OPENING REMARKS
David Swankin, President and CEO, Citizen Advocacy Center

Good Morning.

Since its inception, CAC has regularly heard board executives express frustration about the lack of public understanding of regulatory boards, the absence of citizen support for the boards’ mission before legislators and policymakers, and citizen input into board activities, such as rulemaking proceedings and priority-setting. This is not for lack of effort on the part of some boards to bring about such public involvement.

Numerous boards schedule their meetings at various locations around the state to make it easier for members of the public to attend; some have excellent information on their websites explaining in plain English how the public can participate in the board’s rulemaking. We are aware of a few that have convened consumer focus groups on specific issues and others that have encouraged their public members to take it upon themselves to reach out to community groups. Some have organized speaker’s bureaus and made speakers available at health fairs, community events and talk shows; some have distributed board related articles to community group newsletters. Clearly, significant effort has been expended, and the leadership of some boards is clearly committed to promoting citizen participation; but generally these efforts have been isolated and have yielded disappointing results.

For its part, CAC is just as frustrated as licensing board leadership at the dearth of community participation. We believe it is time to think outside of the box and experiment with new strategies and new initiatives to try to make it happen. We believe it would be productive to solicit ideas from community leaders about how to develop effective mechanisms to generate greater citizen involvement.

Public involvement in board activities could include keeping boards apprised of consumer priorities, concerns and aspirations for board accomplishments. It could also involve nominating public members, testifying at rulemaking proceedings and legislative hearings, and even
petitioning boards to undertake initiatives of importance to the public. The payoff from the board’s point of view would be to more closely align its agenda and priorities with those of the public it is mandated to serve. Boards would enhance their accountability and credibility by demonstrating emphatically that they are not focused primarily on the interests of the regulated profession, a commonly held perception.

Consumer awareness and involvement, or more precisely, the lack of it, is a problem for voluntary certification organizations as well as for licensing boards. In 2013, public member Dottie Jeffries wrote in the Nephrology Journal:

Unfortunately, consumers are not always aware of the certifications that exist or that they can seek out certified professionals. Many certification organizations invest their resources in promoting their programs to professionals and employers; the actual “end user” or consumer of the services provided is left out of the communication loop. The cause may be that consumers represent a very broad target audience that is difficult and expensive to reach.

At a CAC meeting last year entitled, “Public Outreach by Regulators and Certifiers,” Institute for Credential Excellence Executive Director Denise Roosendaal emphasized the cost variable:

Reaching the consumer, en masse, is not only difficult for messaging; it is also very expensive. Because of information overload, it takes as many as three consistent messages just to get consumers’ attention, and seven messages to get them to act. So, slicing up the mass audience is important. Credentialing organizations have had success focusing on employers rather than a mass audience.

One of the things we understand about our credentialing organization members is that the demands of marketing to their own certificant population leave very little left of marketing to the public. Research shows that they now spend about 47% of their revenue for marketing, and this marketing is primarily for their certificant population.

Cost is a real issue, and it must be taken into account.

For both licensing boards and certification organizations, educating the public: including community groups and their leaders: is an essential first step if the goal is to get citizen support and community group advocacy in support of their work. At last year’s outreach meeting, Nancy Kirsch, a member of the New Jersey Board of Physical Therapy and the board of directors of the Federation of State Boards of Physical Therapy, put it bluntly:
If our responsibility is to protect the public, we are responsible for educating the public what that protection represents. We are not doing as good a job at this as we could be doing. Consider our Web sites. Consumers have to click and click in order to find information, and even then, it may not be the information they want and need.

What can regulatory board associations do to help our member boards provide the right information to the public? If we are not providing information to the public about the services they should be getting, how will they know when they are not getting good services? How will they understand what to report, and how to file a complaint?

I believe that both licensing boards and certification organizations can learn from professional associations about the need to give a high priority to promoting consumer involvement. Another speaker at last year’s meeting, Justin Elliott, the Director of State Government Affairs at the American Physical Therapy Association (APTA) explained why his organization believes citizen involvement is critical to carrying out its mission. He said:

APTA educates the public about issues that impact them, including issues related to Medicare, scope of practice at the state level, and therapy caps. We also try to get the public involved in these issues. From our perspective, getting the public excited and involved is important because patient advocates provide a distinctive perspective to policy makers. It is one thing for a physical therapist to tell a legislator how he or she or the profession is affected as a provider of service. It is more effective when a patient tells their story about how physical therapy has helped them… While public policy affects the profession, it can have a bigger impact on the patients we serve.

Mr. Elliott also made the point that effective consumer education does not always mean drastically increasing the outreach budget or taking on a bunch of new projects. Sometimes it is a matter of doing a better job executing an existing program. He used the redesign of his organization’s Web site as an example:

We used to have just one Web site, with lots of information about PT. People complained that it was confusing and difficult to navigate. We retained an outside firm to do a Web site audit. We were told we needed to condense our information and focus on those areas people are interested in. We were told we were labeling things wrong. We were viewing our Web site from the perspective of APTA, rather than thinking about it as a caregiver or patient would.
The audit revealed we needed two entry portals. So, we maintained www.apta.org and fixed it up. We also created another Web site, http://moveforwardpt.com, intended for patients. It contains information on conditions and situations a PT can treat. The two sites are interlinked with each other.

Not only can we learn from professional organizations like APTA, we can learn from licensing boards and certifying organizations in non-healthcare fields. In preparing to give a talk last year at the annual meeting of the association of boards that license general contractors, I looked at the Web sites of the boards in states that had experienced a natural disaster: floods, forest fires, hurricanes, tornadoes, and the like. I was very impressed by some of these Web sites. Right on the home page, I found information that would be enormously helpful to a homeowner facing major repairs following a natural disaster. The FAQs went something like this: “How can I avoid getting ripped off by an unqualified repairperson?” “Am I liable to a subcontractor even though I paid the entire bill to my general contractor who did not pass the money along?” (The answer is Yes; something I did not know). The Web sites I looked at followed the advice of the APTA spokesperson: “Focus on those things people are interested in.”

I will say one more thing about using Web sites to educate the public. Nancy Kirsch (NJ Board of Physical Therapy) related this story about her board’s Web site:

New Jersey is trying to have good public outreach, but we’re really not yet there. I asked a friend what he would do if he needed to find a physical therapist. He has enough computer savvy to negotiate the Web. He did a Google search. I was surprised to find that the New Jersey Board of Physical Therapy comes up first: before the professional association. A click on the licensing board link reveals a very congested, confusing Web site.

My friend was hoping he would find an explanation of the practice of physical therapy. What he really wanted to know was how to choose a PT. What do PTs do? What are their qualifications? How do I know that the person I picked is any good? How do I find out? If I do have a complaint, what should I do? None of that is on the Web site.

As board members, what would we want a consumer to know? What types of services should they expect? What is available to them if they suspect they are receiving substandard care?
Let me conclude these opening remarks by saying a few words about how we designed this meeting. As you know, we entitled it “Public Outreach: Promoting Awareness and Stimulating Community Involvement.” Perhaps we should have titled in “Creating Consumer Demand.”

Some years ago, CAC ran a program for the beneficiary members serving on the boards of directors of Medicare Quality Improvement Organizations (QIOs), known at one time as Peer Review Organizations (PROs). The mission of these groups was to “encourage” providers (physicians and hospitals) to follow best practices when treating Medicare beneficiaries with specific diseases. Initially, most QIOs created separate provider and consumer outreach programs. Subsequently, the outreach programs were merged.

How well did these programs work? At CAC, we recommended that the consumer outreach be evaluated, at least in part, according to what it contributed to improving performance by providers. In other words, did this outreach create a demand (as drug companies do with their direct to consumer advertising) or instill incentives for providers to follow practice guidelines, for example, or spend more time answering questions and making sure patients understand the treatment regimen, or otherwise promote patient engagement?

In the Call to today’s meeting, we said:

We will explore the possible reasons for the limited participation by community groups and members of the public. We will begin to develop novel and creative outreach strategies, taking into account the successes and failures of past efforts.

An essential first step will be to ask community representatives what would motivate them to become involved. The meeting will begin with a focus group composed of community leaders who will take about their health care issues and concerns, and offer their thoughts on what it will take to get community groups interested and involved in the activities of licensing boards and voluntary certification agencies.

In just a moment, we will begin this meeting by hearing from community representatives. I am sure we will all learn a lot from this session.

Immediately following the focus group, we will hear descriptions of two efforts to engage community groups in the work of licensing boards in California. One effort was successful, the other disappointing. At our working lunch, two representatives from the North Carolina Board of Nursing will describe what they believe is a strong public outreach program.
After lunch, we return to California for a case study involving strong consumer participation in a rulemaking proceeding conducted by the board of pharmacy. This is a story I believe demonstrates the value of citizen participation.

The next session will feature four individuals who serve or have served in the past as public members on health professional licensing boards or voluntary certification agency boards of directors. The interaction between public board members and affected consumers and consumer groups will be one of the topics explored at this session.

The final session today explores effective messaging to community groups and the public. It will be presented as a case study from Ohio on the subject of tightening up on opioid prescribing.

Tomorrow morning we will reconvene at 9:00 am for four sessions, all moderated by CAC board member, Mark Yessian. First, we will discuss the merits of citizen advisory committees as a tool for facilitating communication to and from the public. Then we will hear about a successful effort by a citizen group to influence scope of practice legislation in Colorado. A national certification organization lent support to this and other state-level advocacy efforts.

The next session will look in depth at ways in which social media can be employed to stimulate consumer awareness and involvement. Finally, we will close the conference with an interactive discussion among all attendees entitled, “The Voice of the Community: What Can Be Learned from Their Inquiries and Complaints.”

**SESSION ONE: HEARING FROM COMMUNITY LEADERS**

**Moderator:**
David Swankin, President and CEO, Citizen Advocacy Center

**Panelists:**
Ruth Perot, Executive Director and CEO of Summit Health Institute for Research and Education.

Jacqueline Davison, Community Activist and resident in a senior apartment community

Ed Smith, Board member, Maryland Citizen’s Health Initiative

Brenda Richardson, Community Activist in one of the poorest wards in Washington, DC
Swankin: This morning we will engage in a conversation with a panel of community activists. I am going to ask them questions and I invite the audience to participate. First, please introduce yourselves.

Davison: I am a senior and live in a senior apartment community in Tacoma Park, MD, which is a very affluent progressive community. We have many health issues.

Perot: I am the Executive Director and CEO of an organization called Summit Health Institute for Research and Education. Our commitment is to work to eliminate health disparities and help communities of color obtain optimal health. I work in a variety of ways on health issues, including conducting wellness circles with persons who have diabetes and hypertension.

Smith: I serve on the board of the Maryland Citizen’s Health Initiative. We advocate to ensure citizens are getting what they need from the healthcare system. We have a couple of organizations in Prince George’s County that are attempting to advocate for the healthcare needs of people with chronic diseases and people with inadequate insurance.

Richardson: I live in one of the poorest wards in Washington, DC. In my neighborhood, our folks are suffering with diabetes, high blood pressure, cancer, mental illness, and obesity. We are seeking creative ways to help people attack those problems. For example, doctors are prescribing walking to help people lose weight. They are partnering with national parks to make it more attractive for people to exercise there.

Swankin: My first question is this: What are your health issues? The reason that is the first question is because licensing boards and certification bodies may not be able to do anything about some of the problems that communities encounter. For example, if one issue is the cost of pharmaceuticals, there is little a pharmacy board or certification body can do about that. But, sometimes these boards can help. So, let’s find out what is on your minds and on the minds of the people you work with.

Davison: The seniors in my independent living building have diabetes, obesity, hypertension, and all of the other issues mentioned by my fellow panelists. The biggest need we have is when seniors can no longer live independently. There are three levels of assisted living, but across the country, assisted living is unlicensed. The states ignore it because they don’t have the resources. The social worker at our building is having great difficulty finding places for seniors who need more assistance. Since it is unregulated, they can charge $3-5,000 a month. In Maryland, some of the group homes are licensed, but in most states they are not. As you know, we are experiencing
a graying of America. So states are finding ways to keep people out of nursing homes and enable them to age at home.

Other issues: As you know, Obamacare penalizes hospitals for readmitting patients for the same illness. Our seniors are in the hospital a lot and planning for the hospital-to-home transition is faulty.

Another issue is medical transportation. We have Medevac access, which is very inefficient and expensive.

