



**MaineHealth Access Project:
Findings from Consumer
Focus Groups**

May 2000



**MaineHealth Access Project:
Findings from Consumer Focus Groups**

By Erika C. Ziller, MS

Prepared for MaineHealth with funding from the Robert Wood Johnson Foundation

University of Southern Maine
Edmund S. Muskie School of Public Service
Institute for Health Policy
Portland, ME

May 2000

EXECUTIVE SUMMARY

This report presents findings from a series of focus groups conducted with uninsured adults in Cumberland, Kennebec, and Lincoln counties. Six focus groups were held during the month of April 2000, during which 44 individuals were asked to comment in detail on particular aspects of being uninsured. These aspects included: 1) the reasons participants are uninsured; 2) where, if anywhere, they receive health care services; 3) their experiences with the health care they receive; 4) barriers to care; and, 5) their unmet health care needs. In addition, participants were asked to respond to potential features of the proposed MaineHealth Access Project.

Key findings from these focus groups include:

1. The majority of participants worked at least part-time. The single greatest reason given for being without health insurance was being unable to afford the plan offered by an employer. Other reasons included being self-employed or working for an employer who did not offer insurance.
2. Although a large percentage of participants had a usual source of health care, a large portion either had no provider or else pieced together their health care services through a number of different providers.
3. Nearly all the participants reported avoiding or delaying needed health care services while uninsured, sometimes at great threat to their health and safety.
4. Unmet needs are substantial, and include: prescription drugs, preventive health services, maintenance of chronic illnesses, affordable urgent care, and specialty care including vision and dental.
5. Many participants were unaware of the reduced cost or free health care services that are already available in their communities, suggesting that marketing and outreach will be important for any new program.
6. Participants were eager to hear about potential health access program options but had significant concerns about maintaining personal dignity, assuring medical privacy, minimizing the bureaucratic demands of application and continued enrollment, and having the freedom to choose one's own provider(s).
7. Case management, in particular, was a potential program feature that evoked mixed reactions. Many participants were wary of having someone that they perceived to be a bureaucrat involved in making decisions about their health care.

PURPOSE

As part of its “Communities in Charge” planning grant from the Robert Wood Johnson Foundation, MaineHealth has commissioned the Muskie School of Public Service to complete a series of focus groups in the three counties targeted for its proposed MaineHealth Access Project. These focus groups are part of a larger effort to assess the scope of the problem of medical indigence in Cumberland, Kennebec and Lincoln Counties, and to guide program planning and outreach strategies. The first component of this assessment, a household survey, will provide prevalence estimates and socio-demographic profiles of the uninsured in the three counties. The focus group component complements this quantitative analysis by permitting a deeper exploration of the issues facing uninsured, low-income individuals in the MaineHealth Access Project target area. Specifically, the focus groups were convened with four key purposes in mind:

- 1) Identify distinct market segments of the uninsured;
- 2) Identify access barriers;
- 3) Understand current utilization and health seeking patterns; and,
- 4) Assess attitudes, preferences, likes and dislikes for potential program features.

APPROACH

Methods and Participants

During the month of April 2000, six focus groups were held in Augusta, Boothbay, Damariscotta, Portland, Waterville and Windham (two groups per targeted county). Staff at MaineHealth was responsible for selecting these towns as focus group sites. Participants were recruited by staff at Consumers for Affordable Health Care through a variety of methods, including posters in local businesses and community organizations, letters to patients of safety net providers, newspaper public service announcements, and the telephone household survey. To be eligible for participation an individual needed to be uninsured, aged 18 to 64, and have a household income below 300 percent of the federal poverty level (see Appendix A for federal poverty level thresholds). Eligibility was confirmed prior to the focus groups by the administration of a screening questionnaire that collected basic demographic information, including age and family income. A copy of this questionnaire is provided in Appendix B.

A total of 44 individuals participated across the six groups, with an average group size of seven. These participants ranged in age from 21 to 64, with a mean age of 42. More than two-thirds (31) of the participants were female and all appeared to be white, non-Hispanic, although the participants themselves did not verify this. Three-fourths of the participants were employed at least part time. Of the 11 participants who were not currently working, three reported that another family member was working, while another five have chronic illnesses that impede their ability to seek employment. During a focus group we discovered that one of the participants actually did have Medicaid because of a disability. In spite of this, she is included in this report because her \$2,300 per year deductible has left her facing many of the barriers experienced by the uninsured.

