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Covering The Affordable Care Act: Researching Consumer Stories, Finding New Ideas and Securing Real-World Examples Kaiser Family Foundation November 14, 2013

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PENNY DUCKHAM: Hello everybody and I'm sorry that we're still coinciding with the President's press conference. We delayed this, as you know, by 15 minutes to allow you time to listen into that, and we will not be answering detailed questions needless to say on that today. We have much to cover and, indeed, today's session as you know comes close to the heart I think of what many of you grapple with everyday, how to cover the Affordable Care Act, how to respond to the deluge of questions from viewers and readers, how to find new ideas, and secure real-world examples. We're fortunate in this fourth webinar, which is exclusively for journalists, in having two reporters who are stars in doing all these things.

Just as a reminder, this webinar as the previous three webinars, will be available online on the Kaiser website, and the transcript will be available a little after that. We look for your e-mails and your chats and call-in questions so please keep those going and we'll be spending the bulk of this hour responding to them.

Just as a reminder, if you're not familiar with Kaiser Health News, this is, of course, the editoriallyindependent news service started by the Kaiser Foundation in 2009. This webinar program is part of the Kaiser Foundation's Media Fellowships Program, which I run.

Now, without further ado, I'm going to turn this over to my two colleagues, Michelle Andrews and Sarah Varney.

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Michelle, who isour Insuring Your Health columnist for Kaiser Health News, we're going to start with you please.

MICHELLE ANDREWS: Thanks, Penny. Hi, everybody. This is Michelle, and I'm happy to be here. I'm going to talk just a little bit about what I do, putting together the Insuring Your Health column. As you know, if you read it, it's a weekly column that Kaiser Health News runs and then it also runs in the Washington Post and really anywhere else in any other media that wants to pick it up from the website.

I focus on how the healthcare system and particularly health insurance works for consumers and, well, actually often doesn't work for consumers. I started writing the column just a few months after the Affordable Care Act passed in March of 2010. That has been a clear focus for the column ever since I got started with it, and I think there's a slide that I've got that will let you browse through the columns by year if you want. That's the first one there.

The Affordable Care Act is a big complicated law and how it affects individuals is something that's really hard to figure out sometimes, particularly since the rules and regulations are still changing and emerging as we're seeing today with the President. It's a challenge sometimes to understand exactly what the rules are and how they affect people. Today, I'm going to talk a little bit about some of the things that I do and the tools that I use when I'm trying

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to figure out how the law affects someone that I'm writing about or how it affects a larger consumer group like young adults or immigrants, for example. I just want to say this isn't a comprehensive overview in the sense that I'm going to talk about what I do. I know that you guys, a lot of you, do this every day in your own work, and you probably have your own resources that you use and ideas about how to do stuff, and actually, I would love to hear about those ideas and your own ways of doing things. If you want to get in touch with me, I think my contact information is up there because I'm always interested in figuring out how I can do it better.

There's another slide there that just posts links to some of the stories that I've done that are ACA-related subjects. Of course, practically everything I do is related to the ACA right now. There's a mix there because, although I do a lot of narratives as Penny mentioned, I do a lot of Q & A's these days. Readers are writing in with a million questions about how the law works and how it affects them and while I can't answer what specifically one individual should do as that would be impossible, I do try to take their general themes and take a look at what the answers might be for them.

All of the stories are different but what seems to be a constant is that simple questions turn out to be more complicated than you'd expect. I'm thinking about a piece that I did last week, actually, I think it was, where we weretrying

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to figure out the answer to the question about whether adult children-- who under the law can stay on their parents' plans until they reach 26-- whether they can get subsidies on the health insurance exchanges if they've access to their parents' health insurance plans. That's the last link on the examples of the stories that you have, and it's an important question because a lot of young people are going to find themselves in this boat where they've both income that qualifies them for subsidies on the exchanges but they also have access to their parents' plan. Well, when I started making calls about this, I was getting two different opinions and all of these from really smart people and so I put out e-mails asking where in the regulations do I find this. Someone sent me a link which I didn't really understand very well and so I went back to my folks and I said please walk me through what does this mean. At that point, I had the right answer and I felt like I was confident to actually present it in print.

Just quickly a couple of things. What I do when I'm trying to sort out answers like that, and you guys probably do some version of this already so I'll just go through that. What I found is often the most helpful thing is to first just Google the subject and ACA, and that will turn up a bunch of stuff. Then, I'll read it and see what I'm really talking about, what issues have been raised, what reports are out there, and then I'll put out phone calls or e-mails to experts,

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do those interviews and ask them to send me relevant regs, fact sheets, et cetera, and then I'll Google those and read them. I just want to make a brief plea to say please do take the time to read the regulations or the fact sheets of the FAQs that the IRS and HHS are putting up because they can really help and I've learned a lot just by reading them. Then, I will go back to people again and try and sort out any questions that I have. That's what I do often.

