

Speaking From Experience:

# **VIEWS FROM IOWANS ON HEALTH CARE, WELLNESS, AND PREVENTION**

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## Focus Group Report

As part of the Real Iowans Research Initiative  
SPPG, Inc.

**MARCH 2010**



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# Introduction

In the context of health care policy, access, cost, and benefit, the voices most often heard include policymakers, health care providers, pharmaceutical companies, and insurance companies. Employers contribute to the discussion with their perspectives and their checkbooks. Without a doubt, all of these industries and interests are critical to the discussion and to ensuring affordable access to quality health care in Iowa and across the nation.

The story is not complete, however, without the value and rich context brought to the table by the people – ordinary, real Iowans.

The Real Iowans Research Initiative (RIRI) brings quantitative and qualitative data from the people of Iowa into the discussion. One key element of the research is the qualitative data gathered in a series of eight focus groups with Iowans in their communities across the state. Findings reported here reflect the perceptions of Iowans of their situations and experiences with health care, wellness, and prevention. The focus group process and findings are one way to provide a fresh and significant viewpoint from Iowans who represent segments of the population frequently underrepresented in other research.

Iowa's employers and employees in the private and nonprofit sectors face growing challenges in maintaining health care benefits. The cost of health care benefits provided by employers to employees continues to increase steeply, while organizations struggle to maintain health care coverage and access to wellness benefits. Since 1999, premiums for employee-only coverage have increased by 115 percent, and family premiums have increased by 109 percent. (David P. Lind & Associates, LLC *2009 Iowa Employer Benefits Study*. 2009.) Lind's 2010 survey showed an increase of 132 percent since 1999 for both groups.

Expanding access to high-quality and affordable health care has become an urgent priority, and the Real Iowans Research Initiative was developed to provide a collective voice for all Iowans, a voice all too often missing in health care policy forums. Data more frequently address employer, health care provider, insurance, or public program findings. Seldom are regular Iowans asked for information, even though they are directly impacted by the systems being debated.

The Real Iowans Research Initiative engages Iowans from all sectors and population groups through three strategies:

- » Focus groups of underserved and under-represented groups who are less likely to participate in a traditional survey;
- » A population-based survey on Iowans with a primary goal of identifying health needs, priorities, and opportunities of the population; and
- » A series of individual conversations with leaders in all sectors.

The Real Iowans Research Initiative is a non-partisan, collaborative project of three organizational partners who understand the importance of health care in the workplace and seek to identify needs, priorities, and opportunities for employers, employees, and those without employer-based health plans. The initiative is led by the Healthier Workforce Center for Excellence (HWCE) at The University of Iowa's College of Public Health. Partners are the HWCE, David P. Lind & Associates (DPLA), and State Public Policy Group, Inc. (SPPG).

## Overview

In this year-long effort, the Real Iowans Research Initiative partners sought to fill a data gap in Iowa research on health protection and health promotion that can guide development of evidence-based employee well-being programs. A statewide telephone survey was determined to provide a reliable best-case option for data collection. However, even this approach left a gap in the data from several segments of the population who, for one reason or another, are less likely to participate in a telephone survey. In addition, there are segments of Iowa's population whose voices are important to the issues but are not easily identifiable in a telephone survey.

The set of eight focus groups was designed to ensure inclusion of those hard-to-identify and hard-to-engage segments of the population that otherwise would not be heard. The focus group methodology offered an opportunity for more in-depth questioning regarding issues facing those populations. Iowans included in the focus groups were elderly Iowans, people with disabilities, people with mental health considerations, African Americans, Latinos, and uninsured and underinsured. The qualitative research allowed RIRI to paint a picture of the impact of health care coverage on Iowans in these populations.

The focus group findings contributed significantly to the understanding of the priorities of, benefits for, and challenges facing Iowans in these population segments related to health care access, affordability, employer-based benefits, wellness, and prevention. The findings stand alone in their value to decision makers in Iowa's health care and insurance industries, as well as to employers of all sizes and types.

# Methodology

Eight focus groups were held in rural and urban locations across Iowa in February and March 2010. Three sessions were held with uninsured and underinsured Iowans. One session each was held with elderly Iowans, people with disabilities, people with mental health considerations, African Americans, and Latinos. A list of locations and populations is included in the Attachments.

The target populations were selected by SPPG, in consultation with partners from DPLA and HWCE. In the focus groups, the partners sought perspectives from Iowans who may have a special need for health care coverage and related services, who may have unique cultural or behavioral characteristics that may impact their interaction with health care coverage and related services, who may be part of a small but significant portion of the population, or who may be less willing to participate in a telephone survey or other quantitative research effort.

In short, the qualitative research sought to elicit important information about health care, prevention, and wellness issues from individuals less likely to respond to more traditional, quantitative research methods.

Because of the heightened reluctance of the identified populations to participate in research initiatives, participants were recruited and invited to the focus groups through trusted third parties. SPPG identified and contacted organizations across the state known to have credible and reliable relationships with the populations sought. Those organizations advised SPPG in such details as the best locations for hosting the session. SPPG provided the details and a letter of invitation from the HWCE and SPPG to the trusted, third-party organizations. They, in turn, issued invitations for the sessions in each location.

For example, to identify and invited uninsured and underinsured individuals, SPPG contacted a community health center (CHC) that offered to host the session since patients were accustomed to coming there and were comfortable. CHC providers gave the invitation and details to an array of patients over the course of several weeks. Those patients, later, independently chose whether to attend the focus group.

As an incentive for participation in the focus groups, a \$50 gift card to a local grocery store was provided to each participant at the close of the session, and was limited to one gift card per family.

Each focus group session was held in the afternoon or early evening and was two hours in duration. An SPPG facilitator led each session, and SPPG staff took detailed notes of participant comments. A representative of HWCE also attended each focus group. Participation ranged from 4 to 19 individuals, with a desired group size of 10-12.

SPPG facilitated the focus groups using a script for consistency across all sessions. Minor adaptations in the script were made to relate to and engage the specific population. The script opened with introductions of the facilitators and the purpose of the focus group, and participants introduced themselves. SPPG outlined the guidelines and time frame for the focus group. SPPG structured the focus groups as a series of premises, each followed by a set of related questions. The premises consisted of a statement and description of points typically believed to be true. The questions that followed each premise elicited the perceptions of the participants related to the premises. The initial premise and questions were introductory in nature and allowed participants to speak in general about the issues; this served as a time for participants to become comfortable with the setting and speaking in front of the group without taking great risk in making their comments. As the focus group proceeded, the premises and questions become more complex and delved more deeply into the issues of health care, prevention, and wellness.

Participants became more open and forthright. A final question was asked to elicit each individual's highest priority.

The premises in these focus groups were issue based. The five premises focused consideration and comments on:

- » the participants' description of what health care means to them,
- » whether and how health care coverage is provided or available to participants,
- » where and how participants access health care and other health services,
- » participants' perceptions and experiences related to cost of health care and related services, and
- » priorities of participants related to health care coverage, health care, wellness, and prevention.

Throughout the focus groups, SPPG staff took notes of participant comments using a laptop computer. Those notes were not attributed to specific participants and were written as near as possible to verbatim comments.

# Findings

The qualitative research methodology brought regular Iowans from all walks of life to the table for discussion of how their lives intersect with the health care system, health care coverage, access, prevention, and wellness. Their responses and examples provided critical context to the overall research initiative and demonstrated the real-life impacts of the issues of wellness, prevention, and health care coverage on these distinct subsets of Iowans. Stereotypical thinking was exposed through the comments of various participants. In all focus groups, it was strikingly clear from the examples and comments that health care is entwined throughout people's lives and often defines their life options.

A number of cross-cutting themes emerged across all of the target populations. Though these focus groups occurred during the time that health care reform was being debated at the federal level, participants did not center their attention on that element. Rather, they responded succinctly and firmly to the issues of health care coverage, prevention, and wellness. In addition, other findings reflected perceptions and situations of a particular subset of the state's population.

In the focus groups, participants spoke of health care coverage in very broad terms, and were not expected to adhere to a pre-determined definition of health care coverage. This provided the RIRI with a greater level of understanding of how participants perceived and understood "health care coverage." Coverage, to participants, meant any way they could find to get their health care paid for, including such means as Veterans benefits, charity care, free clinics, Medicaid, Medicare, local public health and community services, and private pay or employer-offered insurance. Participants did not typically perceive Medicaid, Medicare, HAWK-I, or IowaCare as insurance.

## Common Themes

The common themes are listed here, with elaboration following.

- » Wellness is understood and is a priority for most participants.
- » Health care, to many participants, means health care coverage.
- » Equity in health care coverage is needed.
- » Medicaid and Medicare coverage are considered better and more complete than employer-based insurance.
- » People without health insurance become expert and entrepreneurial at accessing services, or they do not seek care at all.
- » People recently unemployed and the uninsured have a more difficult time understanding how to navigate the fragmented health care system available to them.
- » Wellness and affordable, accessible health care coverage are the two most-frequently cited priorities of participants related to their health care and that of their families.