Another issue is substance abuse. Many seniors become addicted to pain killers.

**Perot:** I would like to share an experience of a dear friend who was in the hospital with diverticulitis. She had surgery and was sent to a rehab facility well before it was apparent she could benefit from rehab. The rehab facility was unclean. There was no hot water in the bathroom. There weren’t people there who were skilled in changing the colostomy bag. The facility should be appropriately regulated and staffed.

On another issue, we know that telemedicine is a way to provide care to persons who live in rural areas or have no access to specialists. Licensing boards have been reluctant to license doctors across state lines. Without that, you can’t offer telemedicine from one state to another, let alone within a state. This is a problem given the scarcity of providers and the need for access in rural areas.

Personally, I am on my fourth ophthalmologist. I like this one. I left one of the others because he played rock music in the operating room while he was doing my shunt. I don’t know whether that is a licensing issue, but I did complain. I was told that rock music keeps him awake.

**Smith:** My wife recently had a healthcare experience that was managed very badly. She was told that her throat was hard to intubate. This was not true because the next provider who tried to intubate had no difficulty. If a patient wants to do something about a situation such as that, they have to find someone who is licensed in that specialty in that state to testify that the doctor in question made a mistake. The medical society in the state where this happened (Virginia) is very strong, so a patient has to have a well-articulated case to get redress.

In Prince George’s County where I live, one of the big issues is being able to get care in the first place. People have to have insurance and available providers to get needed care. There is a shortage of physicians in certain areas. Even in a wealthy county, a lack of facilities and skill sets in certain locales can make it inconvenient for people to obtain care.
Richardson: I find in my work that if someone is diagnosed with cancer, oftentimes they are ready to give up because of the way the doctor presents that information. A growing number of young people are being diagnosed with schizophrenia or bi-polar disease. Parents don’t understand what has happened in the environment to cause their child to have this diagnosis. A working mother had a suicidal daughter. The mother lost her job and could not afford to buy her daughter medicine and her daughter almost killed herself. During the time the mother was trying to get on Obamacare, the daughter was hospitalized so she could get some medication.

Then there are street drugs. We don’t know how they are affecting our kids. The police can’t keep up. The marketing is really effective. Kids are turning to pills and drugs to help them deal with their daily lives. We are concerned about side effects because kids are exhibiting crazy behavior.

Finally, I hope you guys can find a way to talk about menopause so it is not taboo. If we had doctors who took the time to talk to us, we would know that problems may arise from a normal condition, such as menopause. Patients would appreciate it if doctors and nurses took the time to explain what we are going through.

Swankin: Many of you talked about bad communication. One of you said doctors don’t know how to tell people they have cancer. I think the ophthalmologist who plays rock music is a communications story also. You also spoke about access to care: transportation issues, barriers to the use of telemedicine. These issues involve more than boards of medicine. They involve nurses, social workers, psychologists, discharge planners, and more.

Have any of you or your family or friends complained to a licensing board?

Davison: I went to a dentist who told me I needed gum surgery. I said, I had seen another dentist six months earlier. Why didn’t he tell me this? I wrote to the first dentist to tell him he didn’t do a thorough job and I planned to report him. I refused to pay him. He dropped the matter immediately. That’s as far as I had to go. I was coached about what to do by another professional.

Perot: I should have filed something with that ophthalmologist, but I didn’t because I think at that point I was still trying to come to terms with a diagnosis of glaucoma. I think sometimes a personal situation keeps you from doing what you know is probably the right thing to do. We don’t think about licensing boards necessarily. We think about suing. We know there are lots of reasons not to sue. Ed didn’t think about going to a licensing board about his wife’s case and he didn’t have enough ammunition to sue.
**Swankin:** Do you think people in your communities even know about licensing boards?

**Davison and Perot:** No.

**Smith:** The anesthesiologist in my wife’s situation was licensed in 2011. So, he is obviously new in his career. It is pretty clear a mistake was made. An instrument that normally goes in the trachea went elsewhere. I am wondering what the corrective action is. The next morning, the doctor came and handed my wife a paper suggesting she should not be intubated. She then went to a thoracic surgeon in another hospital. She asked the nurse to please not intubate her because she is difficult to intubate. When my wife awoke, the nurse said she was not difficult at all to intubate. What does that tell us? What is the corrective action for the newly minted physician who clearly made a mistake? He went into her esophagus with an instrument that should have been in the trachea.

**Swankin:** I asked earlier whether you would bother to bring a complaint to a licensing board. You raise another issue: what would you want the licensing board to do about your complaint? If Jacqueline’s dentist hadn’t withdrawn the bill for the unsatisfactory services, what would you have wanted a dental board to do?

Do you think people who complain to licensing boards should be able to offer an opinion about what corrective action they would like the board to take? Do you think boards should ask complainants what remedy they want?

**Smith:** I don’t know much about the boards, so this meeting is really useful to me. If the remedy a board imposes were training, how would we know the professional had learned from the training? If the person is doing something different as a result of training, the only way to know it through observation. Someone has to witness the difference in behavior.

**Swankin:** You have raised the right question. Many licensing boards tell licensees they have to take a certain number of hours of continuing education (CE). They can take it when it is convenient; they can choose the courses, which may have nothing to do with their practice. Even when CE courses do have something to do with practice, how does one know the CE affects behavior? Many disciplinary orders tell professionals to take courses and sometimes require confirmation from a professor that the person attended. But boards don’t now evaluate whether CE or other training affects practice. We’ll come back to this in a minute, after we talk more about experiences with licensing boards.
Richardson: It never dawned on me to call a licensing board. I think many people don’t know what recourse they have. I have read the bill of patients’ rights. I think it would be helpful to add to it the right to call the licensing board if the patient is not happy with the service. There is a lot posted around a medical office about what patients can’t do. Why not have something posted saying I can call the licensing board if I’m not happy with the service?

Swankin: What do you think of that idea: for doctors, nurses, every profession?

Smith: I often notice signs around medical offices. I think it would be good to inform people. We need better information.

Perot: In the situation I just described with my friend, there was a sign saying if you have a complaint, call the ombudsman. My friend had trouble reaching the ombudsman. If there is a sign saying to call the licensing board, someone needs to be on the other end of the line. Don’t post it if it’s not real.

Swankin: In consumer affairs generally, counties have consumer protection offices. Most have rules that retail establishments must have a sign telling customers where to complain. One state tried to do this for doctors’ offices. The argument against doing so is that it would encourage complaints.

Would you generally say that your communities don’t know much about licensing boards and certifying bodies? Even people who know about boards may not know what kinds of complaints they will accept and what is beyond their jurisdiction. It takes understanding and confidence to use a board.

How do you think you could build that kind of awareness and confidence in your communities?

Davison: In my community, you can have all the brochures and signs and information you want, but seniors have to be empowered to take action. There is a certain psychological relationship between a doctor and a patient: and this may be generational, but too many of us are intimidated by doctors and probably wouldn’t even make the phone call. One approach to correcting that is to have advocates for seniors. In the story I told you, I went with my friend to the doctor and I listened and asked questions. I then made the complaint. When you are old, you aren’t likely to read disclosures. More is needed in my community. I envision someone coming to the community and speaking about boards, telling people to know their rights, to go with an advocate, to put their questions in writing, to demand attention. But, most older people don’t assert themselves in these ways.
**Perot:** In the wellness circles we conduct, we tell people they are the head Honcho in their health; they have to take charge of their health. To your question about how to promote awareness and confidence, if you really want to reach people, the outreach has to be beyond paper and into social media and the Internet. If you really want them to know, you find trusted folks you can work with who will help share your message. Don’t expect it to happen for free. People need to be compensated for the time they spend spreading the message. I think it is important to get the message out about what licensing boards do, but that will require some investment.

**Smith:** Earlier you noted the number of times communication seems to be a problem. This is another example. As Ruth was speaking, I was thinking that I don’t see any evidence of social media being used to disseminate information about licensing boards.

**Richardson:** We have to think outside of the box when it relates to doing outreach. If you had a QR code on the wall in a doctor’s office, young people would be more likely to pay attention. Robocalls work beautifully for politicians, so I bet they would work for marketing. Calling 30,000 people randomly doesn’t cost that much.

**Swankin:** Do the people in your neighborhoods know what it means to be board certified? Do they know the difference between licensing and certification?

**Perot:** A board certified provider has something up on his or her wall.

**Swankin:** So does a licensed provider.

**Perot:** I didn’t know about licensing. I am much more aware of whether someone is board certified. Apparently that diploma is fancier than a license. I think most people are more likely to be aware of board certification.

**Swankin:** Would they think that is a mark of quality?

**Perot:** Providers have to have it. I don’t know whether it is an indication of quality, but it is an indication of your right to be a doctor.

**Smith:** I am of the impression that there is testing involved. I have also noted that people speak of board certification as a mark of legitimacy. I take it to mean that the provider is fully qualified and up-to-date.

**Perot:** What is the difference?
Swankin: A license is a requirement. It is illegal to practice a healthcare profession without a license issued by the state. Board certification is not mandated in the same sense. It is not illegal to practice without a certification. However, many hospitals will not grant privileges to someone who is not board certified. So, there is pressure to become board certified in medicine. This is less true in other professions.

What you are helping this audience to understand is how you and your communities perceive licensing and certification. If you moved to a new city and needed to find new healthcare providers, how would you go about finding and selecting them? What do you think the role of the licensing boards or certification bodies should be to help you in the selection of a practitioner?

Richardson: You’d have to have stars by their names. If Dr. Jones has two stars and Dr. Smith has five stars, I will go first to Dr. Smith. I would trust a friend’s recommendation as much or more than information on a Web site.

Davison: At one point, I considered relocating to Atlanta. I asked my doctor for a recommendation. He gave me a list.

Smith: My wife and I have an appointment with a new orthopedic surgeon who we found through a colleague of my wife’s who is a nurse. Is there some way to capture the credibility of a trusted advisor?

Perot: Is there any way in which licensing or certification boards can introduce the concept of quality so it is more evident. A license doesn’t tell you much except that the person hasn’t done anything illegal.

Swankin: As community activists, what would it take to get you or your neighbors involved in policy setting by licensing boards? You mentioned telehealth. The medical boards are developing guidelines for telemedicine. The telemedicine industry thinks licensing boards are standing in the way of using telemedicine by insisting that physicians get a license in every state in which they intend to practice remotely and that physicians have a personal, face-to-face relationship with every patient. You mentioned telehealth as an access issue. It is convenient and solves transportation problems. What would it take to get people in the communities you come from involved in setting board policies related to telehealth?
Another example involves the board of pharmacy in California, which is debating a rule to make patient package inserts easier to read and understand. Consumer advocacy groups made a big difference in what that rule ought to say.

What would it take to get you involved when boards are setting policies such as these?

**Davison:** Tacoma Park Maryland is an activist community. I could see organizations being interested in exploring a role for the community in setting policy regarding licensing boards. It’s a natural area of interest for an organization I know of that is involved in continuing care, but I’ve not heard anyone mention licensing boards.

**Perot:** If people knew how licensing boards impact lives, that’s when they might want to become engaged. It will take some work on the part of the licensing boards to frame the message in a way that will inspire people to become involved.

**Smith:** You have to find the organizations that are interested in licensing issues. Within the organizations, you need to identify the “ready now” people.

**Richardson:** Work through council members and aldermen because they have access to their constituents. Some have roundtable discussions about policy. Information can be disseminated on public access television where hearings and council sessions are broadcast.

**Comment:** I am in Washington State. My father died from a medical error. I regularly attend our state medical board meetings. My observation is that public members and licensee members have a different level of understanding about why people file complaints. Patients and family members who have been harmed by medical errors need to speak up.

**Swankin:** Would any of you consider volunteering to be a public member on a licensing board? Do you think it would interest others in your communities?

**Smith:** I see it as a useful public service. I think community activists would be open to the idea.

**Davison:** I think there are members of the community who would readily serve. How effective are public members? I don’t want to serve on a board if it would waste my time.

**Swankin:** What about a certification board?

**Perot:** What I thought I heard the caller say is that some work is needed at the board level to appreciate the role of the public member. It sounds as if some sensitivity training is in order.
**Question:** I am from Consumers Union where we advocate for consumers on patient safety. Often people who file complaints with a licensing board are disappointed when their particular complaint is not dealt with in the way they would like. My experience, which is anecdotal, is that often the patient who files a complaint receives a letter saying no issues were found with the standard of care. We think it is nevertheless important to file complaints because if there is an accumulation of similar complaints about a particular provider, the board may ultimately take action. How would you communicate to your communities not to have high expectations about their own case, but to file a complaint anyway because of its cumulative value in getting action on problem doctors?