There's a slide there that you can take a look at that has key dates and if you're thinking about stories, I want to just alert you to those. You probably already know about most of those, most of what's up there. Thinking about story ideas, the other and final thing I wanted to alert you to is just that while the dates create opportunities for stories, sometimes you're trying to do a feature, for example, and it doesn't really tie into a date. That's why I included the links to the previous year's Insuring Your Health columns on that first slide, in part because I want to force you to read all of those columns but, maybe, they can be setting up points for other subjects that would be good to write about because a lot of these issues come up again and again -- like I think the first column I wrote was about the high-risk pools and what would happen to those very sick people in those plans. Well, that's still an ongoing issue as they close up those pools. That might be something that's worth looking into. Again, those

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links to the Insuring Your Health columns, they're just for you to take a look at if they might be useful.

At that, I'm going to close and pass the baton to Sarah Varney who's going to talk to you, I think, about looking for real people. Thanks a lot.

SARAH VARNEY: Hi everyone. This is Sarah. I just want to say good afternoon. I'm going to talk a little about-I mostly report for radio for NPR, although I've been doing more and more print stories as well and obviously for radio we build many of our pieces around characters. We have the particular challenge often for NPR in that we really don't like to use people who want to remain anonymous. You're oftentimes asking people for very personal information, either personal health information or personal financial information and then they also have to be brave enough to agree to talk to you on tape.

I'm going to walk you through a little bit about what I do and some of the categories of people that I look for and some of the strategies that I use to find them. Again, as Michelle mentioned, I recognize that a lot of you do this in your work every day so some of this may be repetitive but for those of you especially who don't have a health beat, specifically, maybe you're a general assignment reporter and you're stepping in and trying to understand quick ways to find folks for these stories, hopefully, some of these will be helpful to you.

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I guess the first thing is we're always looking-I always think about my job in the sense almost like that I'm always looking for characters, like out of central casting, but now the categories that I'm looking for are very precise and are often difficult to assess without digging into peoples' personal finances. It used to be that I was looking for people who had a specific illness or faced a specific problem when they went to the hospital; but now because-and I will get into this in terms of what you qualify for--it depends so much on your personal finances. You have to get at those questions really early in the filtering process. People oftentimes assume that they're eligible or ineligible for Medicaid or for the subsidies, and they oftentimes are confused about whether or not their income level actually qualifies them for any of these programs. It's helpful before you sit down, obviously, to be very clear about what's the-I actually have on my iPhone and I had it just in my reporting bag, the printout of the Federal Poverty Level and the number of people in the household, and I have that with me so I can do a quick check, oh, yeah, no, you're 230-percent of FPL as we call it. That means that you're eligible for a subsidy and then we can go into a subsidy calculator later, like the KFF subsidy calculator, and come up with something pretty quickly.

I was just going to say in the last year, just to give you kind of a sense of the places that I've been and where I've

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found people for stories, I have been in Mississippi, I have been in Texas, and I have been in Arizona. Last week, I was in New Hampshire trying to find one of 40,000 people that are caught in this contract dispute between a hospital and an insurer there. It felt like finding a needle in a haystack but you don't necessarily have to go to far-off places. You can also find folks just down the street. I've been working on a story about Chinese-Americans and enrolling them in insurance. I just went to the Chinese Hospital in Chinatown in San Francisco and you can stand outside and find people that way.

Also just as a way I live my life is that I talk to everybody about health insurance. Like the lady that I do Pilates with, I know everything about her family's health insurance situation and how she is going to be eligible for a subsidy. The folks that do the laundry at the same laundromat that I go to. ; There's a Spanish-speaking single mom who has the unfortunate job of helping me trying to keep my apartment clean. Her kids are on Medicaid but she isn't. She said she is documented so we're trying to figure out what she is going to be able to qualify for. My upstairs neighbors who are former airport baggage handlers who retired early and they're not 65, they had this really terrible junk insurance and so they're trying to figure out what to do.

All I'm saying is that there are people obviously in your life beyond just your family members who are facing a big

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transition right now over the next couple of months. A lot of those people are service workers. You probably know a lot of them. You probably buy your groceries from them, and I just in a friendly way, I always ask them, so hey, what's your insurance situation. We end up having great conversation about that.

What I was going to tell you is that there are categories of people and here we can put up on the screen two of the profiles that we've done recently for NPR. I'm going to tell you who the categories of people are that are primarily affected by the law and then we'll talk about how I oftentimes think about trying to find those folks.

The first are people who are newly eligible for Medicaid in states that are choosing to expand. These are in the unartful term "childless adults" who are under 138-percent of the Federal Poverty Level who will be newly eligible for Medicaid should their states actually go ahead and do the expansion.

The second category are people who are currently eligible for Medicaid but are not enrolled. I mean this is going to be important particularly as we move a little bit further into next year, I think. There's a lot of talk about this question of the "Woodwork Effect". With all of this discussion about health reform and Medicaid expansion, there are going to be people who have already stepped forward, who

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are currently eligible for Medicaid under the current rule and decide to sign up, so that's the second category.