### *Wellness is understood and is a priority for most participants.*

Participants in all of the focus groups think about staying well, preventing illness, eating right, and exercising as they consider health care. Some indicated prevention measures and wellness as a defensive tactic to prevent more serious or chronic conditions or illnesses. Others use wellness activities and/or diet to help manage existing conditions. Many lamented the higher cost of eating healthy foods, particularly fresh fruits and vegetables. And many simply admitted to good intentions where healthy eating and exercise were concerned, but lapsed in implementation. While awareness of and attention to

wellness, prevention, healthy diet, and exercise were typical among participants, their emphasis varied according to the subgroup to which they belong.

The following comments from each of the eight focus groups illustrate the widespread understanding of the value of wellness, prevention, healthy diet; and exercise.

- » Diet and exercise are primary parts of personal success. Health care is a very complicated issue but prevention does allow people to put care back in their own hands.
- » Because I am a diabetic, I have to take care of myself.
- » Even if you keep yourself healthy and have good insurance, you still want to keep healthy. Eating right and exercising are very important.
- » Wellness is not a part of our culture. Wellness for me means you are going for your checkups and are up to date on your checkups.
- » The economy has gotten to the point that both parents have to work and there is no time to prepare healthy food, no matter what race you are.
- » If it is a choice between going to the wellness center or getting prescriptions, groceries, or gas in the car, we are going to choose the others, not the wellness center.
- » Children do not want to even go outside since technology is such a big part of their lives.
- » Wellness would mean keeping me healthy, but that is very hard. When I had my first stent put in, I tried to keep myself well, but it was hard without insurance, because every little problem got overlooked.
- » Personally, I like to stay healthy. Eating right and exercising, using a multi-vitamin, I do it. Family wise, it's stress. It's "You better eat right because we can't get to the doctor." If you go to the doctor, then we have to sacrifice something. A small illness can turn into a big problem.
- » Just recently wellness has become part of health care. Now at the grocery store they have the nutritional scores. I don't pay attention to them. I know they're there. You get disappointed because the things I thought were healthy are not really so healthy. It just seemed like a ploy. I think it's nice that health care is promoting wellness. Maybe they are earning money from check-ups rather than other access.
- » I should do better and I try, but I tend to fall back. I try to exercise and follow my doctor's advice. As a fallible human being, I know I fail.
- » Physically and mentally taking care of yourself.
- » I would consider all those things, really. Sometimes it's hard to do them. It's all about your income and timing. Often I think, "I should've done this." It's easier to think about it than do it.
- » Independence and operational function. Do I feel well enough to do what I want to do? In my life it has always been part of health care.
- » My story is that when I've thought of health care, I think of when I get sick someone will help me get well. Now as I age, I understand that wellness and exercise are important. It's my own responsibility, though. I need to help myself.

#### *Health care, to many participants, means health care coverage.*

Most focus group participants, regardless of target population, perceived health care to be directly tied to health care coverage. Many did not distinguish between the two. Others indicated that health care coverage was the only way they could get health care. "Bills" was the response from a significant number of participants when they were asked what health care meant to them. Not all of those first responding about the high bills they received were uninsured, but they cited exclusions for pre-existing conditions or other experiences where their health care coverage was not adequate. It is important to note that participants were not necessarily expecting or referring to health care coverage as insurance provided through an employer-based setting in these responses.

The following comments from each of the eight focus groups illustrate what “health care” means to participants.

- » It means taking care of us throughout our lives, to old age. Preventive medicine is the key to a lot of issues. There are a lot of people who are not getting that. A small issue then becomes a serious issue. These issues are life altering.
- » I think it is a holistic process, a combination of lifestyle and medical providers. It also includes prescription coverage.
- » I think of health insurance.
- » It is about having a comprehensive array of services and supports to help me keep well.
- » I tend to think holistically. I think of the full spectrum – physical, emotional, mental health. The entire spectrum of wellness that puts people at their peak and helps them live full lives.
- » The first thing that comes to mind is that it has to be comprehensive. When I think of health care, I think of the structures and persons that help people to be healthy.
- » To be protected if I am sick or hospitalized.
- » I think of expenses. And also how every time I go to the doctor they find something. It discourages me from going. I think of money and problems.
- » I think of health care as insurance. If you have [good insurance,] you get treated quicker and better.
- » I have seen race play into what health care can be for different people.
- » Being healthy so you would not have to go to a doctor.
- » My first thought is where can I go to get it. I’m uninsured and it scares me and don’t know what is best for me.
- » Yes, care for my children so that they have everything they need. Good medical care, the best team at the medical office, and prevention.
- » I see it as a cycle. If you’re healthy, then you’re OK, you can monitor that from home. But if there is something wrong, then you need insurance to be able to go to the doctor to get attention for your needs.

#### *Equity in health care coverage is needed.*

Participants generally reported that all people should have health care coverage and be treated alike, citing an issue of fundamental fairness. While many agreed with that assertion on principle, others spoke from their experiences of having had health coverage and then losing it. Their treatment experiences became different. Still others spoke from the experience of having various types of coverage, such as private employer-based coverage, public employer-based coverage, Veterans benefits, Medicaid, or Medicare. Some participants had never had coverage; others had health coverage of one type or another throughout their lives. While there was no focus on what type of coverage should be provided to all, virtually all participants spoke in some way regarding the importance of equity and fair treatment for all people, which they perceived to come through having health care coverage.

The following comments from each of the eight focus groups illustrate the views of participants on the issue of equity in health care coverage.

- » The private insurance that I have does not cover dental, vision, physical therapy, mental health, or other regular care.
- » You are required to pay or you are not always treated very well at the doctor.
- » We will get cycles in our community when there is nobody [no provider] that will see people on Medicaid.

- » Yeah, but the medication that they show on television – you may not be able to get that at your doctor. You have to try the generics first to prove they don't work before being prescribed the name-brand stuff.
- » Health care ought to be available to everyone. Doctor, hospital, dental, vision, mental health, etc. These should all be covered.
- » I would make sure all people had affordable health care.
- » Around here, when they realize you don't have insurance, they tell you to go over to Iowa City so the students can treat you.
- » The quality of service changes when they realize you don't have insurance. They treat you very differently when you don't have insurance. The quality changes.
- » When I had Title XIX, I didn't get the follow-up. Even the receptionist treats you differently. And they don't talk to you as much. Sometimes they may even belittle you a little bit. Now that I have insurance, I have to go back again with no answers. With my insurance, he wants me to come back. When they know you have insurance, you are treated differently.
- » Wellness is becoming something that is only available for rich people.
- » When I came to the Community Health Center, I found that I had a lot of problems that were overlooked because I did not have insurance.
- » When I got the mighty private insurance, I was treated like Obama.
- » Working in the nursing home, I know how the pharmacy charges elderly folks and it is very different from what the Community Health Center does.
- » I have a pre-existing condition, and cannot pay for insurance.
- » Something that is affordable and accessible to everyone, regardless of who pays for the system.
- » We need a single-payer system, but a partnership between the doctors, providers, and hospitals.
- » Health care is a system – not a very good one. We do not provide for everyone equally and do not provide equal access for those who are uninsured. I have heard that there are more than 10 million people without insurance. Who pays for this? This should be a public outcry.

*Medicaid and Medicare coverage are considered better and more complete than employer-based insurance.*

Many focus group participants across the spectrum of populations previously or currently had coverage through Medicaid, IowaCare, HAWK-I (for their children), or Medicare. Eligibility criteria met by participants for these federal and state health care coverage programs included income, disability, or age. These programs were cited by participants as having the most complete coverage they had ever experienced. That is not to say the programs are without challenges. Rules are often complicated and recipients need to track reimbursements and sometimes need to appeal denied rulings. The paperwork associated with some of these programs was daunting to participants. Nonetheless, all were grateful for the breadth of coverage these programs provide. Some recipients of Medicare had concerns about the high cost of the premiums they must pay to receive office and pharmaceutical coverage. It is also important to note that those receiving health care through the Veterans benefit system were also very pleased with the services provided to them at no out-of-pocket cost.

The following comments from each of the eight focus groups illustrate the experiences and perspectives on state-funded and federally-funded health care coverage.

- » I go to the doctor every two weeks, and Title XIX let me keep my old doctors in Omaha.
- » I have both Medicare and private supplemental. Many older adults I know are going back to work. They don't have benefits like they should and are totally reliant on Medicare. And there are gaps – especially with pharmaceuticals.