**Richardson:** You are saying that twenty people could have the same complaint and the twentieth person would have his or her issue resolved. That’s not very palatable. If people knew that, they wouldn’t be as likely to file complaints. It is important for people who complain to feel as if they have been heard and something will be done about their problem.

**Perot:** The community has had too many disappointments so, when you ask folks to file a complaint as a matter of altruism because the complaint may not be acted upon, that is asking a whole lot. It is not an easy sell when you are trying to build trust.

**Comment:** I have worked with the medical and nursing boards in Ohio. Ohio has 250,000 licensed nurses. The board receives about 7,000 complaints a year. We need to have the information contained in complaints. We need to remember that everything being talked about today can’t be focused just on a licensing board. There are so many other institutions in the system, such as hospitals, insurers, and the reimbursement system. The licensing board may not be the first place to take a complaint. The Affordable Care Act will change the reimbursement system to pay for quality. This is a huge change.

**Comment:** Recently, I surveyed a group of forty-six members of the ProPublica public harm community. Ninety-four percent of them experienced medical harm. They filed complaints with their state medical boards (16 states). I asked them to describe their experience with their medical boards. Ninety-one percent said they were very dissatisfied. The biggest concern was the boards’ transparency. The complainants found that the boards did not provide enough information for them to understand the boards’ decisions.

**Swankin:** This is something for all of us to think about.
SESSION TWO: REACHING OUR TO COMMUNITY GROUPS: CALIFORNIA CASE STUDY

Becky LeBuhn, Board Chair, Citizen Advocacy Center


Lisa McGiffert, Campaign Director, Consumers Union’s Safe Patient Project

LeBuhn- In this session, we will describe two efforts in the state of California to involve consumers and consumer organizations in licensing board activities. The first example is an initiative CAC undertook several years ago. The second involves Consumer Union’s work with the California Medical Board.

The project CAC engaged in was entitled, *Strengthening the Community’s Voice in California’s Health Care Licensing Boards*. We partnered with the Center for Public Interest Law (CPIL) at the University of San Diego School of Law. CPIL is an academic and advocacy center whose student interns study California’s regulatory agencies. CPIL publishes the *California Regulatory Law Reporter* that covers the activities of 25 major California regulatory agencies. CPIL’s Director, Julianne Fellmeth is a member of CAC’s board of directors. The *Strengthening the Community’s Voice* project was funded by The California Endowment.

The purpose of the project was to get advocacy organizations in underserved areas in California to nominate representatives to public member positions on the state’s licensing boards. We realized that we had to inform these organizations about what licensing boards do. It was an effort not unlike the session that preceded this in that we interviewed representatives from community-based organizations, and our target audience was from underserved areas. We found that these organizations knew very little about licensing boards and what they do. Furthermore, they had very little interest in participating in licensing board activities if they believed it would be in an advisory capacity only. There was a misunderstanding of what it entails to be a member of a licensing board.

We were testing the feasibility of the concept of getting community organizations to nominate people to be on licensing boards. So, we also interviewed the appointment authorities in the state to see whether they would be interested in this. For the most part they were. We also interviewed board executive directors and chairs and current and prior public members. We asked their views of the feasibility of this concept and the desirability of having consumer organizations nominate their representatives. Our hope was that by doing that, boards would be better informed about the
stake of the various demographic groups in the actions taken by boards. Our assumption was that community groups would be able to affect policy, have a role in rulemaking proceedings, and make licensing boards more responsive to consumer issues and concerns.

We completed the feasibility phase of the project. Mark Yessian will tell you a little bit about our conclusions.

**Yessian:** Listening to you and reflecting on the session we just concluded, I think today’s focus group covered it all. Could anybody be surprised that people don’t know much about licensing boards? The types of concerns expressed about the healthcare system and their own experiences are not unique to communities here. We ran into all of these things in the course of interviewing twenty-five community organizations in California.

I want to touch on two or three points before turning it over to Lisa, who has some things to say about a more positive outcome. First, and I mean no disrespect to licensing boards, but from the layperson’s perspective licensure and certification boards are deep into the bureaucratic backwaters of state government. Even people who know about these boards rarely distinguish them from professional associations. We are talking a lot about the medical board even though it is just one among many. A lot of the same issues arise with other healthcare professions.

Second, let us remind ourselves that licensing boards and certification agencies are about licensing individuals. We are not talking about the regulation of hospitals or practices. A lot of the concerns raised earlier this morning are more system concerns. For many healthcare issues, the licensing and certification boards are not the most significant actors. People with complaints probably go to a hospital or other institution first. This adds to the disjunction. It used to be that the individual practitioner was pretty much the only game in town. But in recent decades, institutions have been built up that push the boards more into the backwater.

So, this is a tough connection to try to make. Still, there are things that are in the board’s purview. Telehealth, access to care, and communication issues come to mind. But, such connections aren’t immediately obvious. I think there was wisdom in the comments about how outreach about boards is a difficult sell.

CAC always emphasizes the importance of public members on boards: that is non-licensees. The premise of CAC’s California initiative was that if we could get more representatives of community-based organizations on boards, it would bring community issues to the attention of the board. Questions remain: how do we know these nominees will get appointed and how much impact they would really have?
What might be more salient is for community organizations or coalitions to try to impact the board agenda from the outside by attending meetings, participating in rulemakings, and so on. We found some positive examples of that in California around issues such as language and cultural competence.

I think Lisa is going to give us some reason to feel more upbeat about the possibilities.

**LeBuhn:** May I say a couple more things about what we did in California. We concluded at the end of the brief time we were doing the feasibility study that we thought it was feasible, but at that point the California endowment funding priorities changed, so we never advanced to the next step. We knew it would be a hard sell and would take a long time to have an impact. One reason is that public member vacancies don’t come up all that often. Also, we needed to do the outreach to familiarize the community-based organizations with the licensing apparatus and the desirability of nominating people to public member positions.

The public members we interviewed all felt they had an impact and were respected by their boards and that they made a difference. I think that is significant. Being a public member is not necessarily a frustrating and disappointing position.

**McGiffert:** I am with Consumers Union’s Safe Patient Project. We focus on several patient safety issues: hospital acquired infections, medical errors, the safety of medical devices, and physician accountability. Before I describe a project we have been doing in California for almost five years, I want to add to what has just been said.

When there were several public member openings on the California medical board, we asked state-based organizations that work on health issues to nominate people. The person we nominated was not appointed. One of the problems is that these are often political appointments. So outreach is necessary to the officials who make the appointments. We sent a letter to the Governor listing the things he should look for in a public member. We drew on material from the CAC Web site and from laws in other states that specify public member qualifications. One of the qualities we listed is a record and experience advocating for the public interest. It doesn’t need to be in healthcare. But, people who are used to doing that kind of work come from a different place than people who have served on advisory committees, for example.

Back to the subject of this session: I was asked to talk about our medical board work. Consumers Union has a local office in San Francisco and the Safe Patient Project has been involved in patient safety issues in California since 2003. In our general work across the country, we have created a national network of advocates. Occasionally we work with organizations, such as the
Connecticut Center for Patient Safety, which Jean Rexford is representing today. Mostly we work with individuals who want to change the system. These tend to be people whose personal experiences motivate them to want to change policies and make the system work better for patients. Our ultimate goal is to improve patient safety through public transparency: getting information to consumers when they need it. Our motto is: “End Secrecy, Save Lives.”

Our secondary goal is to create the network of activists, some of whom are professionals and some laypeople. I had a personal goal when we set out in 2003 to get one person in every state to care about patient safety from the consumer perspective and be willing to speak up about it when things happen. We are not there yet, but we probably have somebody in fifteen to twenty states who talks about patient safety in various venues. We support these activists in their work. We have a list serve; they talk to each other and get together face to face fairly regularly. We have built a support system in which Consumers Union is the hub and individual activists are all out doing the things they are passionate about, while communicating with each other. This is a strong design for encouraging people to work on issues, such as medical board activities.

For example, Alicia Cole acquired an infection in a California hospital. She complained to the medical board, but was ignored. She persisted and got them to pay more attention to the complaint and she is now engaged in our work with the medical board. Ann Ling Yu, who is on the phone in Washington, saw her father die from a medication error. Her first encounters with the medical board were very disappointing but she decided to work with us on infection issues and medical device safety.

In California, we first worked on hospital infection issues. We have three advocates who sit on the advisory committee on hospital infection reporting. Following a lawsuit filed by the hospital association to push back on the reporting requirements, we met with advocates and discussed what to work on next. Medical board issues rose to the top because several of the advocates had complained to the medical board. It is very important that the advocates set the agenda.

We have been helped by a grant from the California Healthcare Foundation to raise the profile of consumers and patient advocates in patient safety discussions around the state. Originally it supported an intern who followed the implementation of patient safety laws. Since 2011, it supports a part-time consultant who helps us organize the consumers who attend medical board meetings. The grant also pays for travel. This is key to getting consumers involved in anything. Certainly other community groups might get involved if they had money.

I also think it is important to recognize that licensure watchdogs are likely to be people who have had experience with the boards. It would be helpful if board members welcomed consumers as
valued stakeholders. We have talked to people all over the country who feel they are not appreciated when they come forward and speak at board meetings. Board members can’t talk to these about their individual cases, but they can talk about the policies that were in place that make complainants feel their cases are not handled appropriately.

We have to make the case for policy changes over and over. This is difficult for citizen advocates. We have been able to support them and they have to support each other. We have a group of about ten people who take turns going to meetings.

What are some of the issues important to our activists? One is facilitating public participation. One activist’s fiancé died as a result of a post-surgical infection that wasn’t recognized soon enough. She investigated and learned that the surgeon had a record of arrests for crack cocaine use and was in a diversion program. She was concerned that she was not able to comment at board meetings unless she was present. This led to getting the medical board to permit testimony over the phone. After three years of advocacy, the board’s May 24 meeting was open to comments from people around the state: consumers, doctors, and others who couldn’t make it to the board meeting but had something to say.

The Medical Board of California does Web casts of their meetings. We urged them to broadcast all their meetings and post them online. We think this is a valuable way to improve public participation. Sometimes, the people who view the meetings are reporters who then communicate with the public.

Another issue was that board members were not receiving full information. The staff was summarizing testimony, sometimes incorrectly, and the board members never saw the original testimony that was submitted. We advocated that the board see the actual testimony and now they do.

Another issue is substance-abusing physicians. California ended its diversion program a number of years ago after five audits found serious deficiencies. Several of our activists had experience with substance-abusing physicians. We advocated for the board to adopt the uniform standards the legislature enacted for all licensing agencies. The medical board resisted adopting the standards despite the legal mandate. It took three years to persuade them to develop regulations implementing the law.

Another big issue is outpatient surgery centers, which are licensed by the medical board in California. The board has deferred real oversight to accrediting agencies. The surgery centers are
required to report adverse events to the medical board or be subject to a fine. We have raised questions about the information that is available to the public.

The California statute of limitations ties the patients’ filing of a complaint to the board’s completion of an investigation. We are working to try to change this law. In the meantime, it is important for the board to tell complainants about the time limitations in the law and to notify patients who have filed complaints where they are in the statute of limitations time clock. Way too many cases have been dropped because of the statute of limitations, only to then find actual problems with the doctor.

We are working on the complaint process. We think patients who complain need to be involved in a more meaningful way and the board needs to explain why the complaint was resolved the way it was. Complainants need to be treated as a resource in the investigation. Patients tell us they receive a letter saying the investigators talked to the doctor and looked at the records and determined the problem didn’t happen. The board doesn’t ask complainants to supply evidence to make their case. Patients are often involved when a full-blown investigation is underway, but may not be involved in the determination of whether there is probable cause to start an investigation. Patients often have photographs, recordings, test reports, and other information that hasn’t found its way into the record. They should be seen as a valuable resource. We are encouraging the board to make more information available to the public and complainants about how the complaint process works.

How do we recruit people? We ask people to share their stories. We cull out highly engaged people: the “ready now” people. Half of the battle is showing up. It is not always easy: especially if the board is hostile and unfriendly.

