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

---

[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.
[4] Nelson, C.T. & Mills, R.J. (2001) U.S. Census Bureau [On-Line]. Available HTTP: http://www.census.gov/hhes/hlthins/verify.html
[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
[6] Agency for Healthcare Research and Quality (1998). Medical Expenditure Panel Survey (MEPS). Insurance Component.