- » Mine was provided by my employer at the time of my accident. I was hit by a drunk driver and injured my head. I lost my insurance about a year after. I have IowaCare right now, so if I need surgery I can go to Iowa City. But I can't get the prescriptions I need. They can't prescribe them.
- » The lenses are covered under my plan, but not the frames. Dental care is covered 100%. They'll pay for a YMCA membership - at least some of it. I can get it for about \$30 a year. That is through the Department of Human Services (DHS).
- » The last coverage I had did have inclusive coverage. Through Linn County - the coverage did cover dental and glasses. That was really very smart. If you were impaired and had coverage, you got that covered. It helps people before it's a problem. The mental health coverage is offered, but for me it's limited. That is not through IowaCare - it's through the MHDD (Mental Health/Developmental Disabilities) program of the county.
- » In the past, employers' insurance covered pretty much everything. Now my combination of Medicaid and Medicare cover pretty much everything except dental, for instance root canals and dentures.
- » I am on disability and get Medicare. Before that, I was on IowaCare. I was also a participant in Medicaid for Employed Persons with Disabilities (MEPD), which filled the gap for me. I used to go to Broadlawns and also to the community health center.
- » I go to the community health center and the mental health center. The county pays for mental health since IowaCare does not include mental health coverage.
- » I go to the VA in Des Moines and do not have insurance. I had a cancerous lipnoid taken out of my neck, diabetes, knee replacement, and stent in my heart, all covered. I got married five years ago and unbeknownst to me, he is retired from the Army. Now because we are married, I have an Army ID card. We can go to any doctor we want with TriCare for life. We also have Medicare. Had I known that, I would have married him a long time ago.
- » It is amazing that we have Medicaid, Medicare, TriCare, federal employee health insurance, and people say that they do not want to have government involved. They provide the best insurance!
- » We have Medicare and it takes care of us.
- » I had cancer two years ago and had to have chemotherapy, and it was very expensive. It also made me so sick. I did not owe a dime, and so when the church wanted to have a benefit for me, I had to tell them that I did not need it.
- » I don't meant to speak for all of us, but I think most of us come from a background where our parents didn't have insurance. People say that you don't worry about the money because you have Title XIX, but you still stress.
- » It's a rude awakening upon graduating college and getting my first job. When I graduated, I got a bad earache. Under Title XIX, I just went to the emergency room. Now with my real insurance, I got a huge bill.
- » I get Medicare and Medicaid, and now that it is free aside from co-pays, it is worth it.
- » Now I have Medicare and Part D. My income is low, and that means not much Medicare for me because of what I paid in. In the state of Iowa, I am covered and only live on Social Security. The clinic helps, and I don't worry too much.
- » Fantastic and affordable with the community health center, Medicare, and my supplemental.

*People without health insurance become expert and entrepreneurial at accessing services, or they do not seek care at all.*

Individuals are without health care coverage for a variety of reasons including, but not limited to, loss of a job and its associated coverage, health-related conditions, personal choice, temporary or permanent disability, and cost of coverage. People who were uninsured for a longer period gradually learned about programs available, free clinics, community health centers, and free or special offers for screenings

offered by providers. Services they seek include primary health care, specialty care, mental health services, dental services, vision care, and pharmaceuticals. Chronically uninsured individuals in communities appear to have developed informal networks through which they share information on best places to go for care, providers to seek out or avoid, and shortcuts through the systems. Comments indicated that people without insurance must invest a good deal of time and energy in seeking whatever health care they can access. Conversely, some have given up and simply hope they have no sudden and serious need for health care.

The following comments from each of the eight focus groups illustrate the various steps uninsured people take to access health care.

- » My health coverage is okay but I have to drive all the way to Des Moines for a dentist that accepts Medicaid.
- » Wellness means, to me, being well, exercising, and everything so you have fewer reasons to need health care.
- » I'm an uninsurable commodity. If I was able to find health care, they wouldn't cover what it is. My injuries are a "pre-existing condition." I have a hard time getting vehicle insurance. I have avoided going to hospitals in the past 15 years. It's nothing against hospitals - but it's the whole process from back board to radiology to the emergency room again. They won't admit me again if I go. I've learned not to take the ambulance ride – it's just going to make things worse.
- » There is something that happens with Medicare. I'm convinced it's all part of a grand plan. Things get denied, and you appeal it, and it's covered. Or you do it all again. The typical Medicare customer is unquestioning. I figured about 50 percent of the denials are not appealed. I always appeal mine to the bitter end. I appealed something that took almost three years. It creates a barrier.
- » It's the same way with Social Security. It takes years to get the hearing, and then when you finally get the notice you to have reply within days. If you can't do this then you have to start all over again.
- » I have no idea where I would go if I get hurt.
- » I don't have mammograms or other preventive tests because I don't have insurance.
- » I usually look for alternative medicines as a substitute on my own. I don't think you can depend on the system.
- » Personally, I think it is the culture that we don't think about this. In other cultures, if they have a symptom they go to the doctor right away. First, we try home remedies.
- » I am not going to the doctor, and I limit service frequency despite chronic conditions.
- » I look at alternative and preventive care.
- » I eat right and try stay away from sick people. I don't like to go to the doctor or hospital if I'm not the sick one. Sanitizer and multi-vitamins work for me.
- » I am very aware of my environment and surroundings. I self-diagnose, as well.
- » Hygiene. Good hygiene. You have to keep yourself clean and be aware of your environment. I can't afford to get sick, so I protect myself.
- » I use the toxin cleanse. If I get the flu, I use cough syrup with cod liver oil. If that doesn't cure you, you better go to the hospital. My grandmother had remedies that were sure to work. If I get a sharp pain on one side of my body, I'm going to the hospital. For a sore throat and I am still hungry, that's what they make soup for.
- » Since I do not have insurance, I am not able to stay well.
- » Utilize the programs and services where you can get them in the community. For some services it is associated with income. I have no insurance and take advantage of any programs I can find. I go where I can to get services.

- » I have had these glasses for 11 years. They still work, but sometimes things are blurry.
- » You can shop for services. I know there is a dentist who advertises he will pull teeth for \$75.
- » Recently, I received a coupon for dentistry and for free X-rays and exam. I went and am finding I need a great amount of dental work. There is a program for donated dental services. They paid for everything. For me, it would have cost \$3,000.
- » I shop around to find the cheapest place for prescriptions.

*People recently unemployed and the uninsured have a more difficult time understanding how to navigate the fragmented health care system available to them.*

Those who had recently lost their job and/or were formerly covered through an employer-based health insurance plan typically expressed more confusion and frustration in seeking and accessing health care services than those who were chronically without coverage. Even so, those without insurance have a more difficult time successfully working through the health care system than those with publicly-funded or employer-based health care coverage. People who were newly uninsured experienced shock at finding themselves uninsured and feeling helpless to navigate the unfamiliar territory of health care systems, providers, costs, and payment. Those who have been uninsured for some time continue to face the hurdles of figuring out for themselves how to manage their health care as best they can. Anyone who has coverage through an employer or public program knows that much of the navigation and paperwork is completed for them, making the system seem more patient-friendly.

The following comments from each of the eight focus groups illustrate the challenges experienced by recently unemployed and uninsured individuals in understanding the health care system.

- » I don't have health care coverage. I was employed by the government and had good care. I went on COBRA and had to stop because it is so expensive. The whole thing makes me angry. I guess I never paid attention before. When I was employed I paid for my coverage. The things I didn't know then are embarrassing. I go to the community health center for care and hope that I don't get really sick.
- » I don't have a medical home, I used to when I was employed and went to Methodist. I have had to cut back on tests like blood work because I don't have insurance.
- » I worked 10 years at one place, and then I retired. I had health insurance. Recently I got Medicaid; a short while ago they took both Medicaid and Medicare away from me, and I'm not sure why.
- » It is very difficult to understand.
- » What happens to us is, if you don't have insurance they make you pay cash for everything. That is why it is best to not go to the doctor.
- » Maybe she doesn't know about the community health center program for medicine for that costs \$4.00.
- » Take advantage of free screenings.
- » I am happy that the community health center is here.
- » I don't quite know what is covered. When I had my insurance, I didn't pay attention. It was \$300 a week, and I could not afford it.
- » That is part of my concern about the fragmentation. They don't talk to one another very well. Even with all the technology, they don't communicate. I remind them of my own background to make sure they understand.
- » My first thought is where can I go to get it. I'm uninsured, and it scares me. I don't know what is best for me.
- » When I came to the community health center, I found that I had a lot of problems that were overlooked because I did not have insurance.

- » I worked for the county and had great health insurance, but as soon as I became disabled, I had a hard time with the spend-down requirement.
- » I have never had insurance. I don't have insurance now. And I do not like doctors. I don't hate them, I respect what they do. But every time I see a white coat and a stethoscope, I am afraid I'm going to get a bill. Insurance wouldn't change how I look at them. I would still get a bill. I have a history of going to the emergency room. I always have major issues.
- » When I first moved to this community I tried to find a physician to see me, and they wouldn't take new patients. Then I went to the hospital and racked up all these bills. Unless you've been with a doctor for a while, you can't get in.
- » I have not been employed. I have been filing for disability. I have had a hard time getting insurance, but have still gotten care and medications through health departments and community health centers. I am on IowaCare. There is health care available, but you have to go through a lot to find it and get it, taking months. If you are diligent, it is possible.
- » I am currently unemployed but did have insurance through an employer before. I go to the community health center. I appreciate their services, but they are limited. I had to go to the hospital – not one of my choice – and it was a bad experience. When I had my private employer insurance it was great, and I never had a problem. I got signed up for IowaCare when I went to the hospital.
- » I am literally two days into a gap in my coverage after a divorce. I just now have found out that due to spousal support I no longer qualify for Medicaid. COBRA would cost \$450 per month to continue. I now have too many resources to qualify for my safety net, but I do not have enough to live on.
- » Prescriptions are awfully big things. When I had full coverage I spent \$400 on prescription co-pays. Without insurance, it could cost as much as \$1,200 per month.
- » You always have to jump through some kind of hoop, filling out paperwork to keep up on coverage.
- » If you don't have health care coverage, there is no way to get help.
- » It was a job to get coverage. I felt like I was being discouraged from seeking health care coverage.