We have in-person meetings with the board staff. We told them the issues we had identified. We sent a letter to the governor about the qualities of public members. We have someone testify at every meeting.

We organize conference calls with public members, especially new public members. When the activists speak to the board, they get three minutes. They can submit additional written testimony. The coordinating conference calls give a clearer understanding of why we are at the meetings. Board members could ask to hear more from those members of the public who take the time to speak at meetings so the board can learn more about their experiences.

We become involved with legislation, which sometimes overlaps with the board. The California medical board was under sunset review last year, which raised some of the issues we are working
on: substance-abusing physicians, outpatient surgery centers: which helped our cause. We bring the media’s attention to issues we think will have broad public interest. We issue press releases and connect reporters with people who have personal stories.

We are active on social media and are beginning to train our activists to Tweet during meetings. We made recommendations to the board about using Twitter more effectively to explain the board’s role, inform people how to complain, and so on. The board could Tweet about upcoming board meetings and agenda items and how to access Web casts. This kind of outreach can be directed to licensees also.

In conclusion, we had the luxury of some resources. We had ongoing relationships with activists on other issues and recruited new people all along. A recent new recruit was focused on her own case until she attended a board meeting and saw that there were opportunities to have a broader impact. Boards can encourage members of the public to attend meetings and make it inviting to come. These meetings are long and sometimes boring so it takes a very motivated activist to stay involved. Other organizations that work on health issues may be hard to get engaged, so consider working with individuals who have direct experience and may be persuaded to try to have an impact on the policies.

Sometimes the staff makes board members uneasy about talking to consumers who have filed complaints. Board members just need to be clear what they can and cannot talk about. If they start going into their case, say you can’t talk about that, but you can talk about policy and procedures.

We think it is critical for citizens to be involved, for boards to be fair and accountable to the public. We think the board should not wait for community groups to come to the table but be proactive on drawing people in. Your Web sites can be a lot more consumer oriented and clear about the process and the limits to board authority. Treat people with respect when they come to board meetings. Use social media and PSAs. Invite groups to make a presentation to you about what they care about, like the focus group we just experienced. Do everything you can to appoint public members who are consumer and public interest advocates who will speak up about these issues.

There is a piece of legislation that would reinstate the Medical Board of California’s diversion program. At the last board meeting, the staff gave a compelling argument in opposition to this bill. One of the public members made a motion to oppose the bill. The physician members argued to support the bill. Four people spoke during the public testimony segment and swayed the physician members with stories about being harmed by substance-abusing doctors who were
in confidential diversion programs. This is an illustration of what can happen when members of the public appear and testify.

**Comment:** I was on the Connecticut Health Foundation board for nine years and we used to be paid $250.00 for every meeting we attended. I told them they were paying the wrong people. There needs to be a fund to pay people who sit on these boards as public members. Money is a motivator. We need to value community representation in a financial way.

**Question:** I sit on the Maryland pharmacy board. I am intrigued by the notion of getting public members from community-based organizations. Many of the licensee members of the boards are nominated by their professional organization. This is a political element embedded in an already political process. I wonder what dynamic might result if community-based organizations were to nominate to the governor.

**LeBuhn:** That was the concept behind the feasibility study we did in California and it sounds similar to what Lisa has been talking about. I have some personal experience with this. Many years ago, I worked for a national funeral reform cooperative that had chapters in almost every state. I made it known that I wanted to be appointed to the funeral board in the District of Columbia and I was. I considered myself to be a representative of the way of thinking of the organization I was working for as well as the public at large.

What you say also makes me recall our interviews in California. Public members, other board members and appointing authorities wanted to be clear that even if a public member was nominated by a community based organization, they didn’t want the public member to be very narrowly focused on that organization’s agenda. They wanted that public member to think of him or herself to be representative of consumers broadly. That’s the same appeal you make to the licensee members of the board when you ask them to think not as a member of the profession, but as a representative of all the citizens in the state. So an interesting balancing act is required of the people on the board.

**McGiffert:** I think you need to do more than we did. An organization has to keep going back to the community groups until they produce a name and then work actively to support the nomination. It is important to find board members who have a broad perspective, especially among the licenses members, many of whom are active members of their professional association, which the appointing authorities know influences their opinions. So, why is it a problem if a public member represents the perspective of a consumer organization?
SESSION THREE: MEASURING THE SUCCESS OF OUTREACH PROGRAMS

Julie George, Executive Director, North Carolina Board of Nursing

David Kalbacker, Director of Public Information and Legislative Liaison, North Carolina Board of Nursing

George: We are fortunate in North Carolina to be an independent and autonomous licensing board. So, we have the resources to do some outreach. It is difficult to measure the success of an outreach program, whether you are measuring the engagement of the public in general, involvement of public board members and continued interest, the number of complaints one receives from the public, or something else. My sense is that one of the most important things is that the public knows that the board does much more than handle complaints.

Currently, our board has fourteen members, three of whom are public members. One of the public members is in her third term and is the vice-chair of the board. She told me that on her first day, one of the nurse board members rode with her in the elevator and told her that the board would be hearing a discipline case that the nurse would tell the public member what is important in the case. The public member had been a clinical social worker in a long-term care facility so probably knew more about the standard of care than did the nurse board member.

When we know someone is interested in engaging as a public member, we actively encourage that person to submit an application. We do this rather than going to an organization and asking for a generic person. Public members need to be willing to make a significant time commitment. Licensee members often receive financial support from their employers, but public members may not have a similar source of support. We tell board members to expect up to twenty-six days a year, not counting preparatory time.

We have had a history of reaching out to organizations such as AARP when we undertake major initiatives, such as continuing competence requirements, patient safety, and public health. We have had a fairly successful involvement with AARP in North Carolina. We have also been fortunate to have a public relations director who brought a wealth of expertise and who has done a yeoman’s job in some specific initiatives I’d like him to talk about.

Kalbacker: When I joined the board about eleven years ago, I wanted to build an outreach program based on concentric circles centering on our licensees and building out to other groups. Licensees want to deal with us only every two years when they renew. If they hear from us in between renewals, they worry. With the blessing of the board, I put together some promotional material about the board functions and reached out initially to nursing organizations. I created a
trade show booth and developed collateral material. Licensees told me they appreciated it. So, I built the first circle with our own 140,000 licensees.

The next larger circle includes folks who deal with healthcare issues, such as public health organizations, nurse recruiting organizations, home and hospice, educational institutions, and others.

The largest concentric circle is the general public. It is difficult and costly to reach this group, Friends in advertising and PR tell me that to affect change in a state of the size of North Carolina we would need millions of dollars. But there are ways to chip away at the challenge. I give talks at Rotary clubs and similar organizations. We got together with the boards of medicine, pharmacy and dentistry. Their licensees all have offices, but nurses don’t really have a physical location. A professional designer helped us develop a brochure with information about all four boards. The way it is folded determines which board’s information is on the front page. Even though the other professions have physical offices where they could hand out the brochure, the Board of Nursing gave out the most brochures because I cared about giving out the brochures.

One way to talk about success is to count how much stuff goes out the door. We are redesigning our Web site to include consumer pages. But, people still like real things, especially those in the older demographic. I have given out about 25,000 pens with the name and number of the board and six alternating messages.

Another measure is do we get more complaints? We do, not because I have given out pens, but because we are growing and get the word out. We are looking into how we can isolate whether a complaint is from a member of the public or a licensee.

One thing we did recently to widen the circle was to celebrate our 110th year as a board of nursing. We published a book about our 110 years. The book was advertised in a statewide magazine. This ad was more valuable than the book because the magazine goes to more than 1200 doctors and clinic offices. This is right where the consumer is and the shelf life of the magazine is four to six months.

If your budget is limited, there are still ways to reach the widest concentric circle. We shared a booth with the medical society at the state fair. I ordered 25,000 nail files with our name, Web address and phone number. People love this kind of stuff and it is inexpensive.

We use other people’s stuff, also. Some of the best comes from the National Council of State Boards of Nursing. They have a brochure about what consumers should know about boards of
nursing. I slap a label on the back with our board’s Web address and phone number. If your national organization doesn’t already do so, suggest they produce material member boards can distribute.

**Question:** Do you do anything with social media?

**Kalbacker:** We are looking into it, but we are hesitant. Facebook is a site you are supposed to interact with, but most of the boards that have Facebook pages are just pushing non-interactive data that is on their Web sites. I follow some Twitter feeds, but worry about the limited characters. For now, we want people to become used to connecting with our Web site.

**Comment:** I encourage you to use Twitter to drive people to your Web site. You can see who picks up your messages, which may inform future outreach.

**Question:** The National Council is on Facebook and advertises outreach materials there.

**Question:** Do you do customer surveys or other measures of success?

**Kalbacker:** We are building a better reporting system on our Web site. We also do a complaint survey. The board has asked me to do a survey on the magazine we send to licensees.

**Question:** What have you found to be the most effective way of getting information about the board to the public? The Maryland pharmacy board is trying to get feedback from licensees and the public. We have a short survey that asks whether people have ever visited the Web site, had good or bad experiences contacting the board, and so on. Are you doing this sort of thing?

**George:** Measurements are incredibly difficult because there are so many things one could measure. We regulators are weak in that we don’t have identified measures and are unsure exactly what we want: more complaints and reports or other things? With support from the National Council, our board randomly surveys individuals who have filed a complaint against a nurse, nurses who have been the subject of a complaint, and education systems that have been through program approval. We periodically do surveys on our Web site. This past year, we asked on our public site about board composition and tenure. We received more than a thousand responses, but it was hard to tell whether the respondents were nurses or members of the public.

I want the public to understand that the board is more than a heavy hand, that it does everything from supporting education standards to supporting criminal background checks, to licensing people in an efficient way, to ensuring continued competence, to timely resolution of complaints. We have a lot to communicate and how best to measure that, I don’t know.
Kalbacker: People from the media call me because they know I’ll respond. Not all boards have someone in that capacity. We received a call from a TV station that wanted to do something about chemically dependent licensees. I knew they would do a lurid story about addicted nurses, but the follow-up story was a good story about the board. So, I am willing to go out on thin ice if there is the possibility of a good follow-up story.

SESSION IV: MOBILIZING COMMUNITY INVOLVEMENT IN LICENSING BOARD RULEMAKING: CASE STUDY: THE CALIFORNIA BOARD OF PHARMACY

Jodi Reid, Executive Director, California Alliance foe Retired Americans

Reid: The California Alliance for Retired Americans (CARA) is the state affiliate of the National Alliance for Retired Americans, which has chapters in thirty-three states. The state chapters bring energy and power to our national campaigns, such as protecting Social Security and Medicare. We also influence public policy at the state level. We are a coalition with about 250 affiliated groups ranging from labor union retirees to senior centers, housing resident associations, Democratic and Republican clubs, and others who believe in the work and values of the organization. All in all, there are about 950,000 people in the affiliated groups. We work on a host of issues guided by our members who vote every year at an annual convention. As you might imagine, healthcare is always at the top of the list because as people age, issues of health are paramount. Making sure people have access to affordable, quality, appropriate healthcare is essential for everything else to fall into place.

CARA has done a lot related to prescription drugs, everything from dealing with the impact of Part D, which had a devastating effect initially in California, to transparency, issues around generics, and pricing. One of the issues that rose to the top was the difficulty people had understanding the directions for medication use. Many people take multiple medications and there was no standard language on the labels, which is what people read. They tend not to read the longer patient package inserts with all the warnings and technical information. The directions on the labels differ depending on the pharmacy dispensing the medications. Some say take in the morning; some say take at mealtime; some say take twice a day without specifying what time of day.

We worked with the legislator who introduced the Patient Centered Label bill. It was designed to address some of the most common problems on labels: clearer directions for use, standardized directions, font size, language and translation.
California already requires verbal consultation, including translation if needed. If the pharmacist doesn’t speak the patient’s language, a translator can be accessed by phone. But, there was no provision for translation of labels. The problems are obvious. The person picking up the medication and receiving the verbal instructions may not be the person who will be taking the medication. More commonly, patients may not recall the verbal instructions, so it is really important to have a reminder of the most important instructions on the label in the language people speak. The legislation did not design the rules; it gave the responsibility for implementing the legislation to the Board of Pharmacy. Governor Schwarzenegger signed the legislation, most probably because he had authority to appoint most of the pharmacy board members. This proved to be an important factor in the story.