The third category is people who are eligible for a subsidy on the exchange. This gets a little tricky because in the states that are not expanding Medicaid, people who earn over 100-percent of the Federal Poverty Level will be eligible for some subsidies. In states that are doing the Medicaid expansion, they have to be 138-percent over, or 139-percent to 400-percent of the Federal Poverty Level, to be eligible for a subsidy. This is where it's really helpful like I mentioned to have an app on your phone or just a printout of the Federal Poverty Level and to really get into the details with people as you're trying to figure out if they're right for your story in terms of how many people are in their household. You need to even dig a little further than that because it's not just the number of people in their household but it's actually their tax filing status. You might have people who are not married or there are kids from different partners. I'm finding it to be very common in a lot of families that are eligible for these subsidies where it's the modern family. It's important to know, okay, this is the mom. She claims two children as her dependents but her boyfriend, who lives with them, he files separately. Their total income together isn't what matters. What matters is her income. You just have to really be very clear about making sure that you're getting the right people

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for the subsidies if you're trying to do a profile on someone who's going to get subsidies. Then, you have people who are not eligible for subsidies on the exchange. These are folks who earn more than 400-percent of the Federal Poverty Level. For a family of four, that's about \$92,000 or so a year.

The next category are people who are undocumented and are not eligible for Medicaid or a subsidy. Then, finally, the last category are people who have employer-based coverage or may get employer-based coverage when the employer requirement goes into effect. That, as you probably know, was delayed a year but employers are still figuring out how they're going to handle this question this far ahead of time certainly.

When I think about the strategies for finding the folks in these different categories, the strategies really vary a lot. When I think about low-income people, so these are people who are eligible for Medicaid or, perhaps, a really generous subsidy, I often find that it's much easier to find low-income people since they oftentimes will come in contact with some sort of Social Service Agency. A couple of the places that I look at are like I mentioned Social Service Agencies, legal aid organizations. Generally, most communities have a legal aid organization especially for people who have disabilities. There are also, of course, lots of nonprofit organizations that advocate on behalf of consumers. There's a national group in Washington which many of you I'm sure are familiar with called

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Families USA, and they can put you in touch either with people that they've in a sense prescreened, who are eligible for Medicaid or for a subsidy, or they could put you in touch with a local affiliate. If anybody here is listening and from California, a really good group in Sacramento is called Health Access and that's going to be listed on the resource section at the end of the webinar.

One thing just to mention, though, that Families USA and a lot of these groups are very closely aligned with Enroll America which is, of course, the big organization that's out doing education and outreach to get people enrolled in health plans. I'm oftentimes a little uneasy about stories that look a little too teed up. If I don't find people who I think sound authentic, I'll often move on and I'll say that it used to be back before the Affordable Care Act, a lot of times these groups-it felt like the stories sounded a little bit more authentic. It sounds like a lot of these people have done a number of interviews and while it, maybe, works for print, I find that in radio that their voices just don't sound as convincing anymore so go the extra step to try and find people who have not been in other stories. Sometimes, that's not possible like particularly for instance, there's a story in New Hampshire. It was just so difficult to find people that I did use some kind of clues from the local stories that had run to try and track people down that way; but just be wary if you

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feel like the person isn't telling you-I think their story is probably true but whether or not they really feel like they're telling it fresh and for the first time.

The other thing that's interesting is, I'm finding that the groups that have gotten grants to do outreach in education are pretty happy to help you find people; but those people who have gotten grants to actually enroll people in the Affordable Care Act, with the subsidies through the website, they're getting kind of nervous actually. They've actually been told during their training here in California, they've been told during their certification programs, that because of federal HIPAA requirements and other things, that they're not allowed to talk to the press, they're not allowed to hand any of their clients over to journalists, and they're a little freaked out by the political attention and by losing their grant. I have heard this now from a half a dozen of these groups. You can sometimes talk to them and say, well, how about I stand outside of where you're doing this and see if I can find somebody. There are ways to work around that but just as a heads up, I'm finding that if you can go to the groups like SEIU or others that have gotten grants just, specifically, for education and outreach, they don't have the same kind of requirements as those people who are actually navigators do. That makes sense. I mean the navigators are looking at really personal private

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financial information, and those who were certifying them want to make sure that they're not going to be exploiting people.

Just a couple of other ideas for finding low income folks. I oftentimes go to faith-based organizations and organizations that advocate for specific racial or ethnic groups certainly like Pan-Asian Health or Latino Coalition. The unions, SEIU in particular, are very helpful. Just something to remember that, by and large, most of these people, of course, they're very supportive of the Affordable Care Act and they're advocating for the law so as the attention has turned to how difficult the website worked, sometimes these people are not as happy to return your phone calls because they don't really want to talk about the difficulty of doing 100,000 phone calls to people at night and then what happens when those people try and go use the website. People are a little prickly right now I would say.

The other place that I sometimes find low-income people are food banks at the end of the month, after their SNAP benefits have run out, usually that's the second to last week of the month. You can generally find people standing in line and you can also often find families there. The kids may not be there but the mom or the dad or the grandmother or someone is there.