*Wellness and affordable, accessible health care coverage are the two most-frequently cited priorities of participants related to their health care and that of their families.*

Though motivations may vary, nearly all participants commented that their priorities for their health care and that of their families involved assuring that they had health care coverage that they could afford and that was available to them. Similarly, participants recognized the value of wellness activities and attributed good health to their wellness efforts. Motivations for these priorities included looking out for the health of children in the family and the importance of having healthy parents to care for children. Elder Iowans noted they credited health care coverage and wellness activities for their good health and long lives. Others saw these priorities as allowing them to manage a chronic disease and maintain a higher quality of life. Many participants of all ages and populations held good health and fitness as personal goals and recognized the role health care coverage and fitness played in their lives.

The following comments from each of the eight focus groups illustrate the health-related priorities of participants.

- » Getting lots of exercise and eating right.
- » Right now, it is about wellness for me. Both my wife and I need to lose weight and get in better shape.
- » I would make sure that people with mental illness are treated as well as cancer patients.
- » To keep myself and my family well and functioning. Due to my age, I think about the end of life. I would like to provide myself with a dignified way of dying.
- » Home and family-based care when necessary.

- » Something that is affordable and accessible to everyone, regardless of who pays for the system.
- » I want my network back. I had a primary care doctor, nurse, lab, and pharmacy. I never had to worry before.
- » The ability to go to the doctor that I want.
- » We need something to help the people who are not as fortunate as us.
- » To live many more years through health.
- » My priority is to stay in shape so I don't have to look for insurance. I know I will need it as I get older.
- » Getting insurance is my priority. I am getting towards 30, and I know that as I get to 40 I will need insurance. I started thinking about if I started getting health problems. I worry about how I am going to pay for all that. And if I can't, will I die young?
- » National health insurance at one cost for everyone, make it a law.
- » Educate people about taking care of their health.
- » Make coverage available no matter age, race, and condition.
- » Staying healthy and prevention.
- » That there is coverage for my family.
- » Affordability.
- » Good health, to feel good so you can work. If you have access to be able to exercise and it wouldn't be so expensive, it would help you to feel better. We are a little bit heavy, and you feel it.
- » Health is very important. As parents who are healthy we can work and provide healthy food for our children. It is important to inform ourselves about healthy food and learn about disease.

## Other Findings

Focus group participants offered a wealth of insight into health care coverage, health care access, wellness, prevention, and many other related topics. Included in this section are significant points that were repeated in one or more focus groups and, while not rising to the level of a common theme, are relevant to the Real Iowans Research Initiative. In addition, other findings were specific to certain populations and are also included here.

*Employers fired employees who were injured rather than retain them until they recovered and could return to work.*

Experiences and anecdotes were provided by participants that employers terminated employees when they became injured, even when the injuries happened on the job. Those who had this experience or had friends or family in the situation stated the extreme unfairness of the situation and the belief that those employers were punishing an employee for an injury beyond their control. Participants attributed these types of firings to uncaring employers and to employers driven only by their bottom line, noting that an injured employee costs them money.

Related comments from the focus groups follow.

- » My insurance was provided by my employer at the time of my accident. I was hit by a drunk driver and injured my head. I lost my insurance about a year after. I was hurt in the accident and had surgery. Now I have diabetes and am under workman's comp. I don't know if I can go back to work. I make too much from workman's comp to get any coverage and get health care to cover me. They fired me after I had my accident at work. I'm just sick of it.
- » I had a friend who was in the military, then the hog business, and when he got sick, his employer fired him.

- » I was terminated when I had neck surgery, and I was on the job when I was injured.
- » My friend fell down on the ice while she was at work. She worked at a franchise discount store. They fired her.

*Participants believe employers have a stake in the health of employees, but it is a shared responsibility between the individual and the employer.*

Focus group participants across all sessions nearly universally believe that there is a joint employer and employee responsibility for employee health; healthy employees benefit both the individual and the business. Participants pointed out that employer investment in health care coverage, wellness programs, and prevention programs return the employer's costs in increased productivity, better attendance at work, and healthier employees. Participants who had experience with employer-based health coverage reported wide variation in the attitude of employers toward the value of health care coverage, wellness programs, and prevention programs. Participants recognized the cost to an employer of providing health benefits and programs as significant and worthwhile.

Related comments from the focus groups follow.

- » The problem is that it is hard to know where it ends; being able to afford to help the employee is difficult unless it does not cost much, like providing some [health and wellness] education.
- » I think that employers should create opportunities for employees to have access to a healthy lifestyle.
- » I think that there is company responsibility, and also it is in their best interest, to provide options for employees.
- » Exercise programs have gone a long ways. It's an intelligent choice. The game in the long run – the cost of the equipment versus the costs of health care – is a great return on investment.
- » I guess it would depend on how much the employees get paid. If it's just a fast food employer, I don't think it's the employer's responsibility. You would draw the line on income. People who get paid a lot, they get the benefits to keep them happy.
- » I think it's a joint responsibility. Some savvy employers have committees of employees to look at this. You have to look at the bottom line.
- » I think it would be financially beneficial for employers to take some responsibility related to education for healthy lifestyles, along with incentives.
- » It is a shared responsibility. Our kids' way of life is so different than ours was. They need more exercise because they sit all day at their jobs.
- » It is people talking, magazines, and culture changes that are making a difference, and employers have a responsibility to participate in it.
- » If they want you to be at work every day, they need you to be healthy. If their employees are sick and can't work, that will cost them money.
- » If you have a good employee that is motivated, help that person help you as an employee.
- » Employers are always worried about money: healthier workers is a cost effective idea.
- » It is a shared responsibility, but employers have a huge responsibility.
- » Yes. Without workers, you would have no company.
- » Yes, it comes down to money. It makes better employees that will do a better job.
- » If you come to work, and you are breathing, they are happy.
- » Sometimes, yes; and sometimes, no. You are responsible for yourself and should take care of yourself. Companies that have those benefits and programs for fitness, it helps them to reduce the costs for the employees to go to the doctor. It is all about personal education.

- » The employer has some responsibility. They could put incentives out there to keep people healthy and away from the doctor so much.

*Employed individuals often are uninsured either because the insurance premiums are too costly or coverage is not offered by the employer.*

Among the focus group participants, few employees chose to be uninsured unless there were compelling reasons behind that choice. Certainly, culture was a factor in the case of the Latino population. However, there were two overriding reasons that employed participants who did not have health care coverage were in that situation: the employer did not offer health insurance, or insurance was offered but premiums and the other out-of-pocket costs, such as co-pays, co-insurance, deductibles, exclusions, and uncovered services, were too costly. Some participants noted that their share of the premiums reduced their paycheck below what they needed to pay for basic monthly expenses, so they could not justify spending the money on insurance premiums. Many participants worked in businesses where the employer did not offer health insurance to any employees. Others worked part time and did not meet the employer's eligibility requirements. Participants emphasized that employer-based health insurance didn't do any good if they didn't earn enough to afford it.

Related comments from the focus groups follow.

- » I work part time and do not have insurance.
- » My health plan costs about 20 percent of my salary.
- » I work for a small company, and we do not have insurance provided.
- » There are 50 people employed at my place of work, about 20 are full-time. Only a health savings account is available.
- » There are 15 of us at my job, mainly part-time with no insurance offerings.
- » We have a small business and we cannot afford to provide insurance for our 20 employees.
- » Health care costs seem very high to me. Each emergency room visit is at least \$250.
- » I have a pre-existing condition with a mental health diagnosis, so it would not matter if I had insurance.
- » I am 25 years old and have \$30,000 in medical bills.
- » I saw a man who was helping his father with a nebulizer that costs \$400 per month: that just about drains a person's Social Security. Insurance is a must in this day and age.
- » My husband and I pay about \$7,000 per year for supplemental insurance.
- » My bad credit is a barrier for me.
- » When I had poison sumac and went to the hospital, I was there for 10 minutes. He didn't even take me to the back. He looked at my arms and came back with tubes and pills. He gave me the pills and told me that I would be okay. And I got a bill for \$380. It was spreading so I was worried. I guess \$150 would have been more reasonable. I will stay away from sumac.
- » Considering I don't have insurance, right now the value of what I pay isn't worth it. That's why I don't go. I would love to have insurance. I would pay \$10 to \$15 a month just to know that I have it. Every time I've been to the emergency room, I don't think it's been under \$200.
- » There is a division of opportunities for health care. Not everyone can pay for the price of health care even at a sliding fee clinic.
- » People may have money for about half of what it costs to have a condition treated. You may have the money for the office visit, but not for the prescription.
- » Medicare is not enough coverage for the elderly. Gaps are prescription, co-payment, and then the transportation costs to get to Iowa City. Nobody can afford supplemental payments for extra insurance coverage.