Focus groups were conducted using a semi-structured interview protocol that was designed by Muskie School staff in collaboration with staff at MaineHealth and Consumers for Affordable Health Care. Participants were asked to share information on a number of topics, including why they lacked health insurance, their current use of health care services (if any), what their unmet health needs are, and what features of a health care access program would be beneficial to them. A copy of this protocol is included as Appendix C. The duration of each focus group ranged from just over an hour to nearly two hours.

Limitations

Using focus groups as a research method permits the collection of rich, detailed data on a particular subject, thereby yielding a deeper understanding of many of the factors related to that subject. However, this method is also intrinsically limited in its ability to make generalizations to a larger population both because of the small sample sizes necessary for effective group process and the data collection methods. Specifically, the fact that data is collected from a group poses the limitation that the most vocal participants will contribute more to the findings, even though their perspectives and experiences may be in the minority. We attempted to minimize this potential limitation by using a semi-structured interview protocol and having the group facilitator actively encourage broad participation.

In addition to the small sample size and data collection methodology, the fact that many participants were self-selected (i.e. by responding to flyers or public service announcements) limits the generalizability of this study. Despite efforts to achieve diversity through a multi-method recruitment approach, the non-random sampling of the focus groups participants means that there was a strong possibility of bias in the final sample. Certainly the lack of minority group representation and the high proportion of female participants indicates that some selection bias did occur. Consequently, we cannot conclude that the experiences of participants are representative of all uninsured in the three counties that were included in this study.

FINDINGS

Reasons for Uninsured Status

Participants were asked to describe the factors that have led to their current lack of health insurance. The single largest reason that participants gave for being uninsured was that they could not afford the plans offered by their employer. For these participants, the reported employee share of premiums ranged from \$200 to more than \$600 per month. Not only were these premiums unaffordable, but many participants considered them a bad use of resources. A number of participants who had recently been covered by a private health plan remarked that in addition to paying for premiums, they had substantial out-of-pocket costs for their health care. Consequently, a large number of people considered private health insurance to be a bad purchase since they rarely, if ever, met their deductibles in any given year. A smaller number of individuals also felt that health insurance was a bad investment because it rarely covers alternative health care services, such as acupuncture or massage, that were an important source of care for these participants.

The other main reasons that people were uninsured were that they were self-employed and could not get an affordable health plan or that they worked for an employer who did not offer health insurance. A substantial proportion of the latter group worked in professions that typically do not offer health insurance to workers such as restaurant staff, hair stylists, and daycare providers. Particularly in the Boothbay area of Lincoln County, many participants hold multiple seasonal jobs that do not offer benefits. Other participants reported that their employers were simply too small to be able to afford health insurance for their employees. Finally, a small number of

participants had chronic health conditions that limited their ability to work but were not deemed severe enough to warrant official disability status, or else other household income prevented these individuals from being eligible for Medicaid.

Health Care Utilization and Unmet Needs

The majority of the individuals who participated in the focus groups reported themselves to be in generally good health, and consequently not in need of a high level of health care services. Many of the participants have established relationships with a health care provider, either a private practitioner or safety net provider. The term “safety net provider” is used to refer to both public and privately funded health care services targeted to indigent and uninsured patients that are offered at no charge, or on a sliding fee scale basis. This was particularly true for the participants of the Portland focus groups, nearly all of whom were participating in various free or reduced cost health care programs sponsored by MaineHealth, Mercy Hospital and Portland Public Health. Participant relationships with a usual source of care were more infrequent in the other five areas and were much more likely to be with a private physician or group practice, reflecting in large part the greater availability and organization of safety net services in Portland.

Although many individuals reported having a usual source of care, a large proportion of participants did not. These individuals either had minimal contact with the health care sector or else patched together health care services from a number of different providers. For example, one woman obtained her immunizations through a per diem health care job, routine physicals from a private provider, and sick care from a hospital clinic that charges a flat fee on weekends. Another woman obtains reproductive health care from a family planning clinic and other services from a private physician. A surprising number of individuals reported that alternative care providers were an important component of their health care, particularly in the Damariscotta region of Lincoln County. Among the alternative care providers identified were chiropractors and massage therapists.

Between 15 and 20 percent of the participants reported using emergency room services while they were uninsured. A small proportion of these was for emergent conditions such as when a man amputated a portion of his finger, or when a woman at elevated risk for heart disease

experienced chest pain and an irregular heart beat. In both of these cases, the individuals qualified for charity care and the hospitals forgave a portion of the debt. However, both individuals found the remaining debt to the hospitals and doctors to be large financial burden and, despite regular monthly payments, believe that it will take a long time to pay off these debts.