The second group are the moderate and higher-income folks, and these people are tougher to find, because they

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generally don't come in contact with a lot of social service organizations, per se. The places where I find a lot of these people are listservs. I'm on a bunch of listservs for parent groups or moms' clubs. Some of these are remnants from when I had my son six years ago but I since found a bunch more and I did sign up for a lot of them. If I'm looking specifically for families or for somebody who has kids a certain age, I just put a post on the listserv and people will generally get back to me pretty quickly. If you're trying to figure out, okay, but where do I find these parents' or moms' clubs' listservs, you can actually find them through, this may be a little tougher for a male reporter, but you can find them through breast feeding support groups at hospitals. They often will make recommendations to new moms about listservs but you can also find them at kids' stores like usually, there will be a bulletin board and you can find them that way or any of those other sort of toddler-oriented activities like music-together or Gymboree, those kinds of places which are really popular, particularly, in the suburbs. I would say that those places you're definitely going to find much more upscale people and generally skew pretty white.

The other thing is if you graduated from college and there's an alumni listserv, I've found that that's actually really, really helpful so just to put a plug in for your old alma mater. I have to say I don't really find Facebook to be

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all that helpful. If you're ever doing a story specifically for NPR, you can certainly e-mail me and I'm happy to help you navigate this but they have a Facebook page, which sometimes you can find people on. They also have something called the Public Insight Network which are, I don't know, tens of thousands of people who have agreed to-I think it's tens of thousands, I'm not really sure, don't quote me on that-who have agreed to basically be contacted by a reporter and NPR actually has what are called PIN specialists, public insight network specialists, who can help you comb through that database and find people that way. Let's see. I will speed up here.

Of course, community clinics still have patients who volunteer to speak to the press. Sometimes physicians although they certainly are hesitant to give you-they'll not give you names of patients but if you know a physician pretty well that's kind of an activist physician, you might say what could you give them? Could you pass along my request to some of your patients and then here is my card and have them call them, and I often find people that way.

Just one example of the extreme in finding people is a story from the field. We were doing a story for NPR that was about this wrinkle, that people who didn't have bank accounts were not going to be able to-there was this question of if you don't have a bank account, how can you do an electronic bank transfer to secure your first month premium and to pay the

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premiums for your health insurance. These are people who are considered unbanked and it's actually I think about one in four Americans. It's a very large number of people who don't have regular access to a bank account or a credit card. We were literally trying to find somebody who was unbanked, who was uninsured, and who would qualify for subsidies on the exchange or was going to buy insurance on the exchange. I'll say that I stood in a parking lot of a cable company in Brownsville, Texas, on a Saturday morning where people are coming in and out to pay their cable bills in person and just talked to people that way. I found a guy there but, unfortunately, he turned out to be a foreign national so he didn't really work and I found somebody in a different route. I will just say that I think sometimes if you're having a really hard time trying to find somebody, it's helpful just to really think okay, where do these people go? The cable company parking lot is a fascinating place.

The final bucket of people that I'm oftentimes looking for are people who are undocumented. This has gotten a little bit easier because now there are these DREAMers' groups so this is a DACA collaboration. These are folks who were brought to the United States by their parents when they were young and now, of course, are advocating for legal status. We've got up on the screen a Facebook page for the DREAMers in the Bay Area, the San Francisco Bay Area, but you'll find that if you just

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Google Facebook and DREAMers, you'll find in whatever location you're in, there may be a DREAMers page somewhere in your area.

The other place, of course, for undocumented folks, The National Council of La Raza, can put you in touch with local La Raza affiliates. Community clinics, of course, are the primary place or a central place where I often go, of course.

Let me just add one more thing, which I would like to say is that there are a lot of business stories as well to think about and that businesses, so the Supreme Court tells us, are people too. I wanted to give you just a couple of examples of where rather than having an actual healthcare consumer as the character in a story, in the sense either the industry becomes a story or a business owner is really the character in the story.

The first one that we have up here on the screen is about this, and this story ran on NPR. It was about the Affordable Care Act and the Mental Health Parity Law which in a sense is changing the way psychologists organize their practices. The Affordable Care Act and the Mental Health Parity Law were requiring insurance companies to cover mental health benefits the same way that they cover physical health. This was having an impact then on requiring psychologists and psychiatrists and others, who are now increasingly having to accept insurance and what that meant. We ended up finding this just fantastic psychologist with a practice in San Jose who's

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so funny, and I literally went and just sat on her couch and had a therapy session with her. It was really pretty awesome.

The next story that we're just going to show really quickly is a story that ran in New York Times, and this was about farm labor contractors. These are the middlemen who help farmers find laborers for their field, and there's a huge change coming to their industry. They very rarely have offered health insurance and now they're really struggling to figure out what to do, and this is another example of again where Ithere were many farm labor contractors that I talked to. They were all pretty shy. They understand that they oftentimes are employing people who are undocumented but who are using, in a sense, kind of false documents to secure the job. There's a lot at risk for them to talk to a reporter but then because I really wanted to have somebody who was a pretty interesting character, I sort of went through a bunch of different farm labor contractors before I settled on this one guy who really would let me go down to Central Valley and drive around in his truck in the fields and really talked to me. He really, for me, made the story come alive.