- » I worked, and my company paid my insurance for one year after layoff, but COBRA costs just as much as my rent.
- » I have a pre-existing condition, and cannot pay for insurance.
- » I haven't had insurance for four years. With my last company I worked for, did not have any insurance. It was a national corporation, and they did not offer any insurance.
- » I have problems with my neck, and it is getting worse. This clinic has an orthopedic doctor who comes in, and this is a great help. If I was to go to an actual orthopedic doctor's clinic, I would need a \$400 up front, and I cannot afford that, given that I am unemployed.
- » Insurance costs me dearly, I hardly get a paycheck. My premium is almost \$800 per month.
- » Even for those who do not have transportation, the ambulance is almost \$500 just if you get in it.
- » I was in the emergency room for one hour and it was \$1,600. I can tell you from now on my blood pressure will be fine. They told me before to exercise, diet, and take medicine. \$1,600 for one hour...with four visits you could pay for my funeral. Definitely the cost will keep me from going again.
- » Last year I was self-employed painting houses and cleaning. I didn't make enough to have insurance. I fell and broke my leg and have a bill for thousands and thousands dollars. They told me to go for physical therapy but I did it myself.

*Seniors and those with mental health considerations recognize the importance of wellness, but need direction in taking action.*

The focus groups of older lowans and those with mental health considerations frequently noted their involvement with organized activities and groups that help guide and provide opportunities for wellness strategies. Some senior participants commented that wellness was a fairly new concept to them, and they relied on guidance from health professionals in their own wellness and prevention activities.

Related comments from the focus groups follow.

- » We get quick mandates for urgent care, but not how to be healthy. A great example is that if you are overweight, you will qualify for bariatric surgery, but they won't pay for you to see a dietician.
- » Wellness should be a basic part of health care. My definition is the highest amount of growth possible in mind, body, and spirit. This includes social concerns.
- » A lot of us do not think about prevention until it is too late. People should start a lot sooner.
- » It is about having a comprehensive array of services and supports to help me keep well.
- » Diet and exercise are primary parts of personal success. Health care is a very complicated issue, but prevention does allow people to put care back in their own hands.
- » I went to the hospital six years ago for heart surgery and they discovered I was diabetic, and so they would not do the surgery until I had it under control. I went on an exercise regimen and meals, now I am still diabetic but I take no medicine due to exercise and watching what I eat. I had insurance but they did not push the mentality of prevention. In fact, when I retired my health care coverage went away.

*Older lowans were the most in charge of their wellness and fitness activities, often making them a social activity.*

Older lowans participating in the focus groups ranged from ages 70 to 90 or more. Keeping their individual situations and health conditions in mind, the seniors demonstrated keen interest in wellness and prevention efforts. Some spoke of regular physical activity, others mentioned monitoring their health, and eating right was commonly noted. More than other groups, older lowans tended to seek out group

interaction as part of their wellness and health routines. They also acknowledged the social benefits to those routines.

Related comments from the focus groups follow.

- » One of the fellows in our apartment complex got a Wii, and we bowl. It is a lot of fun and keeps us active.
- » We have everything here: doctor, hospital, friends, and church, so we do not want to leave.
- » I know a lot of people that have to think food before health care. I was on my own, independently working, and I went and got a policy with a high deductible, but it still helped pay for some aspects of health care. I like my current policy because I can go to the YMCA and Curves.
- » I joined Take Off Pounds Sensibly and lost 100 pounds, and I am still working on my weight.
- » Through the VA, I am part of the MOVE program which teaches us how to eat better at home and they all and talk about how to improve choices. They also send me pamphlets and I have been working on an exercise video they sent. I have lost 35 pounds since last July.

*Chronic conditions such as diabetes, cancer, cardiovascular disease, and uncommon conditions were frequent among participants.*

Across the spectrum of the focus group participants, there was a high frequency of individuals reporting chronic conditions such as obesity, diabetes, cardiovascular disease, and cancer. Many of these individuals had a difficult time managing their conditions and often linked the difficulties to access to or cost of health care. Those participants with uncommon conditions or multiple chronic conditions also faced significant challenges, particularly in accessing necessary specialty care and managing their ongoing health care costs.

Related comments from the focus groups follow.

- » I have diabetes and spend \$300 per month on supplies to help me do a better job of management.
- » I have multi-faceted medical problems and see a primary physician for diabetes, sleep apnea, allergies, and asthma. My cardiac care is from a cardiac clinic, and I go to a private dentist. For psychiatric care, I see people in private practice.
- » With my impairments, I have a lot more issues. I have a brain injury. Most doctors don't even know how to deal with it. They think I hit my head and the illness will go away. For me it's so much more. In brain injury, people can't remember what the doctor said. Any kind of mobility issues are included in this group. Doctors just don't understand brain injury from my perspective.
- » When I had my accident and broke my neck, life expectancy in my condition was only five years. I have come a long way since then.
- » It is very important to me because I am not a typical case. I am disabled and unemployed. I have a series of disabilities and I am an advocate.
- » I have a chronic condition. I see the community health center and rely on them for referrals. I have a neurological disorder, but can't see a specialist because there are not resources. I also go to the community mental health center for psychiatric services.
- » I go to the VA in Des Moines and do not have insurance. I had a cancerous lipoid taken out of my neck, diabetes, knee replacement, and stent in my heart, all covered.
- » I am an old lady and I only take pills for macular degeneration due to my taking care of myself. I just try to stay as healthy as possible.
- » I have a pre-existing condition with a mental health diagnosis so it would not matter if I had insurance.

- » I went to the hospital six years ago for heart surgery and they discovered I was diabetic and so they would not do the surgery until I had it under control.
- » We each had cancer twice, and now all of our savings is gone.
- » I had extensive back surgery last month and the overall bill was several hundred thousand dollars and I am responsible for \$900 on Medicare.
- » Yes, we have to pay extra for the cost of an interpreter.
- » One example I am living is that is someone needs to see a psychologist, and it is not because you are crazy. You don't go because you don't have money.
- » Cancer at regional cancer center.
- » Diabetes.
- » Heart problems.
- » Podiatrist.
- » Ophthalmologist.
- » The only specialist we do not have access to here is a rheumatologist.
- » Chiropractor.
- » I told you the high cost of the family coverage, so I bought private coverage for my son. It's \$185 a month, and didn't cover any pre-existing condition. They didn't cover his asthma and acid reflux. But we needed insurance for those conditions. Maybe four years ago I went to the doctor and he told me I have allergies. I got a really expensive medication and now I just don't use the medication.
- » My husband is on dialysis and he deserves the best in terms of keeping him healthy.
- » I would like to find out if I have the breast cancer gene, but the test alone costs \$5,000.
- » Some dermatologists do not know how to deal with African American skin conditions. If you want to go to an African American dermatologist, you have to go to Edina, Minnesota.
- » Because I am a diabetic, I have to take care of myself.
- » I am also a diabetic and definitely got to watch what I eat.
- » And I have diabetes. I try to walk wherever I go and watch what I eat.
- » I have ulcers, and that's causing reflux.
- » Orthopedic services.
- » Ear, nose, and throat, and I keep having to get my esophagus stretched as part of the treatments. That's a pre-existing condition, and I have no coverage for it.

*Individuals with disabilities acknowledged the necessity of their thorough understanding of the system and willingness to challenge the system to get payment for services they need.*

Individuals with disabilities reported that they had experienced coverage from a variety of sources at different times in their lives. Those now receiving public-funded health care indicated the importance of learning about that system, its rules, and tracking their benefits and payments. Some perceived a common practice for a program is to deny payment initially, but upon appeal it most often is paid. Those with less experience with the systems or those with friends or family who are not well-versed in the rules and requirements of health care funding sources cited frustration with the system as well. This finding might be compared similarly with the common theme regarding the difficulties faced by the recently unemployed and the uninsured in navigating the health care system.

Related comments from the focus groups follow.

- » I think I've become more and more aware of it as I get older because I never thought I would be this old. When I had my accident and broke my neck, life expectancy in my condition was only five years. I have come a long way since then. That's why doctors don't know about brain injury - if you

don't go to a specialist, they probably don't know what brain injury is. Doctors also go where the patients are, so many in small communities are forced to go far away for services. I never knew that it wasn't good to question a neurosurgeon about traction. I have always had a voice in my health care, but they haven't always wanted to hear it. Like with pills, I wanted to know what my pills were for before I took them. They wouldn't give me the reasons – but would just say they were prescribed. I asked what it was for and was accused of refusing my meds. You didn't question anything back then.