Most of the emergency room visits that were described by participants appeared to be for non-emergent health needs. For example, one woman with a history of frequent urinary tract infections found that she was not responding to self-treatment and needed a prescription for antibiotics. Because she did not have a primary care provider, she sought treatment at the emergency room and had to pay nearly \$1000 for the visit. Another women described a similar experience and \$600 charge when she went to the emergency room for treatment of a simple gynecologic infection. A third woman described taking her uninsured infant son (now enrolled in CubCare) to the emergency room for a high fever and having to pay more than \$500 when he was ultimately treated with an over-the-counter fever reducer. In each of these examples, individuals were forced to make regular payments, over many months, to cover emergency room visits that may have been avoidable if each had an on-going relationship with a regular care provider.

The single most commonly reported strategy for coping with being uninsured was to delay seeking health care services. Nearly all the participants in the focus groups reported that they had delayed some health care because they lacked health insurance. Most admitted that they preferred to “wait and see” rather than seeking medical attention. As one women put it “In my family we have to be dying before we go to the doctor.” In some cases, this delay has led to more urgent and costly treatment than would have occurred if participants had been able to access care more quickly. For example, one woman delayed seeking care for an infection that worsened and ultimately led to an emergency visit at a Portland Hospital. Another woman suffered through the discomfort of gallstones for a year because she could not afford to have them removed, only to be rushed to the hospital in intense pain for emergency surgery. A man reported that he had recently sustained a deep cut to one of his fingers and, instead of going to the emergency room, had his mother-in-law (an LPN) apply butterfly strips to hold his finger together. Because this was a recent injury, it is unknown whether this man will experience any

long term effects from not receiving stitches, or other emergency medical attention, for this injury.

As might be expected, one area where many participants have delayed or avoided seeking health care services is preventive care. One man who was approaching retirement age reported that the last time he had a complete physical was when he was in the military as a young man. Another woman who has an on-going relationship with a gynecologist stated that the last time she had a comprehensive reproductive health exam was more than seven years ago. This delay occurs even though individuals clearly recognize the value of preventive care for maintaining and improving health. One participant stated that she would very much like to quit smoking but needs the support of a nicotine replacement system that she cannot afford without health insurance.

In addition to routine preventive care, a number of participants reported delaying or avoiding health care services that they desperately need for an on-going health condition, potentially risking their health in the process. One woman has a history of breast disease for which she should be receiving regular screenings, however she cannot afford them. Another woman with thyroid dysfunction can usually afford her medication; however, she cannot afford the routine blood tests necessary to gauge thyroid function and response to medications. A third woman has a potentially life-threatening neurological disorder that needs regular monitoring via catscan, but being without health insurance has put her far outside the recommended timeframe for this monitoring.

Focus group participants in all three counties reported mixed experiences seeking care from private physicians while uninsured. A number of participants who identified themselves as having a private primary care physician stated that, while they have been without health insurance, their providers have tried to accommodate them in a number of ways. These have included allowing patients to spread out payments over time, discounting their fees, ordering only lab work that is absolutely necessary, prescribing lower cost medications, and providing free drug samples. On the other hand, a number of participants reported that when they attempted to access a private physician for services they were told they needed all, or a

significant portion, of the visit cost up-front. One individual reported that after seeing her provider she was given a prescription for an antibiotic that cost approximately \$100, although she believed a cheaper medication would have been sufficient. Another participant stated that when she attempted to make an appointment with a private physician she was told to “call back when you have health insurance.” Although not confirmed by participants, it appeared that the individuals who had been privately insured and had established relationships with private providers had a better experience obtaining health care from these providers than individuals trying to find a new provider while uninsured.

In every focus group, prescription drugs were cited as one of the biggest areas of unmet need, both for acute and chronic health needs. Many participants reported that while they can afford a provider visit if necessary, they frequently find themselves unable to afford the provider’s prescribed medications. According to participants, this is a particular problem because, unlike other provider types, pharmacies do not make payment arrangements with consumers. A couple of individuals with chronic health problems have been able to take advantage of indigent drug programs or clinical trials operated by pharmaceutical companies, however many more have gone without needed medication. Several individuals with asthma or another chronic pulmonary disorder have reported using half the recommended dosage of their inhalants or else using expired medications. One woman with a neurological disorder reported being unable to obtain a prescription necessary to prevent her from having seizures. Another woman who had an emergency hysterectomy in her twenties states that she has extreme difficulties obtaining the estrogen-replacement therapies that she needs to prevent severe, systemic discomfort. Even basic, routine prescriptions such as oral contraceptives were reported to be hard to get for some participants.