Just a final thing that I'll close with, we were asked to mention some underreported stories that we think people can, maybe, spend some time focusing on. I think the main thing right now as reporters we are all covering the Affordable Care Act, as we should, but I think, sometimes, we forget why the

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country is going through this upheaval in the first place. And I know for me, I did so many stories over the years of people with cancer who have their policies rescinded, or middle-class teenagers whose parents couldn't afford insurance and so the kid couldn't play on the suburban soccer team, or junk insurance where it capped out after \$50,000 or something. I think that it's not a bad thing right now to go back to some of those people with serious illnesses and see how the law is playing out for them in the sense kind of remember what the before was like, as we're in the middle of the transition to the after. I think there has been some really powerful reporting on people for whom the changes really didn't come soon enough, people who had cancer, who had since died and their family members have written about it. Also I think whether or not this question if the plans have been offered are really delivering on that promise and I think that's something that we really will start to see next year.

Then, just finally I think if we get through this mess, I think the next big question for us next year is, of course, going to be cost. People are really cranky about these narrow networks, people are in the states where they're not used to that, and I just think you just have to wait. I was doing a story where I happened to be in a urologist's office, and the urologist thinks, basically, any aging man should have endless access to testosterone and Medicare should pay for it.

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I think we're going to have a lot of these questions as to how serious we're about bringing healthcare costs down. Certainly, if not through the end of this year, that will be a big story for us to look at next year. That's all I have to say.

PENNY DUCKHAM: Thank you both very much indeed. We've got every opportunity now to ask questions so please don't be shy. You could ask a question via the chat, via the phone, and I'm going to ask the operator, could you just go through one more time how to call in with the questions on the phone please.

OPERATOR: Thank you. Ladies and gentlemen, if you'd like to register for a question, please press the 1 followed by the 4 on your telephone. You'll hear three tone prompts to acknowledge your request. If your question has been answered and you would like to withdraw your registration, please press the 1 followed by the 3 so that's the 1-4 on your telephone keypad. If you'd like to ask a question via chat, you can use the feature located in the lower left corner of your screen.

PENNY DUCKHAM: Thank you very much. I suspect that a lot of you are out there doing reporting right now after the President's press conference. We're going to continue with questions that we have accumulated in house and ask you, Michelle and Sarah, could you talk a little bit about where to find data. You have done a great job talking about where to

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find people and Michelle talked about looking at the regulations which I think is a notable reminder; but what about looking for data on, for example, enrollment numbers, insurance premiums, how many people are eligible for subsidies, and so on. Any advice on that?

SARAH VARNEY: Sure. I mean, of course, I'm not saying this just because I'm sitting at the Kaiser Family Foundation at Menlo Park where there's free access to Dr. Pepper as much as I want-- but Kaiser Family Foundation, of course, has I mean the best, not only experts but the data that they've got is excellent. It's unparalleled. I would very much encourage you to go to the Kaiser Family Foundation website and look there first.

In terms of the exchanges, Avalere Consulting has really been on top of a lot of this work as well. They've some excellent resources there and they put out some numbers recently looking specifically at the number of people enrolled--or however you want to define that term-- into some of the state-based exchanges as well. I would certainly say Kaiser Family Foundation for data on anything and everything that you want from Medicaid to subsidies across the board and then Avalere, I think, in terms of the exchanges themselves have done some excellent work.

Michelle, do you have something to add?

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MICHELLE ANDREWS: Yes. I was going to say that a lot of the policy groups do some really great research that may not come out there immediately]. For example, the Commonwealth Fund or Georgetown Center on Health Insurance Reforms, the Urban Institute, all of those are great organizations to go to because they're policy folks who are doing long-term research. You can take a look at how many people may be eligible for expanded Medicaid or different subpopulations, and they'll take really in-depth kinds of looks which is really helpful. Another group would probably be the Center on Budget and Policy Priorities because they do some great stuff too. Penny?

PENNY DUCKHAM: Thank you. We're going to take a couple of chat questions now. The first is from Jacob Rogers [misspelled 00:34:58]. Do you have any good suggestions for finding millennials who, of course, are the young healthy folks who are often without insurance now and are going to be important to keep health insurance premiums affordable?

MICHELLE ANDREWS: Sarah, I would-

SARAH VARNEY: Yes, sure. I mean I have found these people. I tend to go back to the listservs but I had found a lot of those people on college listservs and if they maybe themselves are not be on the listserv but their parents are. So I specifically had people say-in fact just the other day, I got an e-mail from a guy who's 23-years old-I was looking for people who-well, I'm working on a whole story about privacy

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issues for people who are under 26. This is, basically, exactly what I was looking for. I heard back from parents who said oh, yes, well my son or my daughter is still on my plan. They're 23, they're 24, and then they'd put me in touch with them. I don't know if this is unusual but, certainly, the listserv from my college has been really, really helpful.