- » Wellness is somebody else's perception of what you need to change. In most of the applications I've seen of wellness, someone like a doctor or counselor wants you to form into their idea of "wellness." People who meet that get good ratings, but if you're independent you're labeled uncooperative and aggressive and get bad ratings. It's someone else's perception. "We want you to do this to get to this goal." It's a part of health care – but much more than just health care. It's not limited to health care. It includes support groups, even.
- » Wellness are those things you do to enable you to function at the level you want to. It can be how you eat, exercise, getting out and about. It can be a job. Whatever it takes. What he was talking about is what I call "nurse speak." If they ask if I have pain and I say "no," I am not denying pain. It is just a fact. If people aren't privy to "nurse speak," you can get comments relating to how you're uncooperative. You can also get denied things because of this. Your wellness is put into jeopardy if all language is constructed like you're denying things and not going with the program.
- » The lenses are covered under my plan, but not the frames. Dental care is covered 100%. They'll pay for a YMCA membership – at least some of it. I can get it for about \$30 a year. That is through the Department of Human Services (DHS).
- » The last coverage I had did have was inclusive coverage. Through Linn County – the coverage did cover dental and glasses. If you were impaired and had coverage, you got that covered. Those options are really smart. It helps people before it's a problem. The mental health coverage is offered, but for me it's limited. That is not through IowaCare – it's through the MHDD (Mental Health/Development Disabilities) program of the county.
- » Yeah, but the medication that they show on television – you may not be able to get that at your doctor. You have to try the generics first to prove they don't work before being prescribed the name-brand stuff.
- » Things are pretty much covered. Right now, for everybody, the whole drug issue is the problem. The preferred drug listing is limited. Whole categories of drugs don't appear on it. My needs are mostly met expect for the drug issue.
- » I've had Social Security hearings, but I physically couldn't get to them. Instead of that being documentation of disability, they mark it as "non-cooperative."
- » That is something that happens with Medicare. I'm convinced it's all part of a grand plan. Things get denied, and you appeal it, and it's covered. Or you do it all again. The typical Medicare customer is unquestioning. I figure about 50 percent of the denials are not appealed. I always appeal mine to the bitter end. I appealed something that took almost three years. I went in to the hospital and they lost my paperwork. That is all part of the plan. It creates a barrier.
- » It's the same way with Social Security. It takes years to get the hearing scheduled, and then when you finally get the notice you have to reply within days. If you can't do it when they say, you have to start all over again.

*Young African American men indicated self-preservation as a key component of health care, and they distrusted institutions.*

One focus group of uninsured and underinsured individuals consisted of four young men estimated to be between the ages of 20 and 30, the majority of which were African American. All of the participants were

strongly independent and self-reliant when health care was concerned. Only one currently had health care coverage, and as children at home, none had ever had health insurance. They viewed their youth and strength as assets in preserving their health and were acutely aware and engaged in wellness and fitness activities. Each had experiences with the health care system that resulted in high bills requiring payment over time. They distrusted health care providers and perceived that they were treated differently because they did not have health insurance.

Related comments from the focus groups follow.

- » Self-preservation. You have to preserve yourself through exercise or using vitamins or getting a check-up. No matter how much it costs, it's a priority. Especially if you have kids, you need health. I can worry about everything else as long as I'm healthy. I can't do anything if I'm not healthy.
- » My priority is to stay in shape so I don't have to look for insurance. I know I will need it as I get older. I say I'm good for the next eight or nine years. Then I'll be old enough to get a good deductible. I stay in shape so I don't think about going to the doctor. I exercise a lot. As long as I put forward my best food and take care of myself then I shouldn't have to worry about my health.
- » The majority of people I associate with, they take pride in their health and appearance. They don't have health care as far as I know, the ones that don't have the same mindset as me. The people I work with have the idea that if they cut a finger off, they will put a bandage on it and get back to work. They use liquid band-aids until it heals. I'm not saying that health is low on their priority list, but I don't think it is affordable for them.
- » I just don't go to the doctor. I try to find home remedies like they said. I don't even like to take Tylenol. Chicken soup I use. I don't like to take anything.
- » It's not always that expensive to go to the doctor. To keep the price low, I ask for generics and samples. I don't want them to charge me for the name. I want the cheaper stuff. Whatever the generic is, I want that. If there is a sample closet, I want that.
- » I don't get in accidents. Once I broke my hand and they told me to come in on Monday. Then I got a bill for them doing nothing but putting it in a splint. I had a bad experience and now I don't go to the doctor.
- » Hygiene. Good hygiene. You have to keep yourself clean and be aware of your environment. I can't afford to get sick so I protect myself.
- » I use mega tea detoxer twice a day. I drink a lot of water. It's working for me so far.
- » I have insurance through my employer. I pay \$5 more per pay period this year. Before, I wouldn't have cared about that addition. That is \$10 more a month. This usually goes towards services I don't use. I don't access many services because of my upbringing. If I put my kids on it, then it would be really expensive. The family plan jumps up in cost. I used to go to the chiropractor. That would be part of wellness. The deductible has gone up now.
- » Wellness is being healthy. Not having to go to the doctor. Not having to get check-ups.
- » Personally I don't eat right. I don't do anything that's good for me. I don't ever want to go to the doctor. I don't want anything to be wrong with me. If it's going to cost me money, then I would rather die. I have bad credit because of doctor bills. The emergency room is so much more expensive. This community health center is really nice to have because it's cheaper.
- » Being able to have a check up without worrying how to pay the bill. First thing that comes to my mind is dollars. When you're well, when you're sick, when you think that your kid is coming down with something.
- » I think of expenses. And also how every time I go to the doctor they find something. It discourages me from going. I think of money and problems.

*African American participants recognized negative impacts on overall health from traditional foods and changes in lifestyle over the generations.*

Cultural and ethnic traditions were cited as having negative impacts on health, particularly those traditions related to ethnic foods. African American focus group participants recognized that traditional cuisine is high in fat, salt, and cholesterol. They further recognized that current lifestyle does not allow people to work off the extra calories, so overweight and obesity are also growing issues. The participants also had strong views on the challenges for African Americans to access health care providers with expertise in health care conditions unique to or common among African Americans. The high cost of health care was also a sensitive issue for African American participants with or without insurance and regardless of age.

Related comments from the focus groups follow.

- » I think that health care is understanding your body and knowing what you need to do to be healthy.
- » The African American culture includes eating a lot. The food is not always healthy.
- » We all think about it, but whether you do it or not is another story.
- » Let's go back forty or fifty years ago. We ate off the land, and there were not so many chemicals in our food.
- » Eating collard greens and fatback is a learned behavior. When you cannot afford what is healthier for you, you eat what is available.
- » What we eat has been learned. People ate badly in the past, but they worked out and worked it off.
- » When I grew up, we did not have access to fast food. I am from Chicago, and we picked greens, corn, and all the rest. Fast food was a great.
- » I go to the store, and fruit is so expensive and organic foods are out of our price range. It is unaffordable to eat right.
- » I am not going to deprive myself of what I like to eat.
- » Turkey used to be the cheapest meat out there, and now it is the most expensive.
- » Society has changed this; it is not just race and culture that has made us unhealthy eaters.
- » This is a McDonald's world. People do not sit down for dinner anymore.
- » The economy has gotten to the point that both parents have to work, and there is no time to prepare healthy food, no matter what race you are.
- » Black families may have been hit a bit harder by the recession, but it has been hard on everyone.
- » There is no time for exercise, unless to you count running around and taking care of kids.
- » If it is a choice between going to the wellness center and getting prescriptions, groceries, or gas in the car; we are going to choose the others over wellness.
- » Children do not want to even go outside since technology is such a big part of their life.

*Latino participants' culture contributes to the perception that any cost for health care is too much, and that buying insurance is paying money for nothing in return.*

In many other countries and regions around the world, including Mexico, Central America, and South America, health insurance is irrelevant because health care is provided at little or no cost by government health facilities and providers. Latino focus group participants view the concept of health insurance as odd and a poor way to spend their money. They believe that if they carry health insurance and then need health care there should be no further cost because they have already paid. This cultural difference, coupled with low income, impacts Latinos' decisions to go without health insurance even if it is available to them.

Related comments from the focus groups follow.

- » Insurance costs are too high; way too high and not enough coverage. The deductible and co-pays are too high.
- » If you're not healthy, you're going to the doctor a lot, but not enough to reach your deductible. You won't get your money's worth compared to what you're paying into your insurance.
- » I work at the school, and I do have insurance. Because of the economy, six and a half years ago it was one of the best coverage. Six years ago it was no copayment. Then it was \$10; last year it went up to \$20 or \$25. For me the premium is free; for my husband it is about \$800, and we can't afford it. We have private insurance for him, not through an employer as he is self-employed.
- » I started working at a meat packing company, and insurance was great then. You wouldn't pay much for the premium then, but now it has gotten where we have to pay so much before we could get some benefits. I had to decide. Now I have no insurance whatsoever.
- » It is very difficult to understand.
- » What she said, they offer you the insurance but they don't talk about the premium and what the cost is. Some don't cover any cancer, and some you have to show them you didn't have it for a year.
- » It's like if they will sell you a refrigerator, but you have to pay extra for the guarantee.
- » It might sound funny but the last two years I go home to my country to get my dental care. It was \$800 for the flight, and that was cheaper than the cost for the care here. Even educated people, like teachers, try to read the insurance papers and can't understand them. Every month I have to pay for my allergy injections and sinus care, and I have one of the better health insurances.
- » I think the diseases get more and more chronic because insurance is so expensive. We avoid going because of the cost, and then the diseases get worse. Here in the US, you hear from other people so you think that health care is so great, but it is a big lie. You go to a family practice doctor and they want to do everything. It was going to be \$4,000 here, so she went to Mexico where it was about \$400.
- » In Mexico there are health centers where they give you free medicines and consultations. Here they charge you for everything, even the interpreter. In Mexico it is free.
- » I need a clinic where they give you the medicine or give it half price. Somewhere they will give you the basic care.
- » I take my son, who is nine months, to the same doctor. You want to trust your doctor. One of my sons has a fractured kneecap, and the doctor immediately called a specialist and 15 minutes later I was with the other doctor. I think there are a lot of problems with emergency services here; they are very expensive. A few years ago I had a small burn, and I had to wait four hours for service, and when I saw the bill, I saw a bill for the doctor, and bills for other things. In comparison for two years ago when I went to a private hospital in my country, and it was about \$300 for a good private hospital. I asked myself, in my small, underdeveloped country, why there is a better system there.
- » The barrier is cost. Health insurance is expensive, and I don't have it right now.
- » Transportation and travel costs to get to the doctors are a barrier for health care.