Participants in all three counties reported that access to dental health care is a significant problem. Many participants felt that, while it is often possible to find a medical provider who will discount services or accept partial payment and agree to a payment plan, dentists are rarely willing to make these accommodations. Consequently, a number of individuals have severe dental health problems for which they cannot obtain treatment. Two women reported that they have lost teeth as a direct consequence of this unmet need. One man reported that he repeatedly

is prescribed antibiotics for abscessed teeth but cannot afford to have them extracted. Another woman has TMJ for which she needs dental attention and her inability to obtain it frequently leaves her in great pain.

Other Barriers

In addition to the financial barriers attributable to their lack of health insurance and low income, participants reported other barriers to health care. A number of participants identified the hours that providers are available to be a significant barrier. Several individuals pointed out that because their employers did not offer paid leave for medical appointments they had the added expense of lost wages every time they sought medical care. In addition, a number of participants reported that the stigma of being uninsured has prevented them from seeking care either in the private or public health care sector. Several individuals expressed shame over using safety-net providers or trying to negotiate payment arrangements with physicians. Others felt that applying for Medicaid or charity care was a humiliating process that violated an individual's right to privacy.

Although not explicitly discussed, another barrier to care that emerged from the focus group meetings was that many participants were unaware of the health care resources in their community. For example, a number of participants in Lincoln County were surprised to hear from other participants about the safety net providers in their communities, such as the Miles clinic or St. Andrews' weekend clinic, where services could be obtained at a reduced cost. Similarly, only two Kennebec County participants had applied to the MATCH program, even though others may have been eligible.

Even when participants are aware of different health care resources, there is evidence that these resources are not entirely responsive to the needs of the uninsured. For example, one of the Kennebec participants who had applied to the MATCH program had been categorically denied enrollment because her employer offered health insurance coverage, even though she stated that she could not possibly afford the premium. In Lincoln County, several participants reported confusion about the policies surrounding the walk-in clinic operated through the Miles Hospital emergency room. Two separate individuals felt that they had been misled into using what they

believed were urgent care services and then charged at the emergency room rate. One person described the Miles walk-in clinic as a “bait and switch” scheme whereby the hospital lures people into thinking they will have a lower cost visit and then charges the emergency rate.

Program Design

Consumer Recommendations

Most participants felt that guidelines for program eligibility should not be too limited, particularly with respect to family income, or else a substantial number of the uninsured may not be served. Instead, most participants agreed that having a relatively higher income ceiling and requiring participants to contribute to their own health care on a sliding scale would be the best way to design a program. Participants repeatedly stated that they wanted to pay their own way, but simply could not afford the premiums on any health insurance plans that might be available to them. Lincoln County residents, particularly in the Boothbay region, stressed that income should be considered on an annual basis because of the highly seasonal nature of most employment there. One participant remarked that if participants needed to recertify for a program in July, based on that month’s income, nobody in the region would be eligible because many uninsured adults work two or three jobs in the summer to save enough money to last the winter.

Participants were asked to describe what services would be most important for a health care access program to provide. A significant number of participants expressed that their greatest concern is for catastrophic illnesses. Many individuals stated that they were comfortable paying for primary care services out of pocket, but worried that a chronic illness or accident would cause them to lose their home or other assets. As one participant stated, “I can take care of the nickel and dime stuff, but the big stuff can wipe you out.” On the other hand, an equally large number of participants felt that charity care or Medicaid would probably be available in the event of a catastrophic condition. For these participants, low-cost access to primary and specialty care services was the chief concern. Although not explicitly confirmed by participants, these differences appeared to be based in part upon the relative financial situation of participants, where individuals with higher incomes or assets were more concerned about catastrophic care and those with lower incomes were more concerned about routine out-of-pocket costs.

In addition to these general categories of care, participants specifically recommended that a health care access program provide the following services:

- Preventive health visits and screenings
- Low or no cost prescription drugs
- Eye care
- Dental care
- Immunizations, including influenza shots
- Mental health services
- Urgent and emergency services
- Laboratory services
- Specialty care, including chiropractic services and physical therapy
- Alternative health care such as acupuncture and massage therapy
- Treatment for injury or illness, including catastrophic care

Case Management

Participants were given a brief description of case management and asked to comment about the benefit of case management as part of a health care access program. Participants expressed a broad range of opinions about whether or not case management would be a beneficial feature of the program. Most participants felt that case management could be valuable if available on an as-needed basis, but that it should not be an eligibility requirement for the program.