MICHELLE ANDREWS: There's another, I don't know if you're familiar with the organization, you are, I'm sure Sarah, but the caller maybe not, the Young Invincibles. This group is working to improve all kinds of different policy issues for this particular group whether it's health insurance or student loans, and they've a website. I think it's younginvincibles.org, and I certainly called them on occasion and they've helped me identify people who can address reproductive health issues, preventive care, birth control. That's the one I think I have used most often but they're in touch with a lot of folks.

SARAH VARNEY: Yes. I was just thinking of Planned Parenthood as well. Sometimes, I'll go to them even if I'm not looking for people for reproductive stories, they generally can help you find folks who are in their early to mid-20s.

MICHELLE ANDREWS: Yes. They can be really helpful too.

PENNY DUCKHAM: Here's a broader question for both of you. Given how politically charged the debate is now about the ¹ The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies. Covering The Affordable Care Act: Researching Consumer Stories, 26 Finding New Ideas and Securing Real-World Examples November 14, 2013

Affordable Care Act, how do you avoid bias in your reporting and, in particular, the sources to which you go for your reporting. Michael Tomoli [misspelled? 00:37:49] is asking what about the local Chambers of Commerce, the National Federation of Business and/or even the Tea Party group amongst the sources you might be checking in with?

SARAH VARNEY: Sure. Well, I was asked to talk about how you find people who are uninsured and trying to find insurance so the local Tea Party groups are just not really doing that. I'm not going to the SEIU and those places for their perspective on the law; I'm going to them because they've access to people that I'm trying to put in the story and the people that they connect me with are not necessarily ideological in any way. They just happen to be uninsured, for instance. If a Tea Party group was working to find people who are uninsured, certainly I would find them but I can tell you that that's just not the case. If I would be, I've certainly called on many occasions on the Chamber of Commerce, of course. When I was in Texas working on a story about Texas not expanding Medicaid, the Chamber of Commerce was very helpful to me. It just depends on the story you're working on. If you're doing a story that the profile of a person who-that we've started off on NPR doing these series of people who are in these different categories so somebody who's going to be going on Medicaid for the first time because Medicaid is expanding or

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somebody who's eligible for subsidy or somebody who isn't eligible for a subsidy but is still going to be required by insurance, those are profiles of those people and it's really about their experience, what do they know about, what's required of them, and what do they make of their choices that are in front of them. Once they get the coverage, did they like it, did they not like it, did they think it's too expensive, or did they think they can't get into a doctor? We're going to be following these people over the next year if not more and trying to understand through their eyes what the experience of this massive upheaval is like.

Certainly, for health policy stories that I think is probably where Michael's question is more relevant, obviously, we go to NFIB or the Chamber or other groups for their perspective as well so I would say that.

MICHELLE ANDREWS: Yes. I think Sarah and I, neither of us are really doing a lot of stories that are very political or have that slant. That's not really what I do on a daily basis. I mean I'm certainly focused on consumers. If it's an issue that it's going to have-we both say the NFIB as Sarah mentioned, they've one perspective on small businesses, whereas the Small Business Majority, which is a health reform supporting organization, may have a different perspective. I would just make sure that I went to both.

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PENNY DUCKHAM: Here's a question from Christine Deponda [misspelled? 00:40:39]. She asks what's one of the best ways to approach people who are potentially a good fit for a story without putting them off? Either of you could take that one.

MICHELLE ANDREWS: Well, I'll just briefly say, Sarah, is out in the field much more than I'm. I'm doing a lot of my work by phone, and so typically, I have to go through it at a two-step process. I'm often finding a doctor's office that's going to help me identify someone or I'm going to a cancer support group that's going to help me identify someone. They kind of do some of that leg work ahead of time and then, the person that has at least said, well, yes I might be willing to talk with that person. I would say that sometimes the people say they're not interested in talking with me or not interested in using their name, I always say, well, just let's chat a little bit. Frequently, I think, once they get comfortable with you-I mean I think it's human nature to be a little anxious if you haven't ever talked to a reporter before, but then, they tend to loosen up and relax and people like to tell their stories. I think if you're genuinely interested in hearing what they've to say and approach them in a nonconfrontive, nonaggressive way, I find that people are really, really open to it.

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SARAH VARNEY: Yes. I would actually echo that. I mean I think if I'm doing what we would call vox pop in PR terms where I'm just on the street trying to introduce myself cold to strangers. Obviously, it takes a lot out of you actually as a reporter to do that because you get a lot of rejections. I mean the thing, of course, I think that helps the most is just to be really friendly and smile a lot. I'm sure this isn't news to you because to really smile and be very open and warm and welcoming and say absolutely straight upfront what you're doing, hi, I'm here; I'm working on a story about this; I'm looking for somebody who fits this particular category; here is where it's going air; just to be really upfront right away and to really gain their trust. That would be what I'd say in terms of the vox pop stuff where you're standing in a parking lot kind of saying.