CARA has a legislative committee composed of senior volunteers. We worked on the bill and went to the hearings and collected stories, which is important for all of this work, of things that had happened to people because the labels were not accessible to them. We picked this issue in the first place because of the horrendous stories we had been hearing.

The importance of the font size and standardized directions and language was brought home by stories of people who were unable to read their prescription labels so they were taking medications at the wrong time and in the wrong way. One Spanish-speaking woman had a medication that was labeled to take once a day. “Once” in Spanish means eleven, so she took eleven pills and wound up getting her stomach pumped in the hospital. This is why we keep asking for translation if requested.

The bill was passed and went to the Board of Pharmacy. We realized we needed to be part of the conversation about how the board was going to set rules around the vague bill. The national standard for minimum font size was twelve at the time. In California, the standard was eight-ten point. Even with that, the bulk of the label was taken up by the store logo.

The conversation at the board was around encouraging pharmacies to change the design of the label to reduce the size of the logo, standardize the directions, use the national standard font size, and to translate if requested into the thirteen standard Medical languages already being used by California’s Medicaid program. We brought in experts from California and other states to inform the discussion. The rest of the country was watching what we were doing because many other states were considering similar legislation.

We realized early on that this would be a hard lift. One board member, a member of CARA who we helped get appointed, made it clear to us we had an uphill battle. A couple of board members
appointed by the governor to represent chain pharmacies tried to talk the board into doing nothing.

The board moves around the state for its meetings. We showed up wherever their meetings were held. Our representatives weren’t experts on the technicalities of the proposed rule. They were expert in how patients can safely use their prescription medications. Medication error is the second most common reason seniors end up in emergency rooms.

The board was given two years to develop its rules. We were able to persuade the board to standardize the instructions for use. So now in California there are only seventeen directions that can appear on a label in some combination or another. This makes it easier to translate. But, the board wasn’t ready to accept translation. The board also asked for a certain amount of white space on the label and smaller store logos.

On the font size, they stuck with an eight-ten point font, saying that if the consumer requested a larger font size, they would provide it. This put the burden on consumers to request a larger font without any plan for informing consumers this option was available. Eventually, they decided to require pharmacies to display a poster telling consumers they could ask for a bigger font size. Not only are there many competing notices hanging on the wall, the font size on the poster was too small to read easily. To have the program available to print a label in a larger font, and to have the larger label to accommodate the larger font meant that pharmacies would have to have two sizes available instead of just mandating the larger size, which would eliminate the need for the poster and two different programs. The board postponed action on translating printed labels, saying that it was enough to make translation available in the verbal consultation.

The original author of the bill came herself or sent staff to some of the board hearings and argued that the legislature’s expectation was that the board would base its rule on the best evidence-based research. This legislator was so upset about the board’s rule that she introduced another bill in 2013. The new legislation specified at least a twelve-point font and specified that translation had to be available in the thirteen standard languages, if requested. Meanwhile, California has a new governor who appointed other members of the Board of Pharmacy who aren’t simply toeing the industry line.

We appeared before the Board of Pharmacy and asked them to support the bills. The board refused, saying they had already done its job in the earlier rulemaking. Some of the new board members proposed reevaluating its rules. The board isn’t used to having outsiders attend its meetings and we kept reappearing. They knew we knew what we were talking about and that we had become more sophisticated as the process went on. We had learned a lot about legislation
and the rulemaking process and the outside pressures on the board. The beauty of doing this at the board is that these are people who don’t see the public very much, so we had an impact because we wouldn’t go away.

The board eventually agreed to the twelve-point font, in part to get the state senator out of their hair. Governor Brown vetoed the twelve-point font legislation because the board said it would enact that standard by rule. It didn’t want that in legislation.

Translation is still an issue. The bill is still before the legislature. Two of Governor Brown’s appointees on the board come from non-English speaking families. So, the board voted to endorse the legislation. We are waiting to see whether the board will ask the governor to sign the legislation if it passes, or if the board will insist on doing it by rule.

The moral of the story is that it isn’t enough to get legislation passed. It is essential to engage with the licensing board to make legislation a reality. As much as I think the legislation avenue is one activists need to master, working with boards and other administrative agencies is in some ways more productive and more accessible. There are many members of the legislature and lots of lobbyists trying to influence them. The boards, whose members are appointed by the legislative body, tend not to have a lot of public energy around them. Some people are from the industry, but because they aren’t used to dealing with the public, that can be taken by surprise, and there is more opportunity to raise the important issues and engage in conversation about policy.

Question: It is unusual for consumers to know about boards and recognize that the action takes place at the board level at least as much as the legislative level. What makes your organization different?

Reid: For this particular issue, it was clear in the legislation that the board had to develop the implementing rules. We hadn’t been to the Board of Pharmacy prior to this, but now we continue to attend meetings because a lot of other policy issues come up and we now know how much what the board of pharmacy does impacts consumers. For example, they are now talking about dispensing medications through vending machines, with telephone access to a pharmacist if instructions are needed. The vending machine company was asking the board to okay a pilot project.

Why don’t other organizations do this? We are all taught in school that the way policy is made is primarily through the legislative process so that’s where advocacy organizations concentrate. The public is rarely informed about how policy is developed and implemented through the day-
to-day work of agencies that implement laws. Boards have a lot of authority to make changes that have huge impact. Now when we decide to become involved with an issue, we look at all the places where we might work to accomplish our policy goal. It is often easier to work with administrative agencies than to influence legislation.

SESSION V: ROLES OF PUBLIC MEMBERS IN EFFECTIVE COMMUNITY OUTREACH

Moderator:
Becky LeBuhn Board Chair, Citizen Advocacy Center

Panelists:
Jean Rexford, Executive Director, Connecticut Center for Patient Safety; public member Connecticut State Medical Examining Board, Connecticut State Chiropractic Examining Board, Federation of State Medical Board, and National Board of Medical Examiners

Zeno St. Cyr, public member, Maryland Board of Pharmacy; formerly public member Maryland Board of Dentistry

Whitney Hunter, public member Idaho Board of Nursing

Mike McKeown, former public member, National Certification Commission for Acupuncture and Oriental Medicine

LeBuhn: Was an affiliation with a community organization or consumer advocacy group a factor in your wanting to be on a board? Do you think it was a factor in your selection to be on a board? Do you believe such an affiliation it enables you to do outreach or help your board do outreach?

Rexford: The creation of Emily’s List in 1990 inspired us to start a political action committee in Connecticut. Eventually, some of the men and women we supported financially got into office. Politicians don’t forget who has given them money. In addition, the Connecticut Trial Lawyers asked me to organize victims of medical negligence, which evolved into the Connecticut Center for Patient Safety. So, yes, I was noticed because I was working with the public and patients. I was noticed also because I had given political money.

Hunter: I came to the Idaho Board of Nursing through a group called Go Lead Idaho whose mission is to funnel women into positions of leadership and influence in the private, public and non-profit sectors. When the group announced a vacancy at the Idaho Board of Nursing, I
phoned the board’s executive director who encouraged me to contact the governor’s office and apply. I believe the affiliation with Go Lead has affected my ability to do outreach.

St. Cyr: I work at the U.S. Department of Health and Human Services and I have a background in public health. I have always been active in community affairs and have served on numerous boards and commissions. Through a chance meeting with Maryland’s Secretary of the Department of Health and Mental Hygiene, I was asked to submit a resume. The appointments secretary offered a choice of several boards and I first chose the dental board. I now serve on the pharmacy board.

As board members, we are there to represent all the citizens of the state. The licensee members of the boards have various constituencies. We all know that the professional members of the board maintain those affiliations and they get lobbied when issues come up. My experience on both boards has been that the professionals take the position that they are there representing the public. Sometimes this means going against the position their professional association advocates. From the public member’s position, it might be helpful to have a grassroots organization to go to for support.

McKeown: I worked for fifteen years at AARP where I made many contacts, among them a public member on the Certification Commission for Acupuncture and Oriental Medicine named Ben Shimberg. Also, I was familiar with the Citizen Advocacy Center, having worked with them while I was at AARP. The Commission asked CAC for a recommendation to fill a public member vacancy and CAC thought of me. I served three terms.

LeBuhn: At CAC, we often talk about outreach traveling in two directions: the organization reaches out to inform the public about its existence and what it does; it also does outreach to find out what the public thinks and get feedback. In your position as a public member, have you thought of yourself as having any special responsibility in encouraging your organization to engage in outreach to inform the public? Have you thought of yourself as the person who can help bring information to the board about what members of the public and advocacy groups want the board to do?

McKeown: I certainly embrace the idea that I had a special responsibility to watch for issues related to the public. At the same time, I had a responsibility to the organization. That meant I had to be a consumer advocate and simultaneously work for the good of the organization. The first question is who is the public? Acupuncture’s public isn’t those in the U.S. population that seek out traditional medicine. Our public is a very small group scattered all over the country and we didn’t know who they were so we couldn’t reach them through traditional channels.
St. Cyr: One important role of all board members is to get information out to the public. When I served on the dental board, a public member of the state psychology board organized the regulatory board public members and we met regularly to talk about the best ways to get information out to the public. One way is going to senior citizens’ homes, churches, and other venues to present information about the boards.

I agree with Julie George that the public needs to know more than just how to file a complaint. The pharmacy board does a number of outreach events each year. We participate in conferences and events, such as the flower mart. We set up a booth with pharmacists and pharmacy students to perform blood pressure screenings, advise people on taking medications, and so on. We also try to collect information from the public to help us do our job better.

Rexford: I have not really felt a responsibility to reach out to the public. I have seen my role to be building allies on the medical examining board around specific procedures or issues. Right now I am very concerned about opioid overprescribing. The physicians are as concerned as I am, so we are trying to figure out how to tackle this in Connecticut.

The chiropractic board does not have the same drive for improvement. They view chiropractic students as public members. So, I have a much different role on that board, which is often to vote, “no.” I am not an effective public member on that board, but I am very comfortable on the medical board trying to build the alliances that I think will make a difference around the state.

Hunter: I consider outreach to be part of my role. When I first joined the board, I didn’t know what regulatory boards do. I have learned that the board is a resource, not only for the profession, but also for other regulators, healthcare agencies, and the public. I’ve worked with several educational organizations in allied health where people are afraid of the board of nursing. I’ve been able to dispel this. I agree it is equally important to have information coming in from the public. To stay innovative and relevant, our board invites the public to attend meetings. We ask questions during open forum and encourage conversation.

LeBuhn: When you say the public that comes to your meetings, who are they other than students?

Hunter: Recently our statutory language regarding assistive personnel was being amended. It was controversial so many nurses, members of the public, and some lobbyists attended our meetings.
**Rexford:** Our medical board meeting is always covered by the media, particularly the online media. So, the media already does some of the outreach a public member might do.

**LeBuhn:** Have you been through a rulemaking proceeding since you have been on the medical board? Would it occur to you to invite input from the Connecticut Center for Public Safety or another advocacy group during a rulemaking proceeding?

**Rexford:** No. The venue for that kind of input would be the medical society or the hospital association.

**Swankin:** Many medical boards are passing rules governing safe practice in office-based surgery centers. If there were a rulemaking like that in Connecticut, especially since your organization is focused on patient safety, would you ask them to come in a testify?

**Rexford:** At the board, we have had a lot of scope of practice discussions, but what you are talking about is something the Department of Public Health would do. Connecticut has a different model.

**St. Cyr:** Members of the public have attended a few hearings, but it is very rare at a board meeting. Professionals and students come out, but about the only time I recall the public getting engaged was over a drug repository issue.

**Comment:** At most board meetings there is an opportunity to bring up topics that are not on the agenda. As board members, you could suggest that a community organization come to speak about a particular issue during that period.

**St. Cyr:** The subject of telehealth, or telepharmacy, comes up more and more frequently. Retail chains and department store pharmacies are looking at this. Our board has been very slow to address the issue. Perhaps I can get a consumer organization to come in and talk to the board about it from the public perspective. We have had some of the pharmacy organizations come in and speak against it.

**Rexford:** Our meeting is not open to the public. People can listen, but do not speak at our meetings. The only outside person is the individual responsible for an addicted practitioner.

**Hunter:** Our staff takes calls from the public and often will invite callers to appear at the open forum time. One individual came in and talked to us about the unregulated tattoo removal clinics popping up in Idaho.
**LeBuhn:** Mike, can you imagine a situation in which a certification organization would want to get public support for licensure for its profession, or an expanded scope of practice, or some other issue important to practitioners?

