households with incomes below $35,000. Third, uninsured Illinoisans are disproportionately people of color, with 32.2 percent of uninsured people in the non-white category, while only 16.3 percent of insured people belong to the non-white category.

Table 3 Comparison of Demographic Characteristics Between Uninsured and Insured Illinoisans, December 2000 – May 2001

Demographic Characteristic or Population Group	Uninsured (%)	Insured (%)
All Adults (18-64 Years of Age)		
Young Adults (18-29 Years)	39.4	25.8
Adults Aged 30-64 Years	60.6	74.2
Income Groups		
Income Less than $15,000	23.4	4.1
Income $15,000 to $35,000	53.2	19.3
Income $35,000 to $50,000	10.8	20.0
Income $50,000 and Above	12.6	56.6
Race		
White	67.8	83.7
Non-White	32.2	16.3
Sex		
Female	55.3	50.3
Male	44.7	49.7
Geographic Region		
Chicago	35.8	17.2
Other Metro (Collar Counties, Downstate Metro)	46.5	63.0
Rural	17.6	19.8

Source: Illinois BRFSS December 2000--May 2001 Enhanced Survey

At the current time in Illinois the uninsured also are more likely to be female than male, with 55.3 percent of uninsured people being female. Lastly, there is a strong geographic pattern of uninsuredness in Illinois, with uninsured people living in Chicago with a disproportionate frequency compared to their presence in the insured category. Chicagoans comprise 35.8 percent of uninsured Illinoisans, while only 17.2 percent of insured Illinoisans live in the City of Chicago.

Table 4 Percentage Uninsured By Demographic Characteristic, Illinois, December 2000 through May 2001

Population Group	Percentage Uninsured
All Adults (18-64 Years of Age)	9.8
Young Adults (18-29 Years)	14.2
Adults Aged 30-64 Years	8.1
Income Groups	
Income Less than $15,000	36.7
Income $15,000 to $35,000	21.8
Income $35,000 to $50,000	5.1
Income $50,000 and Above	2.2
Race	
White	8.1
Non-White	17.6
Sex	
Female	10.6
Male	8.9
Geographic Region	
Chicago	18.4
Other Metro (Collar Counties, Downstate Metro)	7.4
Rural	8.8

While examining demographic composition of the uninsured versus the insured is important to understand relative frequency of lack of health insurance coverage by demographic characteristic, considering the percentage of different groups that are without health insurance helps to further quantify the issue. Table 4 reports on the percentage of people without health insurance for different demographic categories. While the overall rate of lack of health insurance is 9.8 percent for adults aged 18-64, more than 14 percent of young adults (18-29 years) are without health insurance coverage. The relationship between household income and lack of health insurance is seen in the percentage uninsured by income group. While 36.7 percent and 21.8 percent of people in households with incomes less than $15,000 and between $15,000 and $35,000, respectively, lack health insurance, only 2.2 percent of people in households with incomes about $50,000 lack health insurance.

Again, Table 4 shows the difference in lack of coverage across racial lines, with Non-Whites nearly 10 percentage points more likely to lack health insurance coverage than Whites. A difference in health insurance coverage by sex is also observed, with 10.6 percent of women without health insurance in the 18 to 64 year age group, compared to 8.9 percent of men. Lastly, while 18.4 percent of Chicagoans lack health insurance, a lower percentage of Other Metropolitan residents (Collar Counties and Downstate Metropolitan Areas) and Rural residents lack health insurance coverage.

IV.B Coverage By Employer and Occupation Type

Some significant differences in health insurance coverage exist across types of employers

Figure 7 Coverage by Type of Employer, December 2000 through May 2001

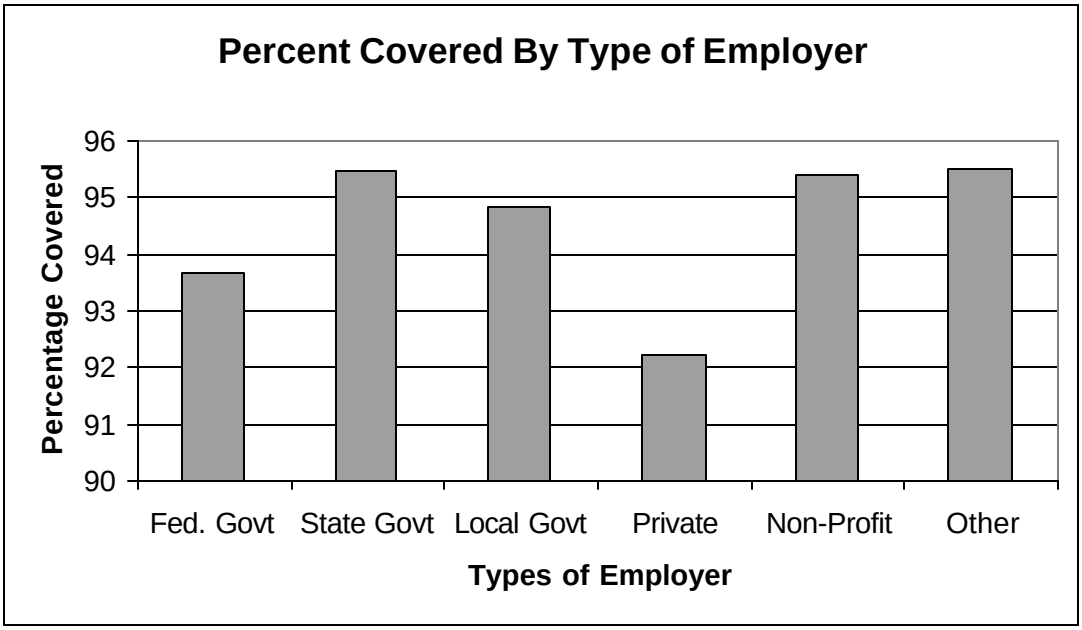


Table 5 Percentage Insured by Occupation Type, December 2000 – May 2001

Occupation Type	Insured (%)
Management, Business, Finance	99.1
Technical, Computer, Engineering, Science, Social Science	97.9
Social Service, Legal, Education	96.7
Health Care Support and Personal Care	85.1
Construction, Maintenance, Production, and Transport	88.1
Arts, Design, Media, and Sports	87.0
Heathcare Practitioners	94.5
Protective Service	97.7
Food Service	74.2
Building Maintenance and Cleaning	93.0
Sales	90.9
Office Support	95.6
Agriculture, Fishing, Forestry	Insufficient Data

Source: Illinois BRFSS December 2000--May 2001 Enhanced Survey

as Table 7 demonstrates. Of the six employer types, workers employed by the private sector and the federal government are more likely to be without health insurance than are employees of state and local governments and of the not-for-profit sector and other category employers.

Of all the occupation types examined (Table 5) Food Service workers have the lowest level of health insurance coverage (74.2 percent), with Health Care Support and Personal Care workers (85.1 percent) the next lowest. Two other groups that have less than 90 percent of workers with health insurance coverage are workers in the Arts, Design, Media, and Sports industries (87.0 percent) and workers in Construction, Maintenance, Production, and Transport areas (88.1 percent). The employed persons with the highest level of coverage work in the areas of Management, Business, and Finance (99.1 percent). This occupation information is new to the BRFSS and it allows the monitoring of coverage by occupation area, and it strongly suggests possibilities for targeting of any initiative that might be aimed at employers (food service, some home health agencies, etc.). This information would also be useful in developing outreach strategies if a public decision is made to expand Kidcare into a Familycare program.

Of course, it is important to remember that unemployed persons lack health insurance coverage with greater frequency than employed persons. In the December 2000 through May 2001, an estimated 19.8 percent of unemployed persons lacked health insurance coverage, compared to 6.7 percent of employed persons. This suggests that if the economy weakens significantly we will see a greater percentage of Illinoisans without health insurance coverage.

IV.C Coverage, Health Care Utilization, and Health Screens

Like the period 1991 to 2000, the Enhanced BRFSS data show a strong link between health insurance coverage in utilization. For people with a health plan (in the 18 to 64 year range), only 5.5 percent reported that they had avoided a doctor because of cost (*Medcost*). Meanwhile, 35.4 percent of uninsured people reported that they avoided the doctor because of concerns over the cost. This pattern is very similar to what was found over the 1991 to 2000 period. With respect to a person's last routine checkup (*Checkup*), this differential in utilization holds for health insurance coverage. About 70 percent of insured people had a routine checkup in the past year, as compared to 50.2 percent of uninsured people. Both of these differences between insured and uninsured people with respect to *Medcost* and *Checkup* hold up statistically at the 5 percent level.