Then, certainly, what Michelle said on the phone, often, actually almost always, I say, let's just chat, I'm going to take some notes just for myself but none of this-they don't know what on-the-record or not, back-on, background means, or anything like that. I usually just try and put it in much simpler terms. I'm just really interested in understanding a little bit more about your story, can we chat a little bit and some of these people, I will talk to multiple times and then we'll start to really get into it and I'll really start to take notes. Then, when I sit down with them in

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person with the microphone, I really have a good sense of their story. This kind of violates a typical radio rule which isthey always used to say or many people will say that you should never turn on-you should never have anybody start talking unless your microphone is on because they may something that you really wish you could capture. I think that can be true but because what we're trying to find are these people who, again, fit very specific categories, you have to know so much more about their story before what they actually say is relevant. I'm finding that I spend a lot more time doing preinterviews, getting to know them on the phone and then going and meet them in person, and I was like I almost feel like I'm part-I know them. I know their family. I know when they go to church. I know lots of things about them. Then, I just when I walk into their home, I'm just very respectful like if I notice that their shoes are at the door because there's no shoes allowed in the house, I always kick my shoes off. If they offered me a cup of tea or some water, I always say yes. I never pull my equipment out before I really sat down and made eye contact with somebody and really chatted with them. I just try and do as much as I can to make sure that they trust me, that they feel comfortable and that they know that they can trust me with their story.

MICHELLE ANDREWS: Sarah, you make a really good point when you say that people don't realize that what on-the-record

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is or off-the-record is, and I think that that's so critical when you're talking with real people. I think when you're pulling out a microphone, they're more likely to realize that, oh, well, this is on-the-record, but when I'm doing phone interviews with people and they're telling me stuff that's really very private and they're comfortable and so they're going on and on and I just always make a point of really being clear that this is something I might use in the story and I'm going to use your name and part of the way you do that's, of course, by asking them to spell their name and give their age and their city so they can't escape that but just to bend over backwards in a way that I might not do if I were interviewing an official, that wouldn't do, because I figure they should know the rules but real people, especially, where it's really private stuff, you want to make sure that they realize what they're doing.

PENNY DUCKHAM: Can I ask you a follow-up on that because anecdotally you do hear about stigma-- people feeling that to be uninsured or indeed to be eligible for Medicaid is perhaps something they don't want other people to know about them. What are you finding on that?

SARAH VARNEY: Yes. Well, it's interesting because I think that's absolutely true. I mean I was just actually hearing from an editor of mine about a reporter who's-I want to say in the South somewhere; and they were trying to get some

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folks who were newly eligible for Medicaid and people were saying, well, I don't want to be known to be taking government help or handouts. They've a very specific perspective on what it means to receive healthcare from the government. I don't find that quite honestly as much here in California, although, I did just have an incident where in Southern California, we had a woman who stepped forward to talk about her trying to navigate this process and it turned out she was eligible for a subsidy. She didn't know that until I told her. She got a lot of flak from some people in her community that she was sucking off the government and just very negative things about her and her young children when, in fact, she is somebody who graduated from dental assisting school and has always worked. I think we can't underestimate the-not only has Washington politicized this issue more so than anything that we've seen in a long time, but for individuals in their own communities who are trying to make this decision about do I sign up for Medicaid or do I get the subsidy and what do I tell people. There seemed to be, at least, a pretty profound consequence for some of these people.

PENNY DUCKHAM: Then, on that note, I also wanted to ask you, Sarah, you mentioned about needing to get into peoples' finances in some considerable detail and you did mention HIPAA and privacy issues, can you talk-because people on this webinar who are not regular health journalists and

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don't, perhaps, follow the HIPAA rules as closely as you do-could you and Michelle talk a little bit about those kinds of questions?

SARAH VARNEY: Sure. Michelle, do you want to start?

MICHELLE ANDREWS: Sure. Penny, do you mean just what HIPAA protects? I mean I think what's generally true is that peoples' medical information, their medical records, and their health insurance information, that's all protected, and health providers can't really send to you nor can insurers. I mean that's where I run into it. HIPAA is a big law. There's a lot else that goes into it but that's where I run into it. When I deal with patients who are getting treated at a facility, I pretty much always have to have the facility make a decision that they're willing to help me and they're going to help identify this individual and ask them if they're willing to talk with me and then I have the one-on-one with them. It's interesting, though, I just wanted to mention when you talk about financial details, Penny, you mentioned that, and how important that is, and Sarah is absolutely right, about needing to know all that stuff sometimes now in order to do stories. What I found and I don't know, Sarah, if you found this as well, but people sometimes really think that they've got X, Y or Z, is true for them financially, and that means that they're eligible for something or this is how their finances play out. Then when you really walk through it with them, you realize

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that, in fact, well, they didn't have it right. Just as a reporter, it's really important to go through those steps because the last thing you want is to be saying, well, so and so is eligible for a subsidy when, in fact, it turns out that they're not, not because they're trying to make [inaudible 00:50:11] but just because they're mistaken.