**McKeown:** Several states still do not have a practice act for acupuncturists. In the early days, several states put acupuncture within the jurisdiction of the medical board or chiropractic board. NCCAOM would support the certificants in the states by analyzing legislation and helping them understand how to set up a practice act. We didn’t try to get the public to weigh in. We had to go through the practitioners to reach the public. We helped the practitioners with brochures and other outreach materials explaining why it is important to select a certified practitioner and how to file a complaint if patients run into a problem.

**Comment:** My emergency nursing certification organization is working with AARP to get their members to demand that their nurse be certified. We reached out first to AARP because the organization is active and has a strong voice. Also, many people who go to the ER are elderly.

**LeBuhn:** Would you consider recommending to your boards that they periodically invite in a panel similar to the one we heard this morning to have a similarly freewheeling and open conversation to uncover issues that would be appropriate for the board to put on its agenda?

**Hunter:** Every year our board has a retreat. Last year our assignment was to interview a public member. I love the idea you have suggested. The concerns we heard this morning are not unique to this part of the country. We have issues with access to care, transportation, scope, delegation, all of those things. We need to start by listening to our constituents.

**Rexford:** My medical board conducted an analysis of our processes. Board members were interviewed, but not patients or people who had filed complaints with the Department of Public Health. I keep asking when we will do that because I believe it would make a really important contribution to the functioning of the board.

**St. Cyr:** I was impressed by this morning’s panel. The pharmacy board meets tomorrow. The public relations committee meets before the meeting. I will certainly report on this meeting and make that recommendation.

**McKeown:** I think I could go back to NCCAOM and recommend that the state chapters meet with their patients / clients.
SESSION VI: EFFECTIVE MESSAGING TO COMMUNITY GROUPS AND TO THE GENERAL PUBLIC: CASE STUDY: OHIO

Tom Dilling, Adjudication Coordinator / Legislative Liaison, Ohio Board of Nursing

David Swankin, President and CEO, Citizen Advocacy Center

Swankin: To help explain why we asked Tom to speak here, let me read to you from the May 1 edition of the Asheville Citizen Times:

Opiates being used to treat pain are being abused, and as the use of these drugs has grown, so has the number of overdose deaths. Those deaths nationwide jumped from more than 16,800 in 1999 to more than 38,000 in 2010, according to the Centers for Disease Control and Prevention. Of the overdose deaths in 2010, nearly sixty percent involved pharmaceutical drugs. Three of four of those deaths involved opioids, such as oxycodone and methadone, according to the CDC. During a legislative hearing on Wednesday, state officials said in 2010 (the last year they had records for) forty-four percent of North Carolina accidental overdose deaths involved prescriptions that had been filled within sixty days.

You can find similar stories all over the country. This is a problem for the criminal justice system, for licensing boards, for public health, and so on. Let me read something else:

In March 2014, the State Pain Policy Advocacy Network brought together thirteen US patient advocacy organizations in an historic meeting to discuss pain and how to unite our organizations voices. We jointly decided to support the National Pain Strategy and we will submit our recommendations to the Department of Health and Human Services in June of this year… In preparation for garnering public support in a united voice to let Congress and HSS know that change is needed and demanded in how pain is treated, diagnosed and researched, these four principles were agreed to by the presidents of the thirteen patient organizations:

1) Chronic pain is real. It is a complex disease that may exist by itself or be linked to other medical conditions.

2) Chronic pain is an unrecognized and under reported public health crisis with devastating personal and economic impact.
3) Effective pain care requires access to a wide range of treatment options.

4) Allowing people to suffer with unmanaged pain is immoral and unethical.

So, we have undertreated chronic pain coupled with abuse of prescription drugs out on the street. A number of states have begun to do something about abuse, including Ohio. Tom called me to explain one way his state is trying to deal with the opioid problem through regulation of physician prescribing. Tom said there was lots of good material being developed for physicians, but what about the patients who aren’t abusing and have a real pain problem?

So this is a session on messaging. Tom has a good understanding of the difference between messaging to consumers and messaging to professionals. Messages to consumers have to be in plain English and have to be distributed at a time and place where it will be effective. The solution was to write something doctors could give to their pain patients.

Dilling: I am going to talk about promoting public awareness in the wake of an opiate epidemic. Back in 1999, people were saying the medical board was much too hard on prescribing physicians. They were afraid of being disciplined for prescribing pain meds. Patients were protesting that it was difficult to get adequate treatment for pain. So, the pendulum swung and boards made it easier for prescribers.

Between 1997 and 2011 there was a 643% increase in the amount of opioid drugs distributed and a 365% increase in the unintentional overdose death rate. I don’t think the boards of medicine and nursing understood what was happening. It is difficult enough to take action on standards cases, but taking action against pill mills is more difficult. Law enforcement was slow to become involved.

Flash forward, and members of the public put pressure on politicians and policy makers to do something about the increase in drug overdoses. The pendulum had swung again and law enforcement and regulators were going after over prescribing. What about the patients who needed pain care? It was apparent that treatment was needed and resources needed to be devoted to caring for people who had become addicted.

Ohio officials developed a three-minute video entitled Little Pill, Big Problem, which is available on YouTube at: https://www.youtube.com/watch?v=tDKGTGVv-K4. The video had an impact on people in the Ohio government. This is an illustration of the use of social media to communicate a message.
The governor formed a Cabinet Opiate Action Team, which developed a coordinated effort involving education, treatment, and regulation. The nursing board wanted to have a presence even though most fingers were pointed at the medical and pharmacy boards.

In October 2013, the state launched a Web site: www.opioidprescribing.ohio.gov. It advised prescribers not to exceed 80 mg MED for over three months because patients taking doses of opioids that high are at greater risk for overdose. The site was intended primarily for physicians. One section was devoted to patient resources. Dave Swankin and I talked over the phone about how to organize patient-centered material about proper use of medications, disposal of unused medicines, and countering prescription drug abuse. The Ohio Department of Health formed a committee that has regional representation by consumer groups. It meets quarterly to exchange information.

The patient resources section on the Web site says, “Good provider-patient communication is important to successful treatment.” That was the motivation for the patient letters. However, the initial letters drafted by physicians were not really patient-centered; they were classic self-serving letters intended to put something on the record for regulators. We needed to lower the reading level. We needed to shorten the letters. We needed to make the patient the focus, rather than the doctor and the regulators.

The current draft of a patient oriented letter starts by explaining the need for a three-month review of therapy. Informed consent shouldn’t be confined to an initial visit. The idea is that the doctor and patient need to talk again because risks are increasing. The point is made that the doctor is not trying to make the case more complicated, but is committed to working with the patient to provide safe, effective pain relief. The letter contains references to additional information about opioid therapy.

**Question:** Was ethics considered when these letters were being drafted? I ask because I recently had a dental office manager ask about his ethical obligation when an addicted patient comes in and needs anesthesia or post-procedure pain medication?

**Dilling:** Different doctors behave differently in that situation. Some would prescribe opioids and some would look for a different kind of pain medication. The intractable pain rules written in 1999 said that if a doctor sees any signs of addiction, he or she needs to seek out the approval of an addiction specialist to treat the patient with opioids.
We are hopeful that the patient information in combination with other tools from the Veterans Administration and other government agencies will help doctors communicate with patients and help patients become informed.

The governor will call his action team together again to evaluate progress so far. The governor’s Web site has a link to key partner organizations undertaking public education efforts. There is some great grass roots level activity going on to teach children about the dangers of drugs.

**Question:** My doctor prescribed Percocet for relief of pain from a herniated disc and other problems. I take what I believe is very little of it, but it is turning into long-term usage. Do I need to be concerned about this?

**Dilling:** I recommend you talk to your physician. I think this is a great example of what happens when people start taking pain medication and of the importance of engagement between physicians and patients. I understand that there is greater risk with higher-level doses over a long period of time.

Here are excerpts from the current draft of the patient letters, which is still subject to revision:

**Long-term Opioid Therapy: Patient Information**

In some cases like yours, opioids are used to treat long-term pain for longer than three months and at higher levels or greater amounts. Your treatment has reached a point where we need to again weigh the risks and benefits of continued opioid therapy, as we did when I began prescribing to you. Recent medical literature suggests that the risks to your health increase significantly when prescribing opioids at higher levels for this amount of time. I now need to discuss the possible risks and side effects that may occur if you continue to receive opioid therapy in these greater amounts.

I am not trying to make your care more complicated, but I have to make sure prescribing opioids to you continues to be both safe and effective. We must both understand where you are in achieving the daily function goals that have been mapped out by me as your provider and agreed upon by you, my patient. Your ability to meet these treatment goals is important for your health and happiness and to determine the level of adequate pain relief necessary to continue safe opioid therapy. If we need to take additional steps to make sure you are safe, we will.

As we discussed from the beginning of your opioid therapy, opioids can be dangerous if not prescribed and taken responsibly. One outstanding resource for patient information
and patient safety is entitled, “Taking Opioids Responsibly for Your Safety and the Safety of Others: Patient Information Guide on Long-term Opioid Therapy for Chronic Pain.” This guide is published by the United States Department of Veterans Affairs and the Department of Defense and can be found online at:


Continuing to communicate is important to our understanding the possible risks and side effects of long-term opioid drug therapy. If either you or I believe during the course of your care that the risks of opioid therapy outweigh the benefits at any point in your treatment, we will stop or taper your use of opioids in a safe, appropriate manner. Treating your pain will remain a priority, but other pain therapies must be used under those circumstances.

Because the appropriate treatment of pain is a priority in Ohio and in my practice, safety concerns and standards of professional practice may require me from time to time to pause again and consider whether the continue opioid prescribing. Please let me know that your health will always be at the center of that consideration.

SESSION VII: IS THERE VALUE IN ESTABLISHING CITIZEN ADVISORY COMMITTEES?

Mark Yessian, CAC Board of Directors

Spencer Vibbert, Vice President for External Affairs, IPRO

Yessian: Our theme is public outreach to promote awareness and stimulate community involvement. Yesterday, we touched on this topic from different vantage points: community based organizations, drug labels, individual consumer advocacy, opiate problems and how to relate to people with pain management challenges. We will continue to do that today: talking about consumer advisory committees: a time-tested technique with room for improvement. We will look at an experience with expanding the scope of practice of direct entry midwives in Colorado. We will look at social media and then close looking at how we can use data from consumer complaints to signal broader issues or trends so boards and certifying bodies can be ahead of the curve.

As the moderator, I’d like to take a moment to offer some thoughts that put the topic of public outreach in a broader perspective. We all think that public outreach and public relations are
important for any organization, to improve its image, to be more effective in carrying out its mission. For licensure boards and certifying agencies, there is something more significant involved because, like it or not, change is coming.

Boards and other entities composed largely of members of a profession tend to think about things largely from that perspective. Public outreach and public board members can represent: at best: an opportunity to widen the lens, to see things from a broader vantage point and maybe to perceive some of the changes that can’t be avoided.

What do I mean by the changes that are coming? I predict that the public will become more involved in the work of boards and certifying agencies. Compare the current environment to twenty years ago. Technology makes more information available to consumers and patients. Yesterday one of our community advocates talked about telehealth. If licensure bodies don’t get on the right side of telehealth, they will be increasingly irrelevant. Telehealth won’t be stopped. It makes perfect sense.

Distance education is coming like a storm. Traditional educators resist it. But, I would suggest these things cannot be stopped so it is better to figure out how to embrace them in a way that can be relevant to what you want to accomplish.

Boards and certifying organizations are about individuals. Everything else in healthcare is about systems and institutions. One of our panelists talked about how his wife had an intubation problem. In the modern lingo, that is a medical error. System theorists think this is not necessarily of concern to licensure boards. If the hospital were doing what system theorists wanted it to do, it would look at the system causes that led the practitioner to make that mistake.

Demographic changes are coming. We will soon be a majority non-white country. Look at North Dakota. It is changing because of oil. Surely demographic changes will affect the work of a licensure board in that state and how it communicates with patients.

Boards are about regulation. The current mantra is data and analysis. How does regulation fit into the picture?