Figure 7 Health Care Screening Exams By Coverage Status

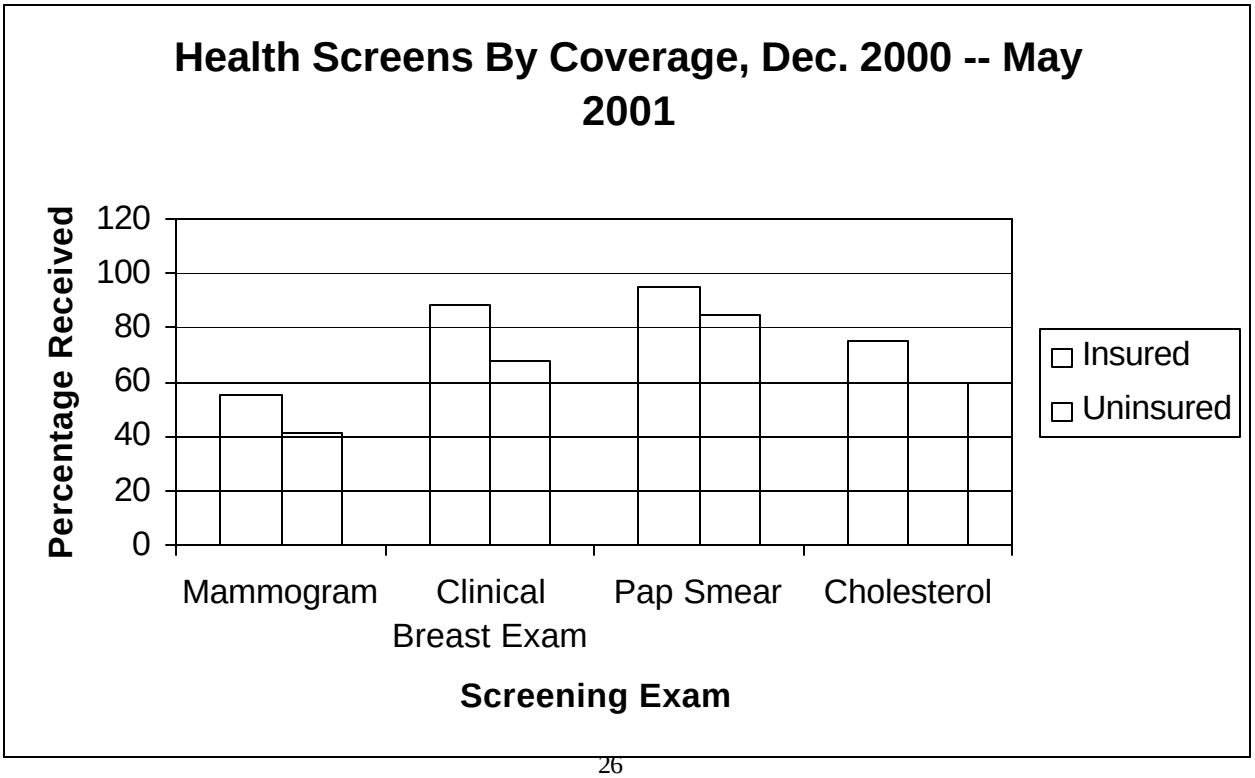


Figure 7 reports the most up to date information about how health-screening use relates to health insurance coverage in Illinois. For each of the screening exams portrayed, insured people were more likely to have had the screen than uninsured people, but only some of the differences in use are statistically significant. The clinical breast exam and cholesterol exam differences are significant at the 5 percent level. One reason that the other two women's health screening exam differences are not significant is that these differences are calculated with subsets of the overall Enhanced BRFSS, thereby reducing sample size and increasing the size of the estimated standard errors.

IV.F Multivariate Analysis of Factors Related to Health Insurance Coverage

A difficulty with simple descriptive statistics, such as those presented above, for the purpose of assessing the factors related to health insurance coverage is the problem of confounding variables. Demographic variables often are highly correlated (for instance, education and income), and while simple descriptive statistics can be standardized by other variables (age-adjustment for example), it is easy to think of another confounding variable the analyst might need to address. Multivariate regression is appropriate in this situation, and it provides estimates of the distinct correlation of an independent variable (income, age, race, geographic location in this analysis) with an outcome of interest. Here we are interested in the likelihood that a given individual has health insurance coverage, given a set of demographic and social variables.

The explanatory variables in the probit regression reported in Table 6 include Age (and a squared

Table 6 Probit Regression Estimates of the Effects of Demographic Variables on the Probability of Health Insurance Coverage for Illinoisans, December 2000 – May 2001

	Coefficient	Std. Error	t-statistic	p-value	dF/dx
AGE	-0.03017	0.03384	-0.89	0.373	-0.00310
SQAGE	0.00042	0.00041	1.02	0.307	0.00004
DINCOME<$15,000	-0.75439	0.31344	-2.41	0.016	-0.12911
DINCOME$15,000to$34,999	-1.11881	0.18847	-5.94	0.000	-0.18943
DINCOME$35,000to$49,999	-0.34075	0.19367	-1.76	0.079	-0.04170
DRURAL	0.08977	0.19554	0.46	0.646	0.00883
DCHICAGO	-0.26154	0.15336	-1.71	0.088	-0.03078
DWHITE	0.33089	0.13592	2.43	0.015	0.04053
DFEMALE	0.08823	0.13047	0.68	0.499	0.00907
DEMPLOYED	0.60474	0.16440	3.68	0.000	0.08266
DRURAL&POOR	-0.49330	0.38528	-1.28	0.200	-0.07381
DWORKING&POOR	-1.17835	0.34503	-3.42	0.001	-0.26186
CONSTANT	1.76127	0.68590	2.57	0.010	

n=1454, Psuedo R2=0.2354, dF/dx denotes the effect on the probability of coverage (calculated at the average dependent variable values) of a change in the dependent variable.

term), dummy (indicator or dichotomous) variables for income level, dummy variables indicating rural residence and Chicago residence, a dummy variable for race (DWhite), a dummy variable for sex (DFemale), and dummy variables for employment and interactions between rural residence and the lowest income group and between employed and the lowest income group. The probit regression allows the determination of an estimate of the distinct impact of a factor on the likelihood that an individual with given characteristics will be insured. The last column in Table 6 reports an estimate of the effect size of the variables. The effect size is how much the probability of being insured will change given a change in the explanatory variable. For instance, being employed leads to an 8-percentage point increase in the probability of insurance coverage when calculated at the mean values of the independent variables. Recall that on average about 90 percent of Illinoisans own health insurance coverage in this data. Therefore, for a low-income person (income less than $15,000) is about 12.9 percentage points less likely

than a person with an income above $50,000 to have health insurance coverage.

Overall, the probit regression results confirm the strong relationship between low-income people and lack of health insurance, and this relationship takes into account the confounding variables of race and Chicago residence. On average, Chicago residents have a three-percentage point lower chance of having health insurance coverage when compared with other residents of the state. Employed people have about an 8-percentage point higher chance of having health insurance coverage when compared to unemployed people, all other characteristics being held constant.

To sum up, this section has reported on the Enhanced BRFSS data that was collected from December 2000 through May 2001. An estimated 9.8 percent of Illinoisans were without health insurance during this period. While a number of factors were related to the lack of health insurance, being in a low-income household was the strongest factor related to health insurance coverage. Other important factors associated with an increased risk of being without health insurance coverage include Non-White race, being a low-income working person, and living in Chicago. Living in a rural area and being a low-income person is also associated with a lower chance of health insurance coverage, but this relationship is statistically significant at the 20 percent level.

V. Recommendations for Future BRFSS Data Collection

The BRFSS is a unique public health information resource for policy makers in Illinois. It provides timely and accurate information about health insurance coverage annually and in a

format that permits analyses to consider changes over time and estimates for regions within the State. The State and the Federal Government have supported the Illinois BRFSS and encouraged its expansion in sample size over the past decade, thereby allowing more precise estimates of public health variables such as smoking prevalence or lack of health insurance. Moreover, fielding a social survey like the BRFSS is a complex task and any recommendations about further variables to monitor must be weighed against concerns such as multiple public health monitoring objectives, respondent burden, competing sources of data and the possibility for public health information to be obtained through alternative means. That being said, this section outlines my recommendations for variables for IDPH to consider monitoring through year 2010 as well as my recommendations for related data gathering and dissemination activities.

First, the Illinois Center for Health Statistics should continue to field the occupation and employer type questions, perhaps with modifications, that were introduced in the Enhanced BRFSS. An issue with the questions as they stand is that they are fairly open-ended and lead to a wide variety of responses that are difficult to categorize in the data organization and cleaning process. Furthermore, in the occupation question, some of the responses more closely resemble answers to a question about industry rather than occupation. Another related issue is the absence of information concerning the size of employer in terms of number of employees, although this is admittedly difficult to ascertain from individual respondents (however the Current Population Survey asks individuals this question). From the point of view of health insurance coverage monitoring, it is valuable to continue the use of follow-up questions and probes such as whynopln, pastplan, whyno12, planothr, medicare, and plantype.

Second, the other access to care variables such as medcost, checkup, prmcare1, prmcare2, dentcost, and prescost should be continued. Previously fielded access variables, including the question about how people get to their primary care provider, should be reconsidered in light of the prominence of access and quality as public health concerns. Consideration should be given to specific quality of care questions to respondents that answer positively to a question about diabetes or overweight or some other condition where interaction with a primary care physician is critical to successful disease management.

Third, the BRFSS (necessarily) is not as in-depth as some other surveys in its questions about income and the respondent's involvement in the labor market. With income, an issue for trend analysis is the use of ranges and the difficulty in adjusting the discrete income values for changes in the CPI. In the labor market, it would be helpful to know directly whether or not a person is eligible to receive health insurance in his or her job. The offer of health insurance by employers is an important part of the coverage issue that the BRFSS does not treat at this time.

As for other research and dissemination strategies, the IDPH should consider partnering with groups in Illinois that conduct surveys of employers (including Employment Security and the Health Education Research Trust in Chicago), if it is interested in obtaining establishment or employer level information about whether or not coverage is offered to employees. Another dissemination strategy would be to hold an Illinois Health Insurance Coverage Summit where analysts and others interested health insurance coverage in the state could meet and discuss current levels of coverage and the issues around the lack of coverage. The annual estimate of the lack of health insurance coverage for Illinois could be released and presented at such a meeting.

Opinions Concerning Access to Health Insurance in Illinois: A Report of Focus Group and Key Informant Interviews

Prepared for the Illinois Department of Insurance State Planning Grant

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I. Executive Summary

In 2000, Illinois was one of twenty states receiving grants from the U.S. Department of Health and Human Services to study the health insurance gap within the state in an effort to achieve consensus with stakeholders and key constituents on ways to close this gap. Quantitative and qualitative research methods were employed to study the uninsured in the State of Illinois and examine solutions employed by other states in order to tailor solutions specifically to Illinois for closing the health insurance gap.

This report summarizes the results of numerous focus groups and interviews with key informants that were conducted during the spring and summer of 2001 around the State of Illinois. Focus group members consisted of seven constituencies with a stake in the problem of the un and underinsured: small business owners offering health insurance, small business owners not offering health insurance, representatives of health and social service agencies, members of the insurance industry, medical providers, members of local governments, and the uninsured themselves. Multiple focus groups within each constituency were conducted across five geographic areas of the state. Most focus group participants participated in a nominal group process as well, a technique that allowed them to brainstorm ideas for solutions to address all or part of the factors that affect the health-insurance gap. Interviews were conducted with high profile individuals in business, health and social services, government, and community activism.