*Latino participants expressed more distrust of the system, greater use of home remedies, and values driven by looking out for their families.*

Latino cultures typically are strongly family-centered. Health care decisions are often based upon looking out for the family. The husband will often seek health care for himself once he becomes convinced there is no alternative, and then only because he needs to ensure the welfare of his family. Participants commented that home remedies, often traditional practices passed from generation to generation, are the first choice of Latinos in treating family members of any age. Not surprisingly, Latinos do not trust the health care system or any system that could be perceived to be connected to the US, state, or other

government. For reasons ranging from trust to cost, confidence in the local community health center was even lacking.

Related comments from the focus groups follow.

- » We have to take care of our health – our family’s and our own health.
- » Even if you keep yourself healthy and have good insurance, you still want to keep healthy because it’s still important. Eating right and exercising are very important.
- » Personally, I think it is in the culture that we don’t think about this. In other cultures, if they have a symptom they go to the doctor right away. First, we try home remedies.
- » Many people don’t have money. We don’t have health insurance, so we try to do home remedies at home.
- » Wellness is not a part of our culture. Wellness for me means you are going for your checkups and are up to date on your checkups.
- » I have always had everything. But there are some times that we don’t know what it is going to cover if you have a very serious disease such as cancer. There was one friend I heard that the total coverage amount would be a million dollars.
- » During the time I was at one job, I know insurance didn’t cover chronic conditions. You could buy another coverage for those extra things, such as dental and vision.
- » At the community health center, it isn’t accessible or affordable. They go by your income. If we don’t qualify you still end up paying for the whole thing. We have to do payments for his check-ups.
- » Sometimes it’s a choice of having food for the week or going to the doctor.
- » For me at my job, I don’t earn very much, but what interests me more is the insurance for my children. At another company, you earn more, but the insurance isn’t good. I have some responsibility for my own health.
- » For me it is very important for me and my children that we are healthy. I’ll tell you, I’m kind of old fashioned. If they tell you that the tamarind fruit is good for your liver, then I believe that. If they said that soda causes cancer, then I eliminate it.
- » I think it’s personal. And sometimes it is your own education of yourself, and if you believe you should try to avoid something so you are healthy, others don’t believe that. You can have bad luck, because you can do all those preventions and still get sick or fail.
- » My wife is diabetic, and I have to motivate her to eat a healthy diet. She has arthritis, and the doctor told her that if now she could walk two blocks, and next year she will walk only one block. So I asked her to get me a glass of water so she would get up and move around; otherwise she would just stay still. I have personal responsibility to help motivate my family. She is doing better and is getting around more. She has five or six medicines, and they can cause problems, too.
- » One thing we have, as Hispanics, is that it is important that we have to inform ourselves to do better, mentally, spiritually, and physically, being positive. When there is so much snow, I get frustrated; we need to think of how much exercise we get when we shovel.
- » Some companies just don’t offer health insurance. For someone who works a long time, they just don’t have access.

*Providing health insurance and health care for their children was of paramount importance to Latino participants.*

Latino parents made significant sacrifices to provide for their children’s health and health care coverage. Many participating parents noted that they did not have health insurance coverage, but they sought coverage for their children. HAWK-I was cited as a good option for eligible children. Sometimes one parent carried coverage through the employer only so the children could have coverage. Again, home

remedies entered the picture in treatment of children. There was little discussion of wellness activities, but there was an awareness of the importance of prevention measures to keep children healthy.

Related comments from the focus groups follow.

- » Yes, care for my children so that they have everything they need. Good medical care, the best team at the medical office, and prevention.
- » Have good health insurance to cover anything that could happen in my children's life. Including accidents.
- » For the kids, yes, that is the first priority. For me, I don't really think about it. I think about my kids and my wife.
- » For me and my family, the same thing happened. The cost kept going up, my husband is covered by the company, and we put our children on HAWK-I. I have none.
- » Right now I have a problem. My kids are on Medicaid, and my dentist told me they need braces, we can't afford it. It costs \$5,000.
- » For children, sometimes you have to travel a little bit because the doctors are not in Storm Lake – to Spencer, Sioux City, or Omaha. Recently, they are sometimes bringing a specialist to Storm Lake, but you have a different specialist for each kid or each condition. It's like a suggestion they give you, they say you can go to a doctor here, or you can wait until the specialist can see them. I have one doctor here that I can take my children to when they need it. I take my children to the same doctor, but she left. I go someplace else because I don't have insurance.
- » For me it is very important. If you have to pay for the health insurance; I still will take my children to the doctor, but for myself I will wait. My husband says I'm too protective. If they have a fever, I will take them the next day. That is why I feel guilty that I didn't take my child the first time he fell and hurt his knee. I will sacrifice to provide health insurance and care.
- » For me at my job, I don't earn very much, but what interests me more is the insurance for my children. For me it is very important for me and my children that we are healthy.
- » I am responsible for my children's lives and my life. You might be lucky and not get sick, but you can help yourself have good luck. My children don't have cavities. I don't let them drink soda, and I only let them eat candy all at once one day. I am learning as I go. I get a physical once a year, and my cholesterol is fine. When I gain weight, I can feel it, and I eliminate soda, tortillas, and the weight comes off again and I feel better.
- » Health is very important. As parents who are healthy we can work and provide healthy food for our children. It is important to inform ourselves about healthy food and learn about disease.
- » Not just for my family, but everyone in general, and we have a lot of lack of health insurance and care for our kids. We have a lot of needs in this community for the many children who don't have health insurance. That is one thing I think we need to improve.
- » The information is there in the schools and companies. It is personal. If you don't have insurance through the school there is HAWK-I, if your children were born here, of course. I go to the doctor and he tells me a term, and I don't know it, I ask him to write it down. If there isn't health insurance, then talk to people at your school and ask where you can go.
- » Take care of my family so everything is good, and help everyone who has needs.

## Conclusion

Regular lowans with and without jobs and families contributed their experiences and perspectives in the eight focus groups. The resulting qualitative data add context, clarity, and, at times, personality and emotion to the important issues of health care coverage, access, prevention, and wellness. Those choosing to share their personal stories in a focus group represented the views of five populations identified as likely to be underrepresented in traditional survey approaches. The focus group findings stand alone and also complement the findings of the telephone survey completed as a separate element of the Real lowans Research Initiative.

The qualitative findings show that there are large numbers of people in Iowa who function outside of the health system as it commonly viewed and experienced by most lowans. Circumstances separating them include those related to individual health situations, culture and tradition, age, and/or living with a disability.

- » Among the five populations included in the qualitative research, there is widespread recognition that wellness and good nutrition are connected to health, but there are few affordable support systems available where they live to assist them. Good intentions for wellness and prevention often are outweighed by other priorities or pressures in their lives.
- » Many focus group participants do not have access to employer-based health care coverage, prevention programs, or wellness programs. Employers, especially those with fewer employees, do not offer these benefits or employees are not eligible to participate. The working poor were a significant portion of the underserved and uninsured who participated in the focus groups.
- » Despite employer-based health coverage, available safety net services, and programs such as Medicaid, Medicare, HAWK-I, and IowaCare, people still have to deal with out-of-pocket health costs that make health care unaffordable and inaccessible for them. Those costs may include premiums, cost as a result of exclusions or pre-existing conditions, co-payments, co-insurance, deductibles, pharmaceuticals, or uncovered services such as dental and vision.

While health care reform is expected to significantly impact lowans and improve health care, those among the populations included in this research may find themselves less affected by the provisions of reform. However, circumstances in which many of these lowans find themselves mean they may remain apart from the mainstream of health care, they may continue to find health coverage and care unaffordable, and efforts to include wellness and prevention in their lives may remain difficult.

The voices of experience heard in the focus groups underscore the understanding that lowans are diverse in their interactions with health care, wellness, and prevention.

# Attachments

Focus Group Locations and Populations  
Focus Group Script  
Real Iowans Research Initiative Overview

# Focus Group Schedule – Winter 2010

## Real Iowans Research Initiative

<b>Population</b>	<b>Location</b>
<b>Elderly Iowans</b>	Area XIV Agency on Aging, Creston
<b>People with Disabilities</b>	Goodwill Industries, Cedar Rapids
<b>People with Mental Health Considerations</b>	Community and Family Resources, Ames
<b>African Americans</b>	Peoples Community Health Clinic, Waterloo
<b>Latinos</b>	Storm Lake Middle School, Storm Lake
<b>Uninsured and Underinsured (3 sessions)</b>	Des Moines Public Library – East Side, Des Moines Community Health Center of Southeast Iowa, Burlington Siouxland Community Health Center, Sioux City

# Focus Group Script

## Real Iowans Research Initiative

### Welcome and Purpose of the Focus Group (10 minutes)

- » SPPG facilitator welcomes everyone and introduces self.
  - Guests from University
  - Note taker
- » This is one of eight focus groups we are conducting throughout the state as a part of a research initiative with University of Iowa's Healthier Workforce Center of Excellence. We will tell you a little more about this project in a few minutes.
- » Before we start, let me explain what is required.
  - In front of you, there is a copy of an agreement letter explaining the research.
  - We will provide each of you participating this evening with a \$50 gift card.
  - At the end of the session, as a matter of information, we will provide you a one-page description of the project.
- » This project is to find out what you think about health care and health care benefits for Iowans who are employed now or have been employed. Our focus groups are one part of a larger research project. **This is not research in relation to health care reform.**
- » We are very interested in what **you** think – and learning your **opinion**.
- » SPPG's role in this effort is to facilitate the discussion and provide the information to the University in a summary report.
- » Self-introductions of participants. Each introduces him/herself by first name.