How can boards and certifying bodies tap into consumers? One of our community activists said something to the effect that we can’t do this on the cheap. If you want to reach out to consumers, you have to show that you are treating them with respect and rewarding people in the community for their involvement.
Did it strike you as it did me when we were listening to those articulate wonderful people from the community, who knew the issues, knew the players, knew where to go to accomplish things, that these informed and effective community leaders had not heard of a licensure board or certifying agency? Could this be because these entities aren’t that important in the scheme of things? Isn’t it odd that nobody reached out to find them? Who would you want more than those kinds of people to be public members on a board? Why weren’t they found? They weren’t quiet, invisible people in the community.

I turn to Spencer Vibbert to talk about using Community Advisory Councils as a way of informing the public and involving the community in the work of Quality Improvement Organizations.

**Vibbert:** Like the panel that didn’t know what a licensing board is, I am confident that many folks don’t know what a Quality Improvement Organization (QIO) is. I work for an organization called IPRO, which is, among other responsibilities, the Medicare-funded QIO for the state of New York. We work with providers to improve quality. Up until this coming August, IPRO also helped consumers and patients who have a complaint about quality of care or feel they have been discharged prematurely from an institution by conducting an external review. So, we have had the dual responsibility of working with providers and protecting beneficiaries, but this will change dramatically August 1.

My charge this morning is to talk about our Consumer Advisory Council (CAC), which we have had at IPRO for at least twenty years. Each QIO is required to have consumers on its board of directors. Intermittently, they were required to have Consumer Advisory Councils. While this is not currently a contractual requirement, IPRO will keep ours because we think it is important.

The Council’s membership comes from the advocate community. We meet quarterly at the AARP offices in Manhattan. We work with groups such as the Center for Medical Consumers led by Art Levin, who is active in this organization. Art was instrumental in performance report cards that IPRO put together beginning in the 1990ies on the performance of HMOs.

Our Council includes advocates from the Visiting Nurses Society, the Institute for Puerto Rican Hispanic Elderly, EPIC, the Centers for Medicare and Medicaid Services, the New York State Department of Aging, the New York City Department of Aging, the New York Business Group on Health (which has been an ally and advocate for public reporting from the very beginning), the Long-term Care Ombudsman program, and a variety of other advocacy groups. It is fair to say you probably need to be an advocate to become involved because what we do is obscure to the average layperson.
The members of the Consumer Advisory Council exchange information. We know that beneficiaries and their families do not know enough about what we do and what we can offer. When a Medicare patient is discharged from a hospital, the discharge notice includes our phone number in case there is a question about quality or a discontinuation of service. But, how many people read the stack of information they receive at a discharge? So, we have always thought it important to spread the word in other ways about what we do.

There have been issues throughout the years about QIO complaint investigations. Few people know how to access the system. By law, complaints must be in writing. By regulation, people receive limited information after the investigation of a complaint. If we make a referral to a licensing board or other disciplinary agency, that information is not necessarily communicated back to the patient and family. So, there are lots of loopholes and technical issues. We weren’t as well known and didn’t do as much outreach as we probably should have.

When Medicare Part D was introduced, advocates were anxious about how to get information out. There was massive confusion. The managed care scandals and concerns over the years have been a big topic. Disseminating information about quality appeals has been another challenge.

Things will change dramatically on August 1. Congress has always been concerned about how QIOs could work with providers to improve quality and simultaneously have the responsibility to represent consumers. Isn’t it an inherent conflict of interest to be working with providers collegially in quality improvement projects and also having authority over investigating complaints against the very same providers? This was finally resolved at the end of 2011 when Congress separated the quality improvement activities from the beneficiary protection work.

Beginning August 1, the new five-year contracts for QIOs will change in major ways. Organizations will no longer be required to be physician-sponsored. It will no longer be required to have a QIO in every state. The dual functions will be separated so that a QIO will either investigate quality complaints and appeals, or work with providers on quality improvement.

There will be two entities nationwide: one in the Beltway and one in Ohio responsible for reviewing all beneficiary complaints and quality appeals. There will be ten to fifteen QIOs working strictly on quality improvement activities. IPRO expects to be one of those.

In addition to the QIO contract, IPRO does Medicaid managed care oversight for eight or nine states. We do external appeals for about thirty states. If you feel you have been denied care inappropriately, your state has two or three contractors to call upon to do a complete review of the clinical case and make a judgment about whether the care was appropriate.
We have a department that publishes report cards for the states of New York and Illinois and for the Commonwealth Fund (http://www.whynotthebest.org). We have focused on the Web site’s presentation for consumers, so it is easy and intuitive. In New York State, we issue report cards for nursing homes, hospitals, home health agencies, and rehabilitation facilities. Another contractor does doctor profiling.

If I had to guess, the Consumer Advisory Councils QIOs have had over the years will probably be de-emphasized by the QIOs that are no longer be responsible for reviewing appeals. There might be provider councils rather than consumer councils. IPRO has made a commitment to keep our Consumer Advisory Council because we think it is important, but it is optional; we are not reimbursed for it. The two major contractors who will be reviewing all the appeals nationwide under the Medicare program will have to demonstrate consumer awareness and collaboration.

I should mention that years ago, Mark Yessian was one of the key authors of a study that was very influential in the thinking of Congress about making sure quality of care complaints are reviewed fairly by the agencies in charge of doing that. We all owe Mark a debt of gratitude for doing that.

**Question:** How will consumers be informed about the new system? Secondly, consumers often think they need to overload a complaint with details to substantiate the problem. Would it be helpful if regulators offered to help consumers state their complaints more succinctly?

**Vibbert:** To the first part of your question, an enormous amount of effort will be devoted to explaining the changeover in review responsibilities. We don’t want cases to go unreviewed because of a time change or not knowing where to send the complaint.

To your second question, at IPRO, when we get a call from a complainant, we help the individual translate that into a written complaint we can then act on.

**Question:** With the changes in the system, if CMS takes action against a physician, will that automatically reported to other states?

**Vibbert:** I think there has always been too little communication between states and licensing boards. There is a National Practitioner Data Bank, which was intended to accumulate information on disciplined physicians and providers. It is not open to the public. I think the system is nowhere near as transparent as it ought to be.

**Swankin:** About twenty years ago, CAC convened a meeting of the CEOs of about seventeen state medical boards and seventeen QIOs to discuss sharing information about complaints. In
only one state: Ohio; the medical board and QIO met regularly to do case reviews. Is there any hope this will change?

**Vibbert:** I think the problem with contractors like the QIOs is that they do what they are told. If you write it into their contract that they have a quarterly meeting with the disciplinary board in the state in which they operate, they will have the quarterly meeting. So long as it is not part of their routine or part of their contractual responsibility, they don’t do it.

**Question:** How did you find the members of your Consumer Advisory Council?

**Vibbert:** It started before I was there. We had an excellent patient advocate named Sheila McCullough who put the committee together initially. I think it was a matter of knowing who the players were in the consumer world. Art Levin was active initially. We did make an effort to reach out to the Hispanic community. We made sure everyone who came to the meetings had an opportunity to speak.

**Swankin:** CAC had a contract with CMS to network all the beneficiary members of the QIO boards. We observed what the QIOs did to create these councils. Most states went to the local AARP and state Office of Aging and asked whom else to appoint. I sat on the council in Virginia. The agendas consisted primarily of reports from the QIO. In Oregon, which along with New York had an outstanding council, there were about fifty members from community groups. The agenda was half reports from the QIO and half community group council members sharing what was on their minds. Oregon’s QIO viewed the council as a resource. It was an inexpensive resource because all it cost was travel reimbursements.

We always asked why licensing boards don’t do this.

**Question:** Will data be more transparent under the new QIO system?

**Vibbert:** Every QIO is obliged to post aggregate data from its review findings on its Web site. I believe there will be more of that under the new regime because there will be a lot of attention on the two contractors and a demand for data about what they do. But, there is not a subcontract that I am aware of yet to organize that information. The group most heavily involved in the all payer claims database is the National Association of Health Data Organizations. You could download data from all the states and aggregate it yourself as long as you are a legitimate researcher with a legitimate request. Then, you need to press researchers to make it available to the public.

**Yessian:** Is the split that is taking place something we should applaud in behalf of beneficiaries?
**Vibbert:** That is a very good question to which I do not have an easy answer. One of the concerns was variability. Why do some QIOs receive hundreds of complaints and others very few? This new regime probably will bring more standardization. A question is how aggressive the new contractors can be without local input. The AMA has always asserted that local practitioners need to review the cases. There will probably be more data available and accountability. Maybe some of the variability will go away.

**Question:** There is evidence that hospitals underreport medical errors. Will the new system focus on reporting medical errors?

**Vibbert:** In New York, we work with the Health Department and substantiate reports of medical errors. I don’t know how many other states follow up on medical error reports.

**Question:** The Joint Commission reports sentinel events on its Web site. Will QIOs look at hospital under reporting of these errors to the Joint Commission or state health departments?

**Vibbert:** I think there is a limit to what a QIO can do. The providers have an obvious incentive not to report.

**Comment:** I can understand why you say that Consumer Advisory Councils will no longer be a contractual requirement, but in this era where patient-centeredness and patient engagement are so fashionable, it seems to me there is a powerful argument that the QIOs engaged in quality improvement really ought to have Consumer Advisory Councils. Consumer input would be very valuable for constructing the quality improvement programs.

**Vibbert:** I agree, especially when the government goes out of its way to adopt the language of patient-centered care, patient-centered medical homes. This really ought to be backed up by requirements for Consumer Advisory Councils.

**Question:** One stakeholder group to include on a Consumer Advisory Council is complainants because those are the people who have been through the process. From my experience, people who file complaints often disagree with QIO’s decisions because they feel that the QIO ignored the evidence the complainant submitted. Is there any process that can guarantee third party review to get the concerns of these dissatisfied complainants heard?

**Vibbert:** What recourse does a family have if they disagree with a QIO’s quality determination? I don’t know of an additional level of review. I think what typically happens is that a complaint can be lodged with the Department of Health and Human Services, which brings additional attention and scrutiny to the case. I don’t know of a review requirement, but writing to a
Congressman or HHS can yield results. You have to believe that QIOs are making independent clinical judgments that are valid.

SESSION VIII: EFFECTIVE COMMUNITY INVOLVEMENT IN SCOPE OF PRACTICE REFORM: CASE STUDY: COLORADO DIRECT ENTRY MIDWIVES

Becky LeBuhn, Board Chair, Citizen Advocacy Center

Indra Lusero, Founder and Director of the Elephant Circle, a consumer advocacy group

Ida Darragh, Board Member, North American Registry of Midwives

LeBuhn: CAC became involved with this initiative when we became aware of a sunset review of regulation of direct entry midwives in Colorado. A scope of practice change was under consideration that would allow them to engage in practices commonly used by their counterparts in other states. At the time CAC was engaged in an effort to encourage consumers and consumer advocacy organizations to become knowledgeable about scope of practice issues and weigh in when change proposals come before legislatures or regulators.

We were impressed with the process used in Colorado, which we thought helped defuse the turf battles which often characterize scope of practice changes. Colorado’s Department of Regulatory Agencies (DORA) prepared a comprehensive report including recommendations for scope of practice expansions for direct entry midwives.

We contacted Ida Darragh with the North American Registry of Midwives, who directed us to Indra Lusaro whose organization was supporting DORA’s recommendations and also recommending additional scope of practice changes. We suggested that our three organizations endorse and thereby reinforce each other’s testimony. For its part CAC submitted written testimony supporting Ida’s and Indra’s recommendations. I will let them tell the detailed story about what happened.

Darragh: The North American Registry of Midwives (NARM) issues the credential that is used for eligibility for licensure in many states, including Colorado. We often interact with DORA when issues come up related to the regulation or licensure of midwives. When the sunset review was scheduled, I received several inquiries from the person overseeing this process at DORA. The agency’s intent was to add to the midwifery scope the use of certain medications in routine and emergency situations. My role was to explain how midwives are regulated in other states.
DORA also did research on each medication they were proposing to develop a rationale for its use and guidelines for use and reporting of use.

In working with the states, I advise on how to involve consumers in legislative efforts. We have a handbook called, *Preparing for Legislation*, in which we advise advocates to determine what committee is going to hear your case and find constituents of the committee members and facilitate personal contacts between constituents and legislators to supplement contacts between midwives and legislators.

**Lusaro:** I want to thank NARM and CAC because we had a great collaboration. I’ll use my experience as an example of a consumer becoming involved in the regulatory process. It started with the birth of my youngest son in 2003. I used a direct entry midwife and became interested in the profession and how one becomes a direct entry midwife. My first engagement with the regulatory agency was through the licensing division. I went from being curious about the licensing piece to being really perplexed about why the regulations looked the way they did. They appeared to be disconnected from what was needed.