Using these strategies of interview and group process, we were able to compile themes that emerged within and across constituency groups about specific experiences stemming from the health insurance gap as well as attitudes towards existing public and private mechanisms for addressing that gap. We summarized these themes in a

presentation to the July 10 Illinois General Assembly Process. The focus group results were intended to provide texture and nuance to the quantitative findings and literature reviews that made up a large portion of the framework from which the Illinois Assembly Process operated. The focus group and interview formats were similar, and were based on the primary set of questions addressing the mandates of the Illinois State Planning Grant. These questions are as follows:

- What are the effects and ramifications of not having health insurance?
- What factors account for why people do not possess health insurance?
- How are people who lack health insurance getting their health needs met?
- What are the perceptions, experiences, and expectations of people working with or utilizing public health insurance programs such as Medicaid and KidCare?
- What factors account for why some businesses provide health insurance to their employees while others do not?
- What types of mechanisms or incentives would help small businesses in their ability to offer health insurance to employees?
- What should be a minimum health insurance benefit that all Illinois residents should have access to?
- By what means could health insurance be made available to all Illinois residents
- What would be effective ways to raise awareness about the availability of new health insurance products that are designed to close the health insurance gap?

This report reflects the discussions, opinions, themes and contradictions offered by individuals on the front line of the health insurance gap in the state of Illinois.

II. Introduction to the Study

In October 2000, The Illinois Department of Insurance received a grant from the U. S. Department of Health and Human Services to study the health insurance gap (i.e., people who do not have health insurance either through private or public sources) in the State of Illinois and to achieve consensus from key constituents and stakeholders for plans and ideas to close this gap. In addition to extensive survey research conducted to understand the characteristics of people who do not possess health insurance, qualitative research was conducted to explore the opinions and reactions of various groups toward the health insurance gap and to gain ideas for closing the gap. Qualitative research is used for the purpose of gaining "rich descriptive" information that can illustrate problems and opportunities, and to put a human face or story onto technical statistical information garnered from survey research. Furthermore, with qualitative research, questions can be explored in more detail, and individual cases can be thoroughly examined in order to shed light on the issues that inform our understanding of the health insurance gap.

We utilized two qualitative research techniques: focus groups and key informant interviews. Focus groups are structured group interviews consisting of individuals who share common characteristics. Although focus group participants may not know one another, they view themselves as similar to other group participants and thus are able to reflect on similar circumstances when forming opinions and reactions. We formed seven different types of focus groups: small business owners offering health insurance, small business owners not offering health insurance, representatives of health and social service agencies, members of the insurance industry, medical providers, members of local governments, and the uninsured themselves. Multiple focus groups within each group

type were conducted across five geographic areas of the state (to be reviewed in section III).

The purpose of the focus groups was to provide texture and nuance to the quantitative findings and literature reviews that made up a large portion of the framework from which the Illinois Assembly Process operated. Moreover, the focus group sessions represent a medium for various constituencies and stakeholders to have a voice in the planning process. Although focus groups do not represent a data source from which broad inferences can be made, they still provide that important "insider's story" that can otherwise become lost in a quantitative maze of tables and figures. Group members gave us their own personal stories about the health insurance gap -- why it is difficult to afford health insurance, why it is difficult to serve those with or without health insurance, why it is difficult to provide health insurance to all state residents. They also discussed frustrations and opportunities in working with public and private health insurance programs, opinions about minimum health insurance plans, and provided ideas for closing the health insurance gap.

In addition to the focus groups, key informant interviews were conducted with high-profile stakeholders and constituents across the State of Illinois, such as insurance industry, business/labor, and social services representatives. These used similar questions as the focus groups interviews. One-on-one interviews were conducted with high profile individuals to protect their concerns for speaking freely in the presence of others.

III. Method of Research

A. Focus Groups and Nominal Group Process

Focus groups were conducted in five non-overlapping and exhaustive regions of the state (Southern Illinois, Central Illinois, Cook County, the Collar Counties, and Northwest Illinois), and were comprised of small business owners offering health insurance, small business owners not offering health insurance, representatives of health and social service agencies, members of the insurance industry, medical providers, members of local governments, and the uninsured themselves. Table 1 provides a breakdown of the number of groups conducted of each type:

Table 1: Focus Group Characteristics

Type of Group	Number of Groups Conducted	Regions Conducted	Average Number of Participants/Group
1. Businesses without HI	2	Central Southern	5.5
2. Business that offer HI	6	Northern Southern Cook County	5.2
3. Health Care Providers	4	Cook County Collar Counties Northern Southern	6
4. Insurance Representatives	3	Central Northern Southern	4
5. Health and Social Service agents	4	Central Cook County Collar Counties Southern	5
6. Local Government Representatives	2	Cook County Southern	5.5
7. Uninsured	6	Central Collar Counties Northern Southern	4

In each focus group we asked a series of pre-determined questions intended to stimulate discussion among group participants about their experiences stemming from the problem of un- and under-insurance in Illinois (see Appendix A). A note-taker compiled detailed notes during each focus group, and each session was tape-recorded, making it possible for note-takers to double check and augment their notes as needed.

These notes then formed the backbone of our analysis. Each literal or paraphrased comment by focus group participants was placed in a database, along with group type and the question to which it was a response. Two research assistants read each comment and independently created a series of themes into which the comments were organized. When this process was complete, the entire focus group team met to review and fine tune the categorization scheme in order to insure a reasonable degree of "inter-rater" reliability. These themes were then entered into the database with the corresponding comments. Themes were augmented or added as information from subsequent focus groups was added to the database. In this fashion, we were able to organize the database, and hence our analysis, by theme, focus group type, question, or region of the state.

We organized the literal or paraphrased quotes into thematic categories broken down by question type and noted the type of group from which the quote/phrase emanated. We selected quotes for the resource guide that we felt best captured the "spirit" or intent of the theme. In some cases, several quotes are included under a theme to illustrate the prevalence of a particular point of view, or alternatively the diversity of opinions regarding some theme (e.g. whether mental health benefits should be included in

a minimum benefits plan). Only themes that were voiced more than once by a particular type of group were included in this analysis. The Focus Group Resource guide (see Appendix B) contains the entire set of thematically organized quotes and phrases. This report expands on the themes that were of primary interest to the State Planning Grant.

We also included a "nominal group process" during most of the focus group sessions (with the exception of the uninsured). Participants were asked to write down five potential solutions for closing the health insurance gap in Illinois. These recommendations could be broad (e.g. make people more accountable for their health insurance status) or more specific (e.g., expand KidCare to cover parents). Participants were then asked to state their primary recommendation, which we recorded on a large post-it. Depending on time and the number of participants, each participant had the opportunity to state 2-3 recommendations. In this manner, 10-15 ideas were generated, discussed, clarified and adapted by group members, as they deemed appropriate. Participants were then asked to independently rank their top five choices. We compiled the ranks across group participants and arrived at a final consensus ranking. We entered the top five ideas from each group into a database, and determined emerging themes. These themes and supporting ideas are included in the Focus Group Resource Guide.

B. Key Informant Interviews

Fifteen personal interviews were conducted with individuals knowledgeable of the problems of insurance and lack of insurance in the State of Illinois. People interviewed included: CEOs, COOs of large insurance companies, Human Resource specialists, health care providers (both large hospital systems and rural clinic providers),

representatives from leading corporations in the State of Illinois, small local firms, union representatives, a large faith-based group, a government agency representative, and state legislative leaders (one state representative and one state senator). In addition to representing different corporations and agencies, the individuals were located throughout Illinois, representing a geographically diverse interview sample.

The purpose of the personal interviews was to gather more specific opinions regarding the problems and solutions related to the uninsured population in a way that would not be threatening to the interview subjects. For example, a COO from a large insurance company might have been reluctant to voice her or his opinions publicly, even in a focus group setting. However, in the setting of a personal interview with anonymity guaranteed, a more free flowing discussion was made possible. Professor Paul Sarvela and Mr. Dan Shannon of SIUC conducted the personal interviews.

The project team identified the personal interview subjects, with special consultation from agencies and organizations. Once identified, Ms. Madelynne Brown sent a letter to the CEO, describing the project and asking for participation in the interview. Follow-up calls were then made to the CEO (or individual designated by the CEO) and, the interview time was sent up. Interviews were conducted either on-site or via the phone. Human Subjects issues were discussed with each interviewee and informed consent was received before proceeding with the interview.

Interview questions varied slightly by particular subject, but core issues covered included:

1. Perceptions related to why people are currently uninsured.
2. Perceptions related to why employer-based coverage is decreasing.

3. Identification of incentives that can be used to get small companies and businesses to help cover their employees.
4. Methods the insurance industry, along with state government and employers, can use to increase coverage.
5. Characteristics of the ideal insurance program.
6. Statewide cost estimates of providing the ideal program to those currently uninsured.
7. Ideas concerning the best partnering structure to achieve the goals of statewide coverage.

IV. Research Findings - Focus Groups & Personal Interviews

Below we present the findings based on the primary set of questions addressing the mandates of the State Planning Grant. These questions were:

1. What are the effects and ramifications of not having health insurance? (Lack of health insurance effects)

2. What factors account for why people do not possess health insurance? (Why people lack health insurance)

3. How are people who lack health insurance getting their health needs met? (How medical needs are being met)

4. What are the perceptions, experiences, and expectations of people working with or utilizing public health insurance programs such as Medicaid and KidCare? (Perceptions of public health insurance)

5. What factors account for why some businesses provide health insurance to their employees while others do not? (Why businesses offer health insurance and their struggles to maintain it; Reasons why small businesses don't offer health insurance)

6. What types of mechanisms or incentives would help small businesses in their ability to offer health insurance to employees? (Mechanism that would help small businesses)

7. What should be a minimum health insurance benefit that all Illinois residents should have access to? (Minimum benefit)

8. By what means could health insurance be made available to all Illinois residents (Funding mechanism/affordability)

9. What would be effective ways to raise awareness about the availability of new health insurance products that are designed to close the health insurance gap (Raising awareness/marketing).