SARAH VARNEY: Yes. One of the big things that keeps coming up for now is people are convinced that they need to include the value of their cars and whether or not they're eligible for Medicaid or if they've any kind of retirement tucked away from a job that they've it long time ago. Yes, I would say that there's a lot of confusion about what actuallythere really is much more about your income, how much you're actually earning on a monthly basis.

In terms of the HIPAA stuff, I'll say that I find thatlike I had this incident in Mississippi where I was going around with this doctor who's a bariatric surgeon and she had introduced me to some of her patients who are getting prepped for surgery and the patients agreed to talk to me. They said, oh, sure, that's fine. No problem. Bring in your recorder. The press information officer for the hospital was apoplectic like came in, no, you can't have that, and they try and use HIPAA as a blanket, sort of hammer that essentially says, oh, no, you can't record any patients' voices, and that's actually not true. As long as the patient agrees, and I carry HIPAA

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forms with me especially if I'm going into a hospital, as long as the patient agrees, that's all that matters. It's not up to the hospital to grant me the right to talk to this patient if the patient, him or herself says it's okay. I would definitely encourage you to understand a little bit about HIPAA and only in that I think what happens is press information officers often overuse it as an excuse because understandably they want to protect patients' privacy. I get all that but it's not a blanket, like you can't talk to anybody in these walls.

PENNY DUCKHAM: That's really a helpful point and not just confined to reporting on the Affordable Care Act. Thank you for going through that.

I wanted to take you back, Sarah, you talked about people who are "unbanked," don't have bank accounts, but some of your reporting has also been addressing the challenges for people who don't have access to computers or indeed an e-mail account and are necessarily not going to be looking for the information online and they're going to need help. Can we talk a little bit about IT and how to do those kinds of stories?

SARAH VARNEY: I guess the thing that comes to mind is a lot of the community clinics have these assisters, people who are authorized to help enroll people for coverage. I was down in San Jose recently at a community clinic. It's a pretty small community clinic actually where they've one of these guys, and he just had a steady stream of people coming in

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whether or not they've computers or not, more they wanted to say they were doing a lot of this with paper and so they were bringing in their files with their tax returns and sitting down in front of him and opening everything up and really filling out the Affordable Care Act applications just on paper. I would say if you're looking-there are a surprising number of people who are very low income who may not have a computer at home but they generally have cell phones so I don't know necessarily what that means. I mean even the people who are on Medicaid, you can generally get in touch with them over a cell phone. They may have these plans that only allow them a certain of number of minutes or whatever, but I do find the community clinics are a good place to go if I'm looking for somebody who seems to be marginalized in some way. I don't know if that answers your guestion.

PENNY DUCKHAM: Yes. I think it does. Michelle, do you have anything to add to that?

MICHELLE ANDREWS: I don't. I actually haven't run into situations where I've been trying to reach people who might not have e-mail access and more technology at their fingertips. I think Insuring Your Health focuses more on people who have insurance. It doesn't do as much as with lower income and public health kinds of stories. It's because this is talking to those readers who are trying to figure out how to

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manage their insurance and I just haven't had as much occasion to be running into that kind of issue.

PENNY DUCKHAM: Michelle, do you think-

SARAH VARNEY: I was just going to say briefly that sometimes what happens to me, though, I would say is, if I have people who have a mental illness that I've interviewed or just, I don't know, are neurotic in some way, I mean I still get phone calls from people who I've interviewed a year or two ago. I mean there's a point at which, sometimes I've gotten 40, 50 phone calls from one guy, just one particular guy, I think he lives in Los Angeles, and I eventually go to the health plan and say we really need to figure out a way to get this stopped and see if this man can stop calling me. So it can kind of go the other way. You reach into their lives understandably and then they see you as a link to something outside, help find them or help them in some way and you oftentimes-I get phone calls at home or on my cell phone, from people who expect me to stay with them and I think that's something that I struggle with a lot because I wanted to help. Obviously as a human being I wanted to help people who are in need but that's obviously not my job either.

PENNY DUCKHAM: I think that's a very good point, and I think with that I'm going to draw this webinar to a close. We've had far fewer e-mails and calls than we normally get for these webinars but I think that's more than understandable

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given the news that was breaking this morning. For those who didn't have the chance to participate today, this will be archived and available on our website so you could check in with it. Sarah and Michelle have come up with a lot of helpful advice and sorts, and it would be good to hear from you if you didn't have a chance to participate today but wanted to do so after the fact. We're not going anywhere.

Indeed, next Thursday, November 21st, we'll be having another webinar in this series on the Affordable Care Act. This one will look at Baby Boomers and Medicare beneficiaries and the implications of the Affordable Care Act for those groups; those who are not yet 65 and eligible for Medicare, and their access to new coverage options in marketplaces and their eligibility for premium subsidies or Medicaid expansions.

Thank you very much those of you who have been able to join us today and thanks to Michelle and to Sarah. If anybody has any questions, the contact information was there in the last slide, either follow up with the Kaiser Family Foundation or indeed the editors at Kaiser Health News. Again, thank you very much.

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