I did something pretty extreme to address my fascination with this profession and went to law school in 2006. One of my favorite courses was administrative law. A few things my professor said stood out. First, there are far more rules made by agencies than laws made by legislatures. I wish more consumers knew and understood this. Second, agencies are like ninja elephants: you don’t really notice them until something goes wrong. This inspired me even further.

I spent the next two years doing independent research into the history of the Colorado law all the way back to 1915 when the state first licensed midwives. I was graduating from law school when DORA released its sunset report in the fall of 2010 so I decided organize a consumer coalition to work on the 2011 legislation. We felt the key to our campaign was the consumer voice. The local midwife association and the medical lobby were involved, but in the history of regulating direct entry midwives there hadn’t been a group representing the consumer voice.

Our coalition was based on existing relationships with organizations including the Colorado Organization for Latina Opportunity and Reproductive Rights, which provided us with their lobbyist. We also had the Women’s Lobby and the Colorado Christian Home School Association, which is active and engaged in regulatory issues around education. We had national partners like Ida at NARM, CAC, and others.

We held meetings across the state with consumers who had used direct entry midwives. We explained how the regulatory process works and how regulations impact consumer experience.
We engaged folks who hadn’t previously been engaged. Many of them remarked that this was the first time they had become civically involved. We tried to make the process accessible communicating every time there was an opportunity to reach out to a legislator, or attend a rulemaking hearing. One of our strategies is to let people know how to become involved.

We wrote letters, made calls to legislators, wrote letters to the editor, and encouraged our coalition members to write their own letters. We held a lobby day where we trained folks how to talk about the issues and how to approach legislators. Then we went around the Capital and talked to legislators.

One of the things we discovered quickly was that consumers look at some things differently than the midwives. There were some points where consumers felt more strongly and wanted to push harder than the midwives’ association. This reinforces how important it is to have consumers at the table. We also noticed that it was harder to get legislators and regulators to listen to the consumer voice, despite the agency tagline that “Consumer Protection is our Mission.” DORA convened a midwifery task force which had no consumer representation despite the fact that we had been active since 2011 and showed up at all of the rulemaking hearings. It is partly because of turnover at the agency and partly because the midwifery program is such a tiny piece. But, I also think it is partly the agency’s inclination to take the profession and its representatives more seriously than the consumers.

At the Elephant Circle, we continue to ponder how we end up with complicated regulations when we really need something simple. We still have a team of people who are able to engage with the agency on midwifery issues, and can engage with the Department of Health and Environment, which regulates birth centers, and with Colorado Medicaid and the Insurance Commission. We find that consumers of maternity care services really need to be involved with all of these agencies because our care is impacted by all of them in ways that interconnect. Our coalition members are hungry for information about how to become involved.

**Darragh:** In my experience, legislators and agency personnel are more responsive when consumers show up for hearings and meetings and make their feelings known. An agency doesn’t have to incorporate the consumer perspective, but they do have hearings. If they aren’t responsive to the public, consumers can tell their legislators that the agency is not responding well. The consumer voice is really important. The profession has its stake, but the regulations have an impact on consumer choice.

**Comment:** I’ve worked at both a medical and nursing board and want to throw in another perspective. My state had a midwifery study council about fifteen years ago and held legislative
hearings that were dominated by the Amish community that didn’t want regulation. The medical board had received complaints about care by direct entry midwives from emergency rooms where patients were dropped off. These complainants didn’t want to appear at study council meetings or legislative hearings. I like that consumers can choose, but they need to know what might happen if things go wrong.

Darragh: The purpose of regulation is to set the criteria for who is qualified to be a midwife, what standards they have to follow, and what care they have to give. If the state does not offer licensure, it leaves it up to whoever wants to do this work and the public is basically unprotected.

Comment: The discussions we had at the state level made it clear that it was hard to equate a direct entry midwife with a nurse midwife or an OB-GYN. The proponents of regulation of direct entry midwives said educational standards weren’t needed.

Darragh: The fact is that certified professional midwives are licensed in more than half the states, in many cases for twenty or thirty years with a record of good outcomes, good reporting, and good relationships with their regulatory agency. It is working and is definitely a better answer than having midwives who are practicing in a way you think is unsafe. The purpose of having licensure and regulation is so there are standards and practicing midwives are held accountable for the actions and outcomes. It is hard for me to understand why a state does not want to license midwives and yet they are willing to worry about babies being dropped at emergency rooms or people without qualifications out there practicing.

Comment: I’m a little more pessimistic about how well regulation is working, but this is why regulators and consumer groups need to work together on issues such as this. I appreciate your input.

Yessian: Indra, you talked about getting consumers involved. Would you talk a little more about substantive issues you had to address that made it a difficult process?

Lusero: It is hard to get consumers involved because the way they experience the world is far removed from the way regulators and legislators see the world. For example, when it comes to birth, the consumers I work with see birth in the hospital being dangerous. There is data to back that up. The U.S. is the only developed country with a rising maternal mortality rate. When the folks on the ground see the world differently, it can be difficult to convince them to speak up. When they do speak up the opposition questions or dismisses their worldview. Some of our training was designed to help our advocates bridge the gap in worldview.
SESSION IX: UTILIZING SOCIAL MEDIA FOR EFFECTIVE OUTREACH TO AND INPUT FROM COMMUNITY GROUPS

Sara Langhinrichs, Social Media Manager, AARP

At AARP, we use social media for many different things for many different reasons. We believe that if you are not telling your story, someone else will be. If you are not communicating what your organization is doing, who you are trying to help, and your victories, someone else will be telling a less flattering story.

Secondly, we really want to know what our members care about. AARP is a huge organization, with thirty-seven million members across the country who have a variety of interests. Suppose I am on twitter and happen to see that it’s Mick Jagger’s birthday. We might want to publicize that because some of our members identify with him. Alternatively, we get complaints from younger people who don’t want to receive our mailings. We can respond to them immediately. We can hear people’s concerns in real time and address them.

If our Web site doesn’t work well on an iPad that is going to be a problem because we know that half of our engagements on our Facebook page are coming from mobile devices.

We also use social media to educate and inform people. We remind people of deadlines: Medicare open enrollment or registration to vote, for example. It is easy and inexpensive to reach people via social media.

People have privacy concerns about saying things on social media. People who worry about over-sharing information or violating laws may hesitate to use social media. You can be a passive listener on social media and never post anything of your own. If you do want to post content, remember that everything you say on the Internet is public. This is a problem primarily if you want to say really controversial things that would be a problem wherever you said them. I find the easiest way to avoid privacy concerns is to stay away from personal things and concentrate on sharing information you are comfortable sharing.

Also, consider what platforms to use. A new social network or app appears every day. Figure out what your goals are, your comfort level of sharing, and what networks are appropriate for those purposes. For AARP, we found that Facebook is the best place for us to be. It is where our target demographic is. It is user friendly. It works on desktops and mobile devices. It is simple to train. Generally speaking, Facebook has an older audience and Twitter a slightly younger one. YouTube and Instagram have a wide demographic.
If your goal is to reach reporters, you need to be on Twitter, but you can’t say very much. If you want to reach consumers, you need to be on Facebook, where there is more space to add context and where there are privacy settings that limit who can see the content. That said, anything on the Internet is ultimately public.

Yessian: What are the possibilities for licensing boards and certifying bodies to use social media to reach the public? You have said social media enables people to tune into the conversation, to educate, and obtain information. Is there a way consumers might use social media to report on their experiences?

Dilling: The nursing board in Ohio has a Twitter and Facebook presence. We use them for messaging. Could AARP connect its membership to the nursing boards?

Langhinrichs: We don’t presently do as much as we could to connect to nursing boards or other organizations, in large part because there are so many organizations out there. I encourage all of you to send information about your organizations to me on Twitter. We are always looking for groups that are doing great work. For example, the Cleveland Clinic produces excellent information pieces and Facebook and Twitter that we highlight whenever we can. We offer AARP Health on Twitter and are always looking for people to partner with.

We have staff working on social media in every state. We also have issue-based accounts, such as AARP Health, AARP Family, and AARP Money.

Question: AARP gets funding from industry. How do you eliminate the conflict of interest with organizations like the Cleveland Clinic?

Langhinrichs: As most of you know, we sell insurance. There is a firewall between that division and the information and outreach groups. You will rarely see AARP make a recommendation in an area where we are in the provider space. Or, we include a disclaimer saying who has paid for a particular post, or that we have a member benefit relationship with a provider. When in doubt, we err on the side of too much transparency.

Comment: Our society is about the “selfie” and in some ways Twitter is an extension of that. Most of us are more concerned about community. I’m not sure how to incorporate community into a Twitter world.

Langhinrichs: Here is an example from my neighborhood where we often lose electric power. Members of the community used Twitter to help one another and to offer an air-conditioned space to people who had lost their power. In the winter, Twitter was used to send people to help
shovel snow where needed. One of the best uses of Twitter is hyper-local information about a traffic jam, for example, or a weather pattern. So, Twitter is a force that can bring communities together and involve people who might not otherwise be engaged.

SESSION X: THE VOICE OF THE COMMUNITY: WHAT CAN BE LEARNED FROM THEIR INQUIRIES AND COMPLAINTS?

Yessian: We all know that boards and agencies are about much more than complaints. Still, the question on the table is whether the information coming in from inquiries and complaints tells you something about issues and concerns, or provides information that can help you take preventive action. In the days when I was more engaged in this arena, the analytical people said quality assurance is going in a different direction that regulation; the name of the game is data and metrics. Complaints could be a canary in the mind shaft that reveals something data isn’t yet showing.

Swankin: Boards and certifying agencies get phone calls that have nothing to do with complaints. A speaker at a CAC annual meeting who had been a reporter before joining the staff of a licensing board prepared the FAQs on the board’s Web site based on actual complaints and inquiry calls to the board.

LeBuhn: Here’s an example from an article in the Medicare Rights Center helpline:

As policymakers the media and the public engage with Medicare issues and it is critical that the voices, the stories, and the lived experiences of people with Medicare inform these debates. In 2012, the Medicare Rights Center received fourteen thousand Medicare related questions posed by beneficiaries and beneficiary’s family members. Those common questions heard on the helpline centered on three themes: affording basic healthcare services, appealing denials of coverage, and enrolling in Medicare.

The article goes on to identify resources for assistance in each of these three areas. So, they develop their resources and policy around what they learn from these phone calls.

Comment: I think advocacy organizations take complaints seriously, but I am not sure about others.

Yessian: Sara said AARP uses Facebook to tune into the conversation. How can boards tune in to the public’s concerns on a real time basis?
**Comment:** When my board gets a call or two about a particular topic, we assume it is the tip of the iceberg. Inquiries such as this may develop into an article in our newsletter, which goes on our Web site and may generate more comments on the same topic.

**Swankin:** Any big retailer thinks that one complaint represents tens or dozens of other customers who have had the same experience. CAC once praised a board of pharmacy for publishing a list of the ten most common reasons pharmacists were disciplined as a cautionary note to other licensees. It would be interesting to publish the ten most common causes of complaints. Consumer advocacy organizations could then monitor what the board does about those complaints.

Is anyone here going through databases to see what information is there?

**Comment:** My certification organization carefully tracks the types of complaints we receive and the actions we take. We look at patterns of behavior that lead to complaints. We are involved on Facebook and Twitter and many inquiries we receive through those venues come from the exam candidate population. As an organization, we are looking at how we can more regularly and consistently engage the certificant community.

**Yessian:** I go to London now and then and stop by the British Medical Council to talk about these issues. They do a lot of outreach. They find consumer advocacy groups: sometimes around a particular topic: and pay them to come in for a focus group discussion or ongoing panel.

**Swankin:** Long-term care ombudsmen have little authority but receive many complaints about long-term care facilities. Sometimes the complaint is about the facility and sometimes about one or more licensees. Do licensing boards tap into the information the long-term care ombudsmen possess?

**Comment:** My board has recently begun to have meetings with other entities that track complaints. I think this was initiated by the Attorney General’s office. Information is becoming more transparent under the Affordable Care Act. Consumers will soon be able to learn the outcomes of individual facilities and practitioners and be empowered to make choices. Boards can act on the bad outliers.