In the sections that follow, the themes that emerged for each of these questions are described and delineated by the type of group(s) from which the theme emerged. Representative quotes are provided.

A. Lack of Health Insurance Effects

All types of groups offered opinions about the ramifications of not having health insurance. Many of the themes that emerged were straightforward.

1. Delaying treatment. Typically the uninsured focus group participants stated that they simply put off seeking medical care until a problem becomes acute or when they can no longer ignore treatment.

Representative quote: *I would rather tough it out rather than lose 1/2 year's salary for medical treatment.* (Uninsured person)

2. Affecting daily living choices. In addition to delaying treatment, uninsured participants told us about the struggles they contend with day to day in deciding how their few resources will be spent -- for example, do they put food on the table or do they get a long overdue medical check-up.

Representative quote: *I have to make choices about going to the doctor or buying diapers, etc.* (Uninsured person)

3. Use of emergency rooms. For uninsured people, the emergency room is often the first and only point of contact with a health professional. The expenses that are incurred are often very high, and payments have to be stretched out over a long period of time.

Representative quote: *My son was so sick that I took him to the emergency room. The bill was $1000 and it took a year to pay it off.* (Uninsured person)

4. Risking financial security. An uninsured person lives with the fear that one catastrophic medical event or accident could ruin them financially. They could lose all their hard-earned assets, such as a house, just to pay one bill.

Representative Quote: *Lack of health insurance affects people's lives in other ways. Some families break up because they owe too much.* (Uninsured person)

5. Rationing payments and treatment. The uninsured and those who work with uninsured individuals and families know that they have to stretch their dollars as far as they can go. Therefore a common strategy is to pay only portions of their medical bills, stretching them out over longer periods of time. Another form of rationing involves taking only a portion of prescribed medications or sharing them with other members of the household.

Representative quotes:

- *We can sometimes afford some health care but we really have a difficult time affording a hospital stay. I pay the people who have to be paid. Hospitals just have to wait.* (Uninsured person)
- *Those who must take their prescriptions regularly (diabetics, high blood pressure) end up sharing their medication with their spouses or family members.* (Local government official)

6. Treated poorly by others. Because of the stigma of being poor or near poor, those who lack health insurance often perceive that they are receiving inferior treatment by health care professionals, their staff, or by public sector/social service agents with whom they must interact to get their health needs met.

Representative quote: *They treat me so poorly at the hospital that I try never to go* (Uninsured person)

7. Falling in and out of the gap. Many uninsured people go through spells of uninsurance that may last for a few years to a few months. This may be due to changes in jobs where one employer offers health insurance but the next does not, being laid off by an employer who offered health insurance, but not qualifying (or unable to afford) COBRA, moving from student (with health insurance) status to non-student status (without health insurance), or moving out of public aid eligibility (e.g., a new mother who had been covered under KidCare while pregnant, but is no longer covered after the child is born). The transient status of health insurance gaps is a source of stress and frustration. The uninsured often live their lives in the hope that nothing serious will happen to them during a spell when they are uninsured.

Representative Quote: *I've been on and off health insurance for several years. My husband works for a small company and there have been times when we really could not afford it. We have been told that we make too much to qualify for public aid. We fall through the cracks.* (Uninsured person)

B. Why people lack health insurance

Reasons for not having health insurance were categorized into four overarching themes: (a) individual access problems; (b) employment-related linkages; (c) inability to access public health insurance programs; (d) Medicaid gap. Sub-themes within each of these categories are described below.

1. Individual access problems

a. Affordability. The most common response we heard from almost every type of focus group participant was that the cost of health insurance premiums are

simply too high to afford without some form of subsidy assistance (e.g., employer-based subsidies). Insurance representatives lamented that the cost of health insurance premiums are so high because of the skyrocketing costs of medical care and the losses incurred from those who do not pay their medical and/or insurance bills.

Representative quote: *People who are struggling to survive financially can't see putting out $150 per mo. for insurance.* (Health and social service agent)

The cost itself; being driven by higher medical costs, cost shifting, making the product so good that no one can afford it. (Insurance representative).

Cost is a huge factor (Rural health clinic administrator)

b. Pre-existing conditions. Because of the exclusions or long waiting periods for people diagnosed with a medical condition before they obtain health insurance, many people are simply ineligible for health insurance. This problem is compounded by the apparent closure/wait list of the Illinois high-risk pool insurance program (ICHIP).

Representative quote: *I have a friend who could not transfer her health insurance to her new job. Health insurance companies do not pick someone up if there is a preexisting condition.* (Local government official).

c. Cultural barriers. People who are not members of the majority culture, i.e., those who are not White or native English speakers experience difficulties in accessing health insurance above and beyond the conditions outlined above due to language barriers, fears of discrimination or poor treatment based on their minority status or cultural practices that are at odds with the normative expectations for seeking health

insurance information. For example, some cultural practices may shun treating medical conditions. Moreover, immigrants often live in isolated communities and may not know where to find information about health insurance, or they may fear that accessing the health care system may jeopardize their immigrant status (e.g., fear of deportation).

Representative quote: *Transient populations (migrant workers; those fluctuating between employment and unemployment)– don't get enrolled in programs because they're not around long enough.* (Health and social service agent)

d. Individual choice. A few uninsured individuals stated that they chose not to purchase health insurance because they felt they were healthy enough to incur the risk and that they had other priorities. This sentiment was expressed more often, however, from people in other types of groups rather than from the uninsured themselves.

Representative quote: *Some think they just don't need it, especially young people who haven't been sick before. Males are more likely to feel this way than females.* (Health and social service representative).

2. Employment linkages. Most Americans obtain their health insurance through their employers who typically pick up some or all of insurance premium. This link between employer and health insurance, therefore, means that some people will be without health insurance because they are unemployed, or their employer, for a variety of reasons, doesn't offer health insurance. There were several sub-themes related to employer-based linkages.

a. Employer doesn't offer health insurance. A common sentiment expressed by various focus group participants was that businesses deliberately employ a part-time or contingent (e.g., contract or seasonal workers) workforce in order to avoid offering health insurance benefits. Employers and other professionals believed that the health insurance industry charged rates that were too expensive for small employers to afford.

Representative Quotes:

- *Since employers don't have to provide health insurance to part-time employees, some of them choose to hire part-timers* (Health and social service agent).
- *In the effort to move people from welfare to work, we have often moved people to minimum wage jobs with employers who do not offer insurance.* (Provider)

b. Portability concerns. Although COBRA provides a mechanism for people to keep their employer-based insurance for a period of time when they leave a job, many people cannot afford this option (often the individual pays the entire cost of the premium), they exhaust this option before finding new employment with health insurance benefits, or they were ineligible for COBRA due to the seasonal nature of their jobs.

Representative quote: *Seasonal and immigrant employees are not usually covered because of the hassles of switching plans as they move from jobs or locations* (Provider).

c. Lack of in-network providers. Employers, especially those in less populated areas, who want to find an affordable health

insurance program for their employees found that the most affordable plan had no or a very limited choice of providers in the health insurance network located where employees live.

Representative quote: *In some cases, health insurance is available but no providers are present in the area.* (Health and social service agent)

d. Employer-insurance expectancy. There were many opinions expressed that our society has created an expectancy that health insurance is the responsibility of employers, not of individuals. Thus, individuals do not take adequate measures to plan and budget for health insurance when they are unable to obtain employer-based health insurance.

Representative quote: *Our society links health care coverage with employment. This is a problem because people are not taking responsibility for covering themselves.* (Provider)

3. Public health insurance inaccessibility. There were many sentiments expressed that more people could be served by public health insurance programs such as Medicaid or KidCare, but these programs were functionally unavailable because of the red-tapes and hassles of accessing or working with these programs, or due to lack of awareness. There were several sub-themes.

a. Long waiting periods for immigrants. Some voiced concerns that one reason why immigrants lack health insurance is because of the long (5 year) wait period to be eligible for public health insurance once legal residence (e.g. green card) has been established.

b. Community development programs thwarted by red tape. We spoke with members of various private or community development programs who had been working on plans to provide access to health care or health insurance for medically under-served populations. They spoke of many frustrations they experienced in trying to coordinate their efforts with existing state rules and regulations.

Representative quote: *Our chamber of commerce tried to do a small business coverage plan, but have not been able to do it because of bureaucratic and legislative problems. Tried to "adjust" to rules, but were thwarted* (Health and social service representative).

c. Perception of people who misuse public health insurance programs. Several focus group participants across several types of groups were concerned about the apparent misuse of public health insurance programs and other forms of public aid. Some were of the opinion that a reason for the high cost of health care, as well as the stigma for accessing public health insurance is because some people misuse or take advantage of the system.

Representative quote:*I also think people take on the attitude that if I get sick other people are going to help me pay.*(Uninsured person)

d. Working poor don't qualify for Medicaid Several personal interview subjects commented on problems related to the working poor being unable to qualify for Medicaid, yet, did not have the funds to pay for private insurance.

Representative quote: *I sense that there is a gap between where Medicaid cuts out and low wage earners ability to pay for insurance because they have*

jobs that don't pay health insurance or require too high a premium for the worker to afford. (Faith-based administrator)

C. How health care needs of the uninsured are being met

We wanted to hear how people who are caught in the health insurance gap take care of their health and medical needs. Such information would shed light on the adequacy of the health care safety net in Illinois as well to learn more about the consequences of not having health insurance. These questions were asked to our groups of uninsured people, health care providers, health and social service agents, and local government representatives. The following themes emerged.

1. Home remedies. In attempt to solve health-related problems at a minimal cost, many uninsured focus group participants stated that the relied on home remedies, typically using products that are found around the house or can be purchased inexpensively without a prescription.

2. Ignoring or delaying treatment for health problems. To the extent that the uninsured are reluctant to seek routine health care or ignore or delay treatment for medical ailments, health problems escalate into more serious conditions.

Representative quote: *Most people go for health care only when they are so sick that they cannot treat the problem themselves. Their first encounter with the system is the emergency room.*(Health and social service agent)

Representative quote: *Some just don't seek medical help for procedures they need* (Elected official).