A vocal minority of participants did not see any value in having a case manager and felt that it would be much more beneficial to put those salary resources toward direct health care services. Some participants were concerned that a case manager might be actually be a barrier to care if he or she needed to be involved in decisions to access health services. Others stated that they were uncomfortable sharing their medical information with a third party, and felt case management could be a threat to their privacy. The undercurrent of these concerns was that participants feared that the case manager could potentially be a mean-spirited bureaucrat who, overburdened by a heavy caseload, would not treat them with respect.

Participants appeared to be more accepting of case management when the health education, versus the administrative, functions of a case manager were used to describe this potential program feature. Some individuals who had recently had private insurance, or those with children covered by Medicaid or CubCare, spoke favorably of experiences with toll free “nurse hotlines.” These participants felt that the case manager should be a medical professional, like a registered nurse, that would be available to provide health information and to triage urgent or emergent health care needs. Others believed that a medical background would be beneficial, however, the case manager should also be well educated about alternative medicine so that they could provide a complement to information provided by a participant’s physician. Most participants emphasized that case management would only be beneficial if the case managers were advocates for consumers, not simply screeners for program eligibility.

Primary Care Provider

For the most part, participants were amenable to the idea of having a program based on a primary care provider model. A large number of people felt that this would be a great improvement over a clinic model because they would be able to see the same provider each time, as opposed to seeing whoever was on duty. Some of the participants stated that they didn’t care what provider was assigned to them, as long as they could have one. On the other hand, participants who already had relationships with primary care providers expressed reluctance over having to switch providers. Despite this reluctance, nearly all of these individuals stated that they would switch to another provider if theirs refused to participate in the access program. However, one or two of these participants said that they would not participate in a program if they were forced to change primary care providers.

The participants’ greatest concern about the primary care provider model was what would happen if they did not like the provider who was assigned to them. A substantial number of participants stated that a good provider-patient relationship dramatically affects both health care access and health outcomes. Most participants felt strongly that individuals enrolled in any program should have the power to switch to a different provider if they clashed with either the assigned provider’s personality or his or her practice style.

Even if there was freedom to switch providers, some participants expressed concern that their choices would be limited because only “bad” doctors might participate in the program. This was particularly true for individuals who had bad prior experiences trying to find providers for themselves or their children who would accept Medicaid, and reflects an underlying concern that those without private health insurance are treated like second-class citizens by the health care sector. One participant succinctly articulated this recurring theme with the comment, “We are just nobodies.”

Some participants also expressed concern about the role of primary care provider as gatekeeper to other services. For the most part, these concerns were typical for any consumer facing managed health care services—they wanted to have the freedom to decide themselves when to seek care and from whom. However, some of the participants described concrete difficulties that they have had in the past with the gatekeeper model. For example, a few participants whose children were enrolled in the PrimeCare or NYLCare plans through CubCare and Medicaid described being frustrated over trying to get a child’s primary care provider to handle referrals appropriately. The chief complaint was that primary care providers frequently did not complete the necessary paperwork in a timely fashion.

CONCLUSION

The focus group participants in Cumberland, Kennebec, and Lincoln counties were an eclectic group, with diverse financial situations and health care needs. For the most part, they were employed and in good health, although a handful had chronic health conditions that impeded their ability to work. Roughly one-third worked for employers who offer health insurance with employee cost-sharing of premiums that prohibits their enrollment, while nearly half were either self-employed or work at a job that does not offer insurance.

The lack of health insurance has led individuals to delay or avoid needed health care services, sometimes at great risk of morbidity or even mortality. These delayed or avoided services have included routine screenings for chronic health conditions, surgeries, emergency treatment for relatively severe injury, and medications critical for the treatment of an on-going health condition. Consequently, participants were eager to

MaineHealth Access Project: Consumer Focus Groups

hear that MaineHealth is working to improve health care access in their communities. There was widespread agreement that access to health care services is a basic human right and people shouldn't have to choose between "paying the power bill or paying for a prescription." As one woman said, "We're just small people trying to live. It's a shame we have to sit here and complain about [not having health insurance]."



EDMUND S. MUSKIE SCHOOL OF PUBLIC SERVICE educates leaders, informs public policy, and broadens civic participation. The School links scholarship with practice to improve the lives of people of all ages, in every county in Maine, and in every state in the nation.

EDMUND S. MUSKIE SCHOOL OF PUBLIC SERVICE
96 Falmouth Street
PO Box 9300
Portland, ME 04101-9300

TELEPHONE (207) 780-4430
TTY (207) 780-5646
FAX (207) 780-4417
www.muskie.usm.maine.edu