### Structure of Focus Group

- » The use of a script is done for consistency across all focus groups. There is not a right or wrong response to the questions we ask. We're only interested in what you **THINK** about the issues we raise. The script is made up of a series of premise statements that we believe to be true. Each statement is followed by a set of questions we want you to react to and comment.
- » Your straightforward opinion is important to us. You won't hurt our feelings by the comments you make. Our job is to find out what you think.
- » Please **BRIEFLY** respond to the question with your first thoughts – and try not to react to what the person before said.

### Rules for the Session

- » Everyone will participate.
- » Be ready to volunteer your comments.
- » Please be brief in your comments and get to the point right away.
- » Session will be limited to two hours, and I will do my best to move the discussion along.
- » Non-attributable comments are in our written summary. We are not interested in who said what, just what is said.
- » Any questions?

### Premise One – What is Health Care

For many people in Iowa, the term “health care” may mean something different. For many, health care is what I have to get when I am sick. For some, it includes a birth-to-death expectation of care for the body and mind. For others, it may be more inclusive with the expectation that prevention, healthy foods, and exercise are essential. And for many, it is an expectation that there are health care providers available

and emergency services, specialists, and pharmacy accessible and affordable. There is more and more discussion and public awareness about health care issues. How should we “be healthy?”

1. When you think of health care, what comes to mind for you?
2. As you consider health care in your own life and situation, is staying well and preventing disease, eating right and exercising part of what you think about? Why is that?
3. When you hear the term “wellness,” do you consider it a basic part of health care? Explain what “wellness” means to you.

### **Premise Two – Health Care Coverage**

There are many ways that many of us receive coverage to pay or obtain health care for ourselves and our families. As we all know, there are some individuals and families who have no health care coverage. Some of us are employed and covered, or partially covered by our employers. Sometimes we depend on our local Community Health Center or Free Clinic for primary care services; and Veterans benefits, Medicaid, Medicare, and HAWK-I often fill gaps and help us to pay for health care. In thinking about your own health care coverage and how your health care providers are paid – whether you are employed, employed in the past, or never been employed – please consider these questions.

1. If you or your family has health insurance, how is it provided? – or if you were employed within the last five years, did you have health insurance where you worked? (and/or what do you do?)
2. If you are working now or work in the last five years, how many people work at your place of employment?
3. Health care services might include prevention, dental, vision, mental health, wellness, chronic disease, management, or other services. What kind of health services were covered by your employers? Was there another source in addition to your employer where you received any of these services?
4. Is your coverage taking care of your current health problems? What more is needed, and what is offered that you don't need?

### **Premise Three – Health Care Access**

There is a certain comfort in knowing who to call and where to go when you get sick or when you need to get a health check-up for yourself or a family member. Sometimes getting health care services is a matter of geography or the availability of a physician in your town or area. Often, it is finding a primary care family physician with whom you are comfortable or where you know you can get answers and advice about other health care issues. Access to health care means many things, including affordability, competence, and confidence. Please respond to the following questions.

1. Where do you get your health care? (note if you get services in one or more places depending upon your need)
2. A medical home is a term to define a health care provider (an office) where you go regularly for services. Do you have a medical home?
3. What specialty health services do use in addition to primary or basic care (your family doctor)?
4. What barriers do you have to accessing health care when you need it?

### **Premise Four – Health Care Costs**

We all know that health care costs have increased for individuals and families over the years. There are many people in Iowa and across the country who have no health care coverage or insurance benefits. Many employers do not provide health care coverage, or have cut back in what their employees' insurance pays for. Some people and employers have purchased insurance policies, but they have very

limited coverage – those people are considered, “underinsured.” For many, any injury, illness, symptoms, or required care for chronic disease strike fear in their hearts because of the lack of health care coverage and the personal cost to pay for the care. As you think about health care costs and how they affect you and your family, please give us your thoughts.

1. For you and your family, how affordable are your health care services?
2. What value do you place on your health care? Is what you pay for health care a fair price for what you receive?
3. Who should take the responsibility for covering and lowering health care costs?
4. What are you doing to minimize health care costs?

#### **Premise Five – *Priorities***

There are always choices that have to be made in our lives. We have all heard the saying, “As long as I have my health, I will be OK.” That certainly indicates priority. But in considering that many people’s definition of health care coverage is different, it is important to think about one’s own priorities and what is important. Consider these four questions.

1. What are your priorities for health care for you and your family?
2. Among your co-workers and friends, what do you think are their priorities for health care?
3. How important is it that individuals take responsibility to keep healthy? Why? What does “keeping healthy” mean?
4. Should employers take responsibility to keep their employees healthy? Why or Why not?

#### **Closing Question**

If you were king or queen of the world, and could make any change you wanted to improve health and health care, what would it be?



IOWA'S EMPLOYERS AND EMPLOYEES IN THE PRIVATE AND NON-PROFIT SECTORS FACE GROWING CHALLENGES MAINTAINING HEALTH CARE BENEFITS. Health care benefit costs provided by employers to employees continue to increase steeply while organizations struggle to maintain health care coverage and access to wellness benefits. Since 1999, premiums for employee-only coverage have increased by 115% and family premiums have increased by 109%\*. As a result, an increasing number of employed Iowans are uninsured and underinsured and lack the wellness benefits necessary to remain healthy and productive.

Expanding access to high-quality and affordable health care has become an urgent priority, requiring fresh and critical viewpoints from a representative sample of “real” Iowans—thus providing a collective voice for all, a voice all too often missing in health care policy forums.

The Healthier Workforce Center for Excellence (HWCE) at The University of Iowa's College of Public Health is one of three national CDC funded centers to conduct health protection and health promotion research and to serve as a state and national resource to develop and promote evidence-based employee well being programs. In the Real Iowans Research Initiative the HWCE joins with David P. Lind & Associates and the State Public Policy Group to assess health care needs and views of Iowa employees, as well as non-employed Iowans. The term “Real Iowans” is intended to convey inclusion of a broad cross-section of all employed Iowans, as well as others who may be uninsured or underinsured.

The Real Iowans Research Initiative will engage Iowans from all sectors and population groups through three strategies:

- personal interviews of Iowa's stakeholders in all sectors
- focus groups of underserved and under-represented groups who are often not registered voters, and
- a population-based survey of Iowans with a primary goal of identifying health needs, priorities, and opportunities of the Iowa workforce and other Iowa voters.

Over the next 10 months, the Real Iowans Research Initiative will be engaging Iowans at all levels and between March and May, 2010 will field a telephone survey of a representative sample of Iowa voters. Research findings will be published by the Healthier Workforce Center of Excellence in late 2010.

\*2009 Iowa Employer Benefits Study<sup>®</sup>, David P. Lind & Associates, L.C.

## Project Partners

The Real Iowans Research Initiative is a non-partisan collaborative of three organizational partners who understand the importance of health care in the workplace and seek to identify needs, priorities, and opportunities for employers and employees (and other Iowans not enrolled in employer-based plans). The Real Iowans Research Initiative is funded by the National Institute of Occupational Safety and Health (NIOSH) of the Centers for Disease Control and Prevention (CDC) with additional financial and organizational support from the Project Partners.

**Healthier Workforce Center for Excellence – HWCE** The Center’s core mission is to research and collaborate with organizations regarding employee health programs, translate to best practices, and disseminate to employers in Iowa and nationally to improve the health of the employed population. James Merchant, MD DrPH, Founding Dean of the College of Public Health and HWCE Director, will lead the project research team. [James-Merchant@uiowa.edu](mailto:James-Merchant@uiowa.edu) Alison Amendola, Center Coordinator and HWCE Outreach Director, is also a member of the research team. [Alison-Amendola@uiowa.edu](mailto:Alison-Amendola@uiowa.edu)

**David P. Lind & Associates – (DPL&A)** For nearly 15 years, DPL&A has provided employer and employee benefit consulting. The Iowa-based firm is a recognized leader in employee benefits consulting and research and conducts the annual *Iowa Employer Benefits Study*<sup>®</sup> to monitor changes and trends in the marketplace. David P. Lind, President, is a member of the project research team. [david@dplaconsulting.com](mailto:david@dplaconsulting.com)

**State Public Policy Group – (SPPG)** SPPG is an Iowa public policy, project management, and research consulting firm. Since 1984, SPPG has worked with public, private, and non-profit sector organizations to affect change. Arlinda McKeen, SPPG President is a member of the project research team. She will lead an SPPG team in support of this effort. [Amckeen@sppg.com](mailto:Amckeen@sppg.com)