3. Use of the emergency room. The uninsured often use the emergency room as their first and sometimes only point of service for medical treatment. They believe that emergency rooms are the only place they cannot be denied treatment due to an inability to pay.

Representative quote: *Many go to the emergency room for health needs because they don't have health insurance, and don't qualify for Medicaid* (Health and social service agent)

4. Free clinics, public health centers, and community programs. When we asked people how the uninsured are getting their medical/health needs met, several noted that they or others they knew used free or reduced-fee clinics. Often there were others in the group who may not have known about such facilities. At the end of the focus group, participants exchanged such information with one another. Several people commented that it would be helpful to have a directory of such services in a community.

Representative quote: *Free clinic in Elgin – for indigent patients who can't pay anything – it's [staffed by] volunteer physicians and [other] volunteers – expansion is opening in July- sliding scale payment*. (Health and social service representative)

5. Charity from doctors. Several uninsured focus group participants as well as several health care providers commented that some doctors provide a certain amount of free or reduced-fee service to uninsured patients. The uninsured often knew of a doctor or dentist who would accept a nominal fee, or would try to provide patients with free prescription samples as much as possible. Many providers commented that they find

it easier to give their services away for free than to try to deal with Medicaid reimbursement processes, but are worried about liability issues.

Representative quote: *It's just easier to provide the service for free than to mess with all the red tape.* (Health and social service representative).

D. Perceptions of public health insurance programs.

As the state-supported public health insurance network (e.g., Medicaid, KidCare, ICHIP) is likely to be an integral part of solutions to closing the health insurance gap, we wanted to gain impressions and opinions about these programs, both from the perspective of potential clientele and as well as from providers and social service agents who work with such programs. There were several themes associated with perceptions of public health insurance programs, which were broadly categorized as (1) reasons for not participating in public health insurance; (2) problems experienced in working with public health insurance; and (3) positive experiences with public health insurance. Sub-themes within each category are described below.

1. Reasons for not participating in public health insurance.

a. Individual barriers. There were a number of reasons why individuals did not utilize public health insurance resources such as Medicaid, KidCare, ICHIP, or various veterans' benefits (e.g., CHAMPUS). Many did not want the stigma of being a public aid recipient and feared being treated as a second-class citizen by health care professionals or their staff. Others noted that they could not find doctors or other providers who would take Medicaid/KidCare patients (Lack of Access to Providers.) Some noted cultural barriers, such as not having sufficient language skills to obtain information about where to seek medical attention by providers who accept public health

insurance, or they feared risking their immigration status if they utilized such services. We heard from several types of people (e.g., providers, social service agents, insurance agents) who complained about the long and complicated application process for KidCare, especially, although several of the parents whose children are on KidCare did not think the process was complicated. For those with pre-existing conditions who could obtain private health insurance, we heard complaints that the Illinois high-risk pool insurance program (ICHIP) was difficult, if not impossible to get into, or they were not aware of this program. Finally, lack of awareness of being eligible for various public health insurance programs was a common remark. For example, many people including some elected government officials had not heard of the KidCare program. Some parents whose children were on KidCare claimed that they had to do the research on this program and inform their social services representative about the program.

Representative quotes:

- *Maybe a newspaper article that explains about KidCare, and other public programs would help people better understand why some need it*. (Uninsured person)
- *I don't want to be lumped together with those who are freeloading.* (Uninsured person)

b. **Provider barriers**. Many health care providers mistrusted government-sponsored health insurance programs. They complained that state bureaucrats who managed such systems had little understanding of the local conditions under which the provider was operating, or little understanding of the medical conditions

upon which the provider was operating. Therefore, some providers were reluctant to accept patients with public forms of health insurance.

Representative quote: *Physicians don't have enough faith in the programs to support expanded statewide efforts.* (Provider).

2. Problems experienced with public health insurance. Despite barriers to utilizing public health insurance programs (listed above), many participants were either primary recipients of such benefits or were part of the provider or tertiary network for such benefits. They spoke candidly about various problems and frustrations they experienced with public health insurance programs. Themes are categorized by individual- and provider-based concerns.

a. Individual concerns. We heard examples of poor treatment by the "system". For example one KidCare parent felt as if she that because she was a public aid recipient, that health care staff assumed she engaged in poor health behaviors, such as drinking or smoking. Others felt ashamed to be on public health insurance because of the perception or understanding that some people misuse or abuse the system and create a poor reputation for others. Finally, many people felt that the *benefits* of public health insurance were inadequate because it may not pay for mental, dental or vision benefits adequately.

Representative quotes:

- *Some are 2nd and 3rd generation welfare, so they know the system and how to play it*. (Provider)
- *I've been treated as if I were a smoker or drinker. I'm neither. I resent the treatment*. (Uninsured person)

- *Mental health is ignored across the board. Period*. (Health and social service representative).
- *It is a problem when we refer someone to a specialty care provider* (Rural health director).

b. Provider concerns. Providers and related professionals who provided services to public health insurance beneficiaries expressed a number concerns when dealing with the public health insurance infrastructure. In particular, they complained of a burdensome bureaucracy. For example, rules for complying with regulations seemed to change without notice – what was acceptable practice six months ago, was no longer valid. It also seemed that providers had less and less autonomy in making medical decisions despite their own concerns for keeping costs low. For example, one provider lamented that a Medicaid patient who presented with problem A was found to also have problem B. The physician couldn't treat problem B while treating problem A unless the patient was discharged from the hospital and re-admitted. A common concern was that Medicaid (and related public programs) had very slow and unreliable reimbursement practices. "Low, slow, or no pay" was a common mantra. Referring patients to specialists was complicated by the fact that there often wasn't an appropriate specialist in the area who was a qualified Medicaid provider. Unrelated to the Medicaid bureaucracy, but nonetheless a concern of Medicaid providers was a sense that Medicaid and/or free-clinic beneficiaries were not committed to therapeutic regimens or to maintaining appointments. One dental provider commented that a free dental clinic he staffed had to close not due to lack of funding, but due to poor patient commitment to the center and the care they received.

Representative quotes:

- *It costs more to use staff to do all the paperwork, than to just do the care for free, and use the staff for something else. Many practices aren't profit driven in the first place.* (Health and social service representative)
- *No longer possible for family practitioner to be family practitioner, doesn't have time to spend sufficient time with patient [due to hassles of dealing with public insurance programs.* (Provider)
- *The no-show rate from the public aid population is huge. This adds to costs.* (Provider)

3. Positive experiences with public health insurance. Despite many complaints and frustrations with public health insurance voiced from providers, recipients, and other agents, we also heard many positive remarks.

a. Good service/coverage. There was a strong sense that public health insurance was a critical component of the health care safety net and that it was often a lifesaver. In addition, both providers and recipients alike noted that the level of coverage in Medicaid and KidCare was very good – better than many private insurance plans, and that reimbursement was often better from public health insurance programs than from private ones.

Representative quote: *The program of Medicaid and KidCare are good and helpful for those we know who qualify.* (Uninsured person)

b. Minimum hassles with KidCare enrollment. Despite many complaints by providers, social service agents, and insurance agents that the KidCare

form was long and complicated, parents whose children were enrolled in KidCare told us that the form was not forbidding. They were grateful that the program existed.

c. Saved from financial ruin. Without public health insurance, several uninsured individuals told us that they would have surely lost all of their personal assets for the cost of one or two catastrophic medical bills. Saving one's livelihood was more important than being ashamed of public assistance.

Representative quote: *I had a man tell me that I should not accept welfare if I were a "true man." When I was about to lose my home I decided that stigma was not important.* (Uninsured person)

d. Right to public health insurance. Many Medicaid/KidCare recipients told us that they did not feel ashamed of participating in public health insurance. They had been paying taxes toward such programs and felt that when their circumstances warranted, they should have the right to such benefits.

Representative quote: *Welfare is paid by taxes. I paid taxes with my job so if I were to lose it, I feel entitled to it* (Uninsured person).

e. Provider Business Perspective Several providers were satisfied with working with public aid programs.

Representative quote: *The programs are fine* (Rural health program director). *We have no real problems with Medicaid* (Hospital system CEO).

E. Why businesses offer health insurance and their struggles to maintain it.

The majority of American citizens have health insurance through their employers who pay part or all of the premiums. Although most large employers offer health

insurance benefits to employees (typically only full time employees, however), small employers (e.g., under 50 employees) struggle to afford, let alone maintain this benefit. The cost of health insurance benefits to small employers is particularly difficult because (1) they often don't have the profit margin to absorb high premiums; (2) they get less favorable rates than large-group employers who can distribute and absorb risk more easily; and (3) they often do not have benefit specialists on staff who can research the best rates and plans for the company. Despite these obstacles, many small employers offer health insurance to their employees, and we wanted to learn their reasons for doing so.

1. Attract and retain high quality employees. Employers emphatically agreed that attracting and retaining high quality employees was the primary reason why they offered health insurance. Many believed it gave them a competitive advantage over competing employers for qualified, loyal employees.

Representative Quote: *We offer health insurance to attract high quality employees and be competitive with other companies* (Insurance managers for a large corporation).

2. Self-coverage. Another reason for offering health insurance benefits to employees was for the owner to be able to obtain health insurance for him or herself. This reason was salient among owners who were unable to obtain individual private insurance because they had high health risks or pre-existing conditions.

3. Moral obligation. Finally, several employers felt that providing health insurance to employees was the right thing to do. They viewed their employees as members of a family. Often, employees had worked with the company for several years, and the employer would never think of cutting back on this benefit. Furthermore,

employers felt grateful that their employees were covered by insurance when a catastrophic event occurred, even if such an event created burdensome rate increases for the company.

Representative quote: *We had an employee with a brain tumor whose bills must have been enormous, but couldn't imagine not having insurance for him. The costs and benefits are incalculable. Can't put a dollar value on this.* (Business owner who offers health insurance).

4. Rate increases and affordability. Maintaining health insurance benefits is a constant struggle for small business owners. We were told that rates would increase by double digits annually. Employers will spend a great deal of time researching the best and most affordable plans. This is time taken away from other duties of their business.

5. Expectations and naivete of employees. Although employers clearly valued the business purposes of offering health insurance, and often felt a moral obligation to do so, they were frustrated by employees' lack of understanding of the cost and hassles to secure this benefit. Furthermore business owners stated that employees expect them provide health insurance, without a good understanding of the hardship this causes for the employer or the true monetary value of this benefit.

Representative quote: *I feel that some employees don't really have an appreciation for getting heath insurance offered to them. They don't know just how much it costs.* (Business owner)

F. Why businesses don't offer health insurance.

Despite the business and personal advantages of offering health insurance, many businesses, especially small ones do not offer health insurance. We wanted to gain a better understanding of why businesses did not offer health insurance to their employees.

1. Affordability. By far the most common reply was that health insurance was simply too expensive and the small business owner did not have the means to afford to offer this benefit and remain viable. Some business owners who had previously offered health insurance had to discontinue this benefit because rate increases in insurance premiums became too high for the business to absorb. Some business owners pointed to what seemed like unnecessary and costly mandates that drove up the price of health insurance. For example, a small business owner with two or three long-time employees felt it was unnecessary to pay for maternity benefits when all of his employees were beyond the age of needing this benefit. Another factor that seemed especially unfair to the small business owner was the impact that one high health risk employee could have on the employers group rates. Larger businesses can absorb the increase in risk ratings of a few high-risk employees, but this is especially difficult for the small employer.

Representative quotes:

- *My business has increased by 5-10% the past few years but my insurance costs rose by several more percent, thus, I no longer carry health insurance.* (Business owner).
- *The illness of one employee raised the costs very high for all of the other healthy employees.* (Business owner)

2. Employees insured elsewhere. Small business owners who may have only a few employees often told us that their employees were insured elsewhere, typically by their spouses, therefore they did not need to offer health insurance.

3. Employees choose not to accept employer's health insurance benefit. Also, although not a frequent remark, some employers stated that their employees turned down their health insurance offer or stated that they did not want health insurance benefits. This remark coincides with some uninsured persons' statements that they would turn down employer-based health insurance if the cost of the premium was too high, or they would rather spend the extra money elsewhere.

Representative quote: *I paid an employee more money so that he could purchase his own health insurance but he chose to spend the extra money elsewhere.* (Business owner)

4. Business employs part time or seasonal workers. Several focus group participants, not necessarily small employers themselves, remarked that businesses that primarily employ part time or seasonal workers do not offer health insurance to their employees. Some participants even went so far as to say that some businesses, not necessarily small ones, deliberately employ a large part-time work force in order to avoid paying such benefits. Others stated that employers who typically employ students as part-time employees believe that these students are either covered by their parents' plans or by a school plan, but this was not always the case.

Representative quote: *We have several part-time workers. Some are part-time students and thus, they don't have school insurance. That's a real concern to us.* (Business owner).

G. Mechanisms that would help small businesses.

Although more specific ideas for closing the health insurance gap were gathered in the nominal group processes (described in a later section of this report), we asked small business owners and insurance agents who help small businesses obtain health insurance for ideas for helping business owners afford this benefit.

1. Purchasing groups. Business owners liked the idea of being able to join together with other business owners to form a purchasing cooperative and thus be able to compete for better health insurance rates. It appeared that most small business owners were not aware of problems that have plagued other purchasing group initiatives, such as adverse selection (i.e. the purchasing group attracting a high risk pool and becoming a disincentive to low risk individuals who could find better rates with an individual plan), but they seemed to be willing to work toward a solution that might make purchasing pools a viable option. Some business owners suggested that the state should create one large purchasing pool for all small businesses.

Representative quote: *If Illinois could offer a small business plan that would cover many employees statewide that might allow us to afford it.* (Business owner)

2. Tax incentives. Small business owners had favorable attitudes toward tax incentives especially if it allowed them to earn a tax credit for the cost of providing health insurance to employees. However, some believe that a tax break does not help employers provide coverage.

Representative quote: *A direct individual tax credit to pay for health insurance premiums might work really well and reduce the [number of] uninsured.* (Insurance agent)

Representative quote: *Employers already get a tax break; however, this is not overcoming the increasing costs of health insurance coverage* (Insurance company executive)

3. Access to providers in the area. Some small business owners were attracted to managed-care forms of insurance because of the low costs, but were frustrated if the choice of providers in a particular network was low or nonexistent. This frustration was particularly felt by small businesses located in rural areas.

Representative quote: *We had to separate our health insurance from the parent company because of the complications due to changes in PPOs etc., so, we're less flexible and powerful than we use to be.* (Business owner)

H. Minimum benefit

To the extent that either a single program or a set of programs and initiatives would be developed to cover all Illinoisans who currently lack health insurance, there needs to be consensus on what level and range of benefits should be offered. We asked all focus group members their opinions on what should be the minimum benefit level for health insurance. There appeared to be two opposing "top-of-the-head" responses: bare minimum, catastrophic only, and comprehensive plans that cover major medical, preventative, and expanded benefits, such as dental and mental health coverage. Upon further discussion and reflection most focus group participants agreed that a good basic

plan that emphasized preventative, maintenance, hospitalization (catastrophic), and dental benefits would constitute a good minimum benefit. However, there were a number of issues pertaining to minimum benefits that various focus group members wanted to emphasize. The follow themes are divided into three categories: (1) issues to consider in deciding a minimum benefit; (2) general plans; and (3) specific benefits.

1. Issues to consider. Focus group participants emphasized that minimum benefits should entail a low deductible, or other means of keeping the benefit affordable, such as having a sliding scale, based on income or ability to pay. In addition, focus group participants were concerned about keeping the cost of health care down, emphasizing the need to ration and prioritize health care services holding to the belief that health care costs are so high because the American public expects gold standard treatment. Furthermore, there was a strong belief that public health insurance programs, like other forms of public assistance, can be misused. For example, recipients of public health insurance are perceived to have a disincentive to find employment that offers health insurance, or they expect high-cost services at the taxpayers expense when such services may not be medically warranted. Therefore participants wanted to be sure that public programs were monitored for potential misuse and abuse. Business owners were particularly concerned about *problems with mandates,* such as coverage for procedures like in-vitro fertilization or other types of "personal choice" procedures, and being penalized for pre-existing conditions. Small business owners were sensitive to the fact that they were singled out by the insurance industry to provide medical histories on all employees whereas larger employers did not have this burden.

Representative quotes:

- *Problem in defining what health care should be provided. E.g., in vitro fertilization, plastic surgery reconstruction after a mastectomy. These are big-ticket items, public now expecting these are routine. Easy for HMO to become bankrupt by a few patients running up millions of dollars.* (Health care provider)
- *20 years ago, the basic package was major medical, not sure of the definition, with X percentage paid by the individual. Over the years this has been changing, due to regulations. E.g., having to carry maternity benefits even though only one or two employees will need it. Hard to get back to the basic medical plan.* (Business owner)

2. General health insurance policies. In considering the concept of a minimum benefit, focus group participants were often divided between two camps: those who felt that a major medical/catastrophic type plan with provisions for preventative care and prescription drugs would be sufficient vs. those who believed in the value of a comprehensive plan that covered many of the benefits that are covered in modern plans. In particular, those with awareness of KidCare believed that a similar plan for adults would be of good quality. A minority of participants believed that a managed-care style plan would be necessary to avoid abuses.

Representative quotes:

- *Managed care is okay. I've been in it before. We hear too many bad things about it but it isn't that bad.* (Uninsured person)

- *Complete health perspective – physical, dental, vision, mental – mental illness (depression) affects everything else. Preventive also includes mental health because it (mental wellness) affects so many other things. (*Health and social service representative).
- *I think that if they pass laws for mandatory health insurance, employers should only have to cover catastrophic. The employees should cover the extras. Groups should be able to get a good price for this, but it will force the employer to go out of business if the employer has to pay for all of this.* (Business owner)

3. Specific benefits. Many times focus group participants and interview subjects commented on specific types of benefits they thought should or should not be covered in a minimal health insurance plan. Most focus participants agreed that dental care, especially coverage for bi-annual check ups should be included in a basic health plan. Interview subjects were split on the issue of dental care. There was even less consensus on mental health. Whereas some participants, especially providers and social service professionals believed in the connection between good mental health and general health, others believed that mental health should not be in a minimal policy. A common explanation was that only a small proportion of individuals require mental health benefits, whereas everyone benefits from dental care. Including prescription benefits was a popular topic with many focus group participants believing that some accommodation for the rising costs in prescription medicine would be necessary. However many voiced concerns that such costs need to be contained in some way. Rehabilitation and vision

benefits were mentioned occasionally, but there was no overwhelming concern that these benefits should be included in a minimum health plan.

Representative quotes:

- *Dental insurance was the first that focused on prevention. Dental policies that paid 100 of bi-annual benefits. People take advantage of this and as such their overall dental health is better.* (Insurance representative)
- *Mental should be part of some medical, but we have a long way to go to clarify this area.* (Provider)

I. Funding mechanisms: Affordability

How to pay for mechanisms that will help close the health insurance gap was an important concern among focus group participants. Although it is important to consider solutions to the health insurance gap, many people had different ideas on how such solutions should be funded. Themes were categorized into issues surrounding affordability, changing cultural expectations about health insurance, considering global approaches, such as universal health care, and helping to solve problems with the current methods of reimbursing health care costs.

1. Maintaining affordability. The bottom line to any solution to funding comprehensive health insurance programs is that it remains affordable. For both individuals and businesses that pay the lion share of the premiums, costs need to be kept reasonable. Thus, both parties are concerned about reasonable deductibles and premiums. However, when we talked to potential beneficiaries of expanded health insurance benefits, i.e., the uninsured, many emphatically emphasized that they would want to

contribute to the cost of health insurance expenses through a reasonable premium, up to about 5% of the household income, or through an affordable deductible. No one felt they should receive health insurance benefits for free. A sliding scale seemed to be the most efficient way to establish an equitable reimbursement schedule. Finally, business owners, insurance agents, and health care providers alike discussed the need to control costs by finding ways to bring the cost of health care under control. A common sentiment was that expensive, experimental, unreliable, or otherwise optional therapies should not be covered by health insurance. Nonetheless, there was much "finger pointing" in attributing blame to the rising cost of health care. Insurance agents and business owners often pointed their finger at health care providers and the pharmaceutical industry for frivolously raising health care costs. Providers pointed their finger at the insurance industry for being too profit oriented and not understanding the medical decisions that doctors make day to day. Much blame was placed on the legal system that allowed patients to sue doctors for seemingly innocuous medical mishaps. Finally many focus group participants, including the uninsured pointed their fingers at public health insurance recipients for abusing "the system."

Representative quotes:

- *How much could I save if I need to buy milk? If I could afford, would already have insurance.* (Uninsured person)
- *There should be some charge, even if it's small. It can't be free because someone has to pay for it. It has to be paid by someone in order to keep going..* (Uninsured person)

- *It's the business; it's not the people. It (the cost) should be regulated..* (Local government representative)

2. Changing expectations. Most of the stakeholders of the health insurance dilemma had concerns about the "take it for granted" attitude that pervades our society. With regard to health care and health insurance this sentiment seemed to manifest itself in two ways. First, there was a call for better patient responsibility in attending to health care regimens, such as showing up for appointments, taking prescribed therapies, and not delaying treatment. To the extent that many, concerned stakeholder groups are working hard to make health care available and affordable, they felt that recipients should do their part to actively participate in these efforts as a responsible patient. Second, many felt the desire to educate young people about the importance of health insurance so they develop expectations from an early age that they are ultimately accountable for their health and for having health insurance.

Representative quotes:

- *Patients don't want to do what they need to do. They want a pill to cure the problem. There needs to be more responsibility put on patients.* (Provider)
- *Health education classes/seminars might also work as an incentive – if they attend these classes their premium can be reduced, etc.* (Health and social service representative)

3. General Systems. With regard to mechanisms to fund health insurance initiatives or to making health insurance more affordable, there was considerable discussion about overarching systems that would manage costs and access to care. In

general, focus group participants expressed opinions about two such systems: managed care and universal health care (i.e., single payer). Both systems generated strong opinions both for and against. With regard to managed care, participants were concerned about the lack of autonomy, both from the provider's perspective in making medical decisions and from the recipient's perspective in choosing providers. Nonetheless, many believed that managed care systems, such as health maintenance organizations (HMOs) are necessary to control costs and thus broaden accessibility to health care. With regard to universal health care or a single-payer system, many participants (but certainly not all) felt that such a system might be the only way to truly make health care accessible to all people. The belief was that as long as multiple profit- and non-profit oriented entities are competing for health care dollars, there would always be holes in the system. The countervailing sentiment, however, was that universal health care would be too expensive and that the business owner and the tax payer would end up footing a larger portion of the bill for health care than they already do. Furthermore, many held the impression that universal health care systems that are in place in other societies are failures. An oft-sited example was the long waiting lists for surgeries and other treatments that people in foreign companies had to endure.

Representative quotes:

- *I had to change doctors for my child, but I was happy to do it because of the fact that my children are now insured [through a managed care system].* (Uninsured person)
- *Single-payer is perceived to be the solution, but this will put a lot of people out of business like local pharmacist. (*Provider*).*

*Already many insurance companies are dropping out of the health insurance business because it's not profitable. (*Insurance representative)

- *Some other countries take care of their citizens and provide care. Ours should too.* (Uninsured person)
- *A voucher based or subsidy based program for health insurance, paid directly to health insurance companies might be a worthwhile idea.* (Insurance company executive)

4. Problems to consider. Although focus group participants were asked to consider ways to fund expansions to health insurance, inevitably they wanted to call attention to problems with the "current" system. The following themes emerged:

a. **Stigma of public health insurance.** To the extent that efforts to close the health insurance gap will involve expansion of publicly funded health insurance programs, such as Medicaid, focus group participants had concerns about the stigma of public aid. Often, it was mentioned that service providers and their staff who seemed to have preconceived negative attitudes toward public health insurance recipients reinforced this stigma. Uninsured people were especially concerned about being prejudged for utilizing public health insurance programs.

Representative quote: *The biggest issue is really the stigma attached to being enrolled in public assistance programs.* (Health and social service representative)

b. Tax incentives good for business but not individuals. Many, but not all business owners held favorable attitudes toward tax incentives, especially tax

credits, as a way to encourage employers to provide health insurance to employees. Business owners strongly preferred a tax break for business owners as opposed to a tax burden to fund public health insurance expansion. On the other hand, many focus group participants, especially the uninsured and social service providers, believed that tax incentives would not be encouraging to the working poor who are without health insurance. The common sentiment was that the tax burden for the working poor is already low and a tax incentive would not be perceived as very valuable.

Representative quote: *Businesses will respond to incentives. The people who are uninsured don't file tax returns and won't see a tax benefit. Employers do. And will benefit more from those types of incentives.* (Insurance representative).

c. Complications of medical savings accounts. Just as many worried that tax incentives would not appeal to the typical person who lacks health insurance, many also believed that medical savings accounts would not be effective. The concern was that such programs require the ability to plan and to accurately forecast an individual's or family's yearly medical expenses. Furthermore, many felt that the hassles of sending in receipts for reimbursement might overwhelm many people. Finally, many people felt that they or people they knew would experience hardship by having a certain portion of their already small paycheck set aside for potential medical expenses.

Representative quote: *People who don't think about the future would not take advantage of medical savings accounts.* (Uninsured person)

d. Problems with mandates. Many times we heard concerns that government mandates to cover certain types of procedures, especially on essential

procedures applicable to only a small minority of recipients keeps the cost of health insurance high. Business owners were especially outraged at having to pay for benefits that their employees did not need. They would much prefer to make such benefits optional.

Representative quote: *If mandates are added to the problem, it causes prices to rise; example [analogy] is minimum wage – no one discusses the ripple effect of these types of policies* (Insurance representative).

e. Reimbursement to providers. Health care providers were often frustrated by the complications of getting reimbursed in a timely and equitable manner from both public and private payers. Whatever mechanism is used to expand health insurance benefits, providers wanted to make sure that it did not add to the burdens they already experience with fair and timely reimbursements. Furthermore, providers did not want to be forced to accept a sub-minimum reimbursement system that would cause them to raise their rates for other patients.

Representative quote: *Medicare is responsible for high costs due to capitation. Forces providers to have high rates because they know they'll only get half back. They have to charge this same rate to the general public.* (Insurance representative).

J. Raising awareness/marketing

One question we asked uninsured focus group members was what sources of information are you most likely to pay attention to when it comes to getting information about health insurance options and medical care. It was acknowledged by virtually all of these focus group members that given the complicated structure of the public health

insurance system, the amount of misinformation circulating about, and the cultural and/or language barriers that many face when confronting a medical situation, a concerted, coordinated, and systematized campaign is necessary to raise awareness of the various options presently in existence. No single source of information rose to the top as most credible or likely to be accessed by the majority of the uninsured. Rather, using multiple sources was seen as the most likely way to mount a successful information campaign about health insurance options.

Representative Quote: *The structure and implementation process are problems. For example, people often ask "Where do I sign up?" and "Where do I got to learn about the program?"* (Rural health clinic director)

1. Multiple sources - general. The uninsured we spoke with had varied habits in terms of television watching or radio use. Public service announcements were seen as important vehicles for information, including Spanish TV and radio. However, many who worked or watched little TV said this mechanism would not be terribly useful. The telephone book could be used to place information about public programs. Campaigns or information booths at public schools were seen as very practical mechanisms for targeting uninsured families with children, especially if this outreach was done during the registration process at the beginning of the school year. Community outreach was also seen as an effective and credible way to apprise people of their health insurance options. For example, institutions such as the Salvation Army, churches, and other community programs should have this as part of their mission to actively work to discover who the uninsured are within their respective communities and to help link them with appropriate resources, such as KidCare. Other highly visible mechanisms

mentioned were billboards, grocery stores, newspapers and magazines, and even advertisements on milk cartons.

Representative quotes:

- *Salvation Army does a lot of outreach with KidCare – making people aware of it and it's services. 80 families in the tri-cities applied for it, but WITH a KidCare representative/worker – they would have never done that on their own though, because it's just too complicated* (Health and social service agent).
- *I found out about KidCare from a national magazine. I doubted that I would qualify for it. I finally learned more about it at the state fair and finally applied* (Uninsured person).
- *I know they advertise on TV now. I see it on billboards, WIC offices, doctor's offices, and even the grocery store* (Uninsured person).

2. Multiple sources - health services. Many uninsured pointed out that all doctor offices should provide information in the way of pamphlets and brochures about medical services available to the uninsured. Several said that hospital emergency rooms should also carry information about available services, because for many uninsured, the emergency room is the first contact they have with a medical provider. Health and social service organizations and health departments were obvious places where credible information could be obtained

3. Employers and the government. Some focus group members said that receiving an official letter from the government about their options for health insurance

would make them sit up and take notice. Some participants said they did not trust media like TV, radio, or a telephone or direct-mail campaign, because they would believe there was likely a "catch", and they didn't want to risk being victimized by a non-legitimate source. Telemarketing was seen as a particularly disreputable way of providing information.

These same members, as well as others, said that an employer would be seen as a credible source of information about public or other options for health insurance programs, even if that employer did not offer health insurance. They perceived their employers as trustworthy sources of information about what options they *do* have. Representative Quote: *When I hire people at my hotel job, we tell them about the local programs like KidCare. I have several single parents who now know how to find help* (Uninsured person).

4. Word of mouth. For many individuals who have been in the public health insurance system for a long time, word of mouth is the most reliable source of information. These individuals "know the system", know its limitations, and even know how it can be manipulated. This "insider network" benefits people who move to a new location to join family members already residing there who have figured out what services are available and how to access them. Clearly this information mechanism is insufficient for community newcomers who are not part of a ready-made network, and a concerted and well-orchestrated information campaign is what is necessary to help bring these people "inside the loop".

V. Research Findings - Nominal Group Process

In addition to listening to people's experiences and gathering opinions and perceptions about the range of health-insurance issues addressed in this study, we also wanted to gather their ideas for solving the health-insurance gap. Therefore, at the conclusion of many of the focus group interviews, we transitioned to a different format called a "nominal group process (NGP). This technique allowed participants to brainstorm ideas for solutions to address all or part of the factors that affect the health-insurance gap. Participants also rank-ordered the suggestions.

One disadvantage to this process is that ideas generated during a particular session did not necessarily carry the same "weight" in terms of specificity, magnitude, or feasibility. This made ranking the ideas somewhat problematic as participants grappled with the task of trying to prioritize concepts that were inherently super or subordinate to other concepts in the list. This problem was alleviated in part by using the group process to combine, synthesize, and integrate ideas that were related, thus reducing and hopefully equalizing the number of ideas to be ranked.

Another problem inherent in the nominal group process is that ideas generated within one group may be inconsistent with other ideas generated by the same group. When this occurs across groups, contradictory themes emerge. The nominal group processes that accompanied the focus groups resulted in approximately thirteen overarching themes, several of which are incompatible with other themes that emerged. The themes are as follows.

A. Focus on cost control measures through government mandates.

Much of the discussion in the focus and nominal groups concentrated on coming up with measures for stemming the spiraling costs of medical care. There was a good deal of sentiment that rising medical costs accounted for much of the rapid increases in health insurance costs experienced by many small business owners. Some nominal group participants felt that the medical profession had gotten too greedy, whereas others pointed to mushrooming litigation threats and the concomitant rise in malpractice insurance premiums as primary sources of increased medical costs. Although there was reluctance on the part of many participants to entrust government with much responsibility for breaking the cycle of rising medical and insurance costs, one common sentiment was that the government, either state or federal, was the only entity large enough to intervene and control costs.

B. Government mandates to insure that everyone has access to affordable health insurance.

We heard from many group participants, the uninsured, small business owners, health and social service agency representatives that health insurance is out of reach for many people because of its cost. They did not subscribe to the notion, as some insurance representatives did, that health insurance is technically available to everyone, pointing out that health insurance is certainly not available to people who have to choose between insuring their family and feeding their family. Once again, some group participants looked to the government for holding down costs of health insurance so that everyone, regardless of financial status, could afford a policy that would protect them and their families in the event of medical crisis.

C. Reduce government mandates regarding required benefits.

Although it is true that many nominal group participants argued for a government role in placing a ceiling on rising medical and insurance costs, there was also considerable sentiment, particularly among small business owners, that government mandates requiring certain benefits not only contributed to those rising costs, but also removed a decision-making role from the business owners. Several business owners complained, for example, that they were required to provide maternity benefits even though they had no female employees of childbearing age. They felt these mandates were an unnecessary intrusion of the government into their business affairs and expressed considerable resentment over this fact.

D. Education about the appropriate and realistic role of health insurance.

One theme that was common across many groups, from business owners to health-care providers to insurance agents was that many people seem to have a grandiose idea about, or sense of entitlement toward, health insurance. Many participants were frustrated with the feeling that others seem to think that health insurance should cover all ills for all people at all times, and that a high standard of medical care was a right in our society. Participants also believed that our society had lost a sense of personal responsibility for providing for one's health-care needs. Several participants called for some kind of on-going education of our citizenry regarding the role of health insurance in maintaining a healthy population. Ideas ranged from requiring the study of health insurance and related topics in public schools or colleges, to apprising employees of the

dollar value of their health insurance benefits as a way of conveying the true cost of medical care.

E. Increase, improve, and make more efficient public systems of health insurance.

Virtually all of our nominal group participants commented on the bureaucratic nightmare of fielding the public health insurance maze. Insurance agents complained that KidCare applications were impossibly complicated with little financial incentive for the broker to facilitate. They also felt that Medicaid eligibility rules resulted in people shifting between different programs or being on or off public aid, compounding the problem of paperwork. Complaints were also heard about unreliable ICHIP funds or the premiums impossibly expensive. Doctors complained of the need to hire extra staff just to sort through the web of paperwork. A host of other stories surfaced that all seemed to point to an inefficient, cumbersome, and overly bureaucratic public health insurance system.

F. Tort reform.

While there was much finger pointing about the sources of rising medical and insurance costs, there was general agreement among the participants that physicians' fear of being sued and the corresponding tendency to provide an umbrella of medical services in order to cover themselves was a major contributor to unchecked medical costs.

Many participants felt that our progression into an overly litigious society has created an environment of fear within the medical community that has resulted in the need for self-protection through massive malpractice policies. This cycle has also contributed to a growing sense of entitlement among patients that not only should all

medical outcomes be perfect, but that we should be fully compensated if they aren't. Many participants, particularly medical providers felt that returning to an environment in which doctors could practice medicine without the fear of reprisals for honest mistakes would remove one of the major factors leading to skyrocketing medical costs, thereby making health insurance more financially feasible for many.

G. Insurance industry to administer and develop state health insurance programs.

Many insurance representatives expressed concern that an increase in government insurance options in order to reach a greater percent of the uninsured would increasingly leave the insurance industry "out of the loop," thus paving the way for a public health insurance plan that would spell the end of privatized heath insurance. Perhaps anticipating what some believed to be an unstated agenda of this project to move towards a state or national insurance program, several participants felt that the insurance industry should be tapped to develop and administer any state-run insurance programs. The feeling among these participants was that the insurance industry could administer a large insurance initiative far more efficiently than states or the federal government would. Moreover, this move would afford a continued role for the insurance industry, albeit with increasing emphasis and stake in the public sector.

H. Everyone contributes his or her "fair share."

One recurring theme was the concept of contributing a "fair share" towards one's insurance needs. Among nominal group participants this theme was particularly prevalent among medical providers and insurance representatives who provided numerous examples of individuals who preferred to take calculated (or sometimes

uncalculated) risks on the assumption that the pubic system would "bale them out" if necessary. Medical providers and insurance representatives both pointed to each other as being unwilling to cut into their respective profit margins, that is, unwilling to invest their "fair share" in order to break the cycle of unchecked costs. We heard from business owners who reported stories of employees who used insurance benefits to negotiate jobs, thereby taking the opportunity to place the burden of their "fair share" on the shoulders of their employers. The concept of "fair share" was apparent by all participants who recognized that cutting into the unmitigated cycle of rising health care costs was a responsibility that needed to be borne by everyone.

I. Local control of medical decisions, and access to local providers.

There was general sentiment among many nominal group participants that managed care removes much medical decision making power from health care providers and places it in the hands of an ill-informed bureaucracy where the bottom line takes precedence over medical judgment. Doctors felt their inability to practice medicine without being confined by HMO regulations contributes indirectly to the cost of health insurance because of the multiple bureaucratic and logistical hurdles that must be negotiated in order to provide basic care.

Added to this was the frustration expressed by many participants, particularly small business owners that the need to stay abreast of shifting HMO regulations, mushrooming premiums, and changing benefit packages made it difficult or impossible to stay with one provider or another, thereby removing employees' access to those providers. Any mechanism to improve access to health insurance, they felt, had to make it easier for medical providers to practice medicine without being encumbered by

questionable regulations, and for patients to have greater say in their choice of health care providers.

J. Prevent undue penalizing for pre-existing conditions.

Small business owner participants told of being subject to precipitous rises in premium costs: 20%, 30%, 40%, even 60% in the case of one participant. These costs were often due to a medical condition of one employee, the insurance premium cost of which was then passed on the rest of the employees. Several participants said that even medical conditions that were well managed or not medically significant were often a red flag to insurance companies, resulting in huge premium increases, reductions in benefit packages, or both. Several business owners expressed bitterness that years of good faith negotiation with insurance companies and a record of no medical claims did not seem to account for anything if an employee got sick. While most business owners understood that age and its attendant infirmities necessitate a different scale of insurance requirements, they felt their entire workforce should not be penalized for the illness or a pre-existing condition of a single employee. Several participants felt that insurance companies should not have access to employee medical records, that premiums should be based on the age profile of the employee pool, and nothing more.

K. Purchasing pools and tax incentives for small businesses.

There was general agreement among business owners that they would welcome some mechanism for helping to reduce their monetary burden for carrying employee health insurance. Although most participants were unaware of the Illinois state law that permits employers to pool their companies together in order to form a purchasing group or alliance, focus group discussions about purchasing pool feasibility stimulated several

business owners to cite purchasing pools as one method for helping to close the health insurance gap. Nonetheless, several participants realized the inherent danger that purchasing pools could quickly be reduced to high risk pools for employees who are otherwise uninsurable, and that some measures would have to be taken to create a large enough pool in order to sufficiently distribute the risk.

There was less consensus about tax incentives as a mechanism for counterbalancing the cost burden of health insurance to small business owners. Although several business owners said they would welcome a tax rebate in addition to the health insurance tax credit they already receive, others wanted nothing to do with any government compensation, claiming that the strings attached would make the incentive more trouble than it was worth.

L. Separate health insurance from employment.

Although most small business owners we spoke with felt committed to their sense of social responsibility in providing health insurance to employees, and looked upon providing health insurance as a necessary tool for attracting and retaining good employees, some medical providers and health and social service agents felt that business owners had different attitudes toward health insurance. Many of the uninsured, these participants argued, constituted the working poor, people who work seasonal or several part-time jobs, thus exempting their employers from providing many of the benefits that full-time employees enjoy. They felt that such critical needs as health insurance should not be left to the vagaries of employment and other economic cycles, that another mechanism providing for a more reliable vehicle was needed to ensure across-the-board

coverage for people who are not otherwise fortunate enough to receive insurance benefits through their work.

M. Universal health care/insurance.

With the exception of business owners, the rest of the groups contained at least some participants who favored some sort of universal health care or universal health insurance. This was not seen as an ideal solution, and several participants suggested this solution with the recognition that some degree of health-care rationing was necessary in order to provide equal access to a large population. Many people were quick to point out that rationing takes place already, but that this rationing is based on ability to pay. With all of its pitfalls, many participants saw some kind of universal approach, either through public insurance or by creating a universal health care system, as the only viable means for providing affordable and reliable access to health care everyone.