Planning for the Whole Community: Addressing Access and Functional Needs Before, During and After Disasters

Moderator: Loretta Jackson Brown

Presenter: Marcie Roth and Pamela Allweiss, MD, MPH

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Coordinator:

Welcome and thank you for standing by. At this time all participants are in a listen-only mode. During the question and answer session, please press star 1 on your touchtone phone. Today's conference is being recorded. If you have any objections, you may disconnect at this time. And now I'll turn today's meeting over to Loretta Jackson. Thank you. You may begin.

Loretta Jackson Brown:

Thank you (Candy). Good afternoon. I'm Loretta Jackson Brown and I'm representing the Clinician Outreach and Communication Activity (COCA) with the Emergency Communication System at the Centers for Disease Control and Prevention. I'm delighted to welcome you to today's COCA Webinar, Planning for the Whole Community: Addressing Access and Functional Needs Before, During and After Disasters. We are pleased to have with us today Dr. Pamela Allweiss and Director Marcie Roth here to discuss how clinicians can work within their communities to integrate and coordinate emergency preparedness, response and recovery efforts for individuals with disabilities and access and functional needs.

You may participate in today's presentation by audio only, via Webinar or you may download the slides if you are unable to access the Webinar. The PowerPoint slide set and the Webinar link can be found on our COCA Web page at emergency.cdc.gov/coca. Click on COCA calls. The Webinar link and slide set can be found under the call in number and call pass code. Again, that Web address is emergency.cdc.gov/coca and click on COCA calls. That's where you can find the Webinar link and the slide set for today's call. At the conclusion of today's session, the participant will be able to understand the true needs of entire affected community before, during and after disasters, discuss strategies to engage aspects of the community in both defining needs and devising ways to meet them and identify resources to strengthening the assets, institutions and social processes that work well in communities on a daily basis to improve resilience and emergency management outcome.

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Today's first presenter, Marcie Roth, was appointed by President Obama to the U.S. Department of Homeland Security Federal Emergency Management Agency, FEMA, in Washington, D.C. in June 2009.

She serves as Senior Advisor to FEMA Fugate and Director of the FEMA's Office of Disability Integration and Coordination leading the agency's commitment to integrate the access and functional needs of children and adults with disabilities in all aspects of whole community emergency and disaster preparedness response, recovery and mitigation. Director Roth joined FEMA after serving as President and CEO of Global Disability Solution Group leading national, international initiatives with a focus on emergency management and disability issues. Over the past 20 years, she has held leadership positions with the National Coalition of Disability Rights, National Spinal Cord Injury Association, National Council on Independent Living and TASH.

Today's second presenter, Dr. Allweiss is an Endochronologist who completed her fellowship in Endochronology at Cedars Sinai Medical Center in Los Angeles and was the Chief Clinical Fellow at the Joslin Clinic in Boston. She received a Masters of Science in Public Health while completing a residency in Preventive Medicine and Occupational Health at the University of Kentucky. She has worked with CDC's Division of Diabetes Translation since 1999 working on projects for the National Diabetes Education Program. These projects have included public and private worksite wellness initiatives and programs for teen care for people with diabetes. She is also the diabetes subject matter expert for CDC's Emergency Preparedness Program. At this time please welcome Director Marcie Roth.

Marcie Roth:

Well thank you very much. I really appreciate the opportunity to be with you all today. I will be talking about planning for the whole community addressing access and functional needs before, during and after disasters. A little bit more about my background. I worked as you heard in disability services, disability rights, disability programs for most of my career. And in the late 90s I went to work as the Director of Advocacy and Public Policy for the National Council on Independent Living .In 2001 on September 13, I got a phone call from one of my colleagues in New York City who said that there was a problem in New York City and that he needed some assistance. And of course I told him that I was very familiar with what was going on in New York City. And he said, "No, we have an additional problem. We in fact have lots of folks who live in the cordoned off area - the frozen zone around Ground Zero and these folks are people who have disabilities and require assistance for getting up in the morning. They use personal assistant services and they need some assistance from folks who don't necessarily live in that area. And the folks who provide that assistance can't get in." And I'll be honest and say that was the first time that I ever really thought about what happens for people with disabilities in emergencies and disasters. So over the next several years I became more and more involved in what those issues might be and how we can begin to address planning that is inclusive of people with disabilities. And then on August 29 of 2005 I got a phone call from a colleague who was seeking assistance for her sister in law who was quadriplegic and lived in the upper 9th ward in New Orleans. Vinova Kasheta had been trying to evacuate for three days and had been unsuccessful and now Hurricane Katrina was about to make landfall in Louisiana and she was in her apartment and was still trying to evacuate. So it was too late to send any first responders to assist her at that point because everybody was locked down in advance of the storm. But I got on the phone with Vinova. She had a cell phone. And I spent most of the day with her talking about, you know, what I was seeing and assuring her that help was on its way as soon as it was safe for them to move again. And, you know, you'll remember that during Hurricane Katrina as bad as it was, we really all thought that the hurricane was passing and that everything was going to be okay. And so I told her that because I could see on the television that the storm was passing. And I assured her that people were going to start moving soon and that somebody would come to assist her. Unfortunately the next thing that

happened was that (Vinova) told me that water was rushing into her apartment and that - if you would advance the slide please. We lost out connection and (Vinova Kasheta) did not survive Hurricane Katrina. I tell (Vinova)'s story a lot so some of you who may have heard me speak before have probably heard me tell (Vinova)'s story. But I'm really on the theme of today because of (Vinova) and because I'm convinced that even though in disasters people are going to die that (Vinova) did not need to be one of those people. And many of the things that we're working on right now are increasing the likelihood that people are going to be able to survive including people with chronic health conditions, people with disabilities, people with access and functional needs.

Administrator Fugate - next slide please. Administrator Fugate is leading the way on planning that is inclusive of people with disabilities and he - from his confirmation hearings and moving forward it's been very clear that we need to move away from planning separately for people with disabilities. We need instead to be planning for the whole community. That includes children. That includes anyone who's been underserved needs to be included and planned for in all of our preparedness and planning activities at every level of government. Next slide. And we know that this isn't easy but as Administrator Fugate says, we don't plan for easy at FEMA. We plan for real.

Next slide. Many of you may be familiar with Presidential Policy Directive 8, the National Preparedness goal, which is a secure and resilient nation with the capabilities required across the whole community to prevent, protect against, mitigate, respond to and recovery from the threats and hazards that pose the greatest risks. So I'll be talking a little bit more about what that means in terms of disability inclusive practice a little further on. But what I do want to do first is talk a little bit about the types of disabilities and health maintenance needs and some of what is really standing out for us.

If you look at the next slide, types of disabilities and health maintenance needs, on this slide you'll see that we've broken out by a variety of disabilities and health maintenance needs. And I'm going to point out a couple of them in particular. It is notable that even though we have typically thought that somewhere around 36% of the U.S. population are people who are deaf or hard of hearing. We have recently heard from a study from Johns Hopkins that as many as 48 million people are in fact - have - are deaf or hard of hearing. And when we look at the numbers of people who take more than one - take one or more pharmaceuticals, those numbers are very high. And it's very important that when we're thinking about what it's going to take to help people to maintain their health, we're taking into consideration for example the large number of people in the general population who take an antidepressant and what happens during a disaster when someone is unable to continue to maintain access to antidepressants. So when children who take bronchodilators are unable to continue to access those bronchodilators, those would be the kinds of things that could have a real dire impact during a particularly trying time. Next slide please.

This slide shows a map of the new Madrid Seismic Zone and while we typically say that 20% of the U.S. population are people with disabilities, about 56 million people. If you look at the new Madrid Seismic Zone counties, so these are going to be all of the states around the Madrid Seismic Zone. Those states are Indiana, Kentucky, Tennessee, Alabama, Mississippi, Arkansas,

Missouri and Illinois. Now you'll notice that those counties are broken out color-coded. So in many of the states particularly in Illinois and in Indiana you'll notice that somewhere between 12.5% and about 20% of the population are people with disabilities. But then if you look in the other states, if you look at the yellow counties, somewhere between 20% and almost 26% of those - of that population are people with disabilities. And then if you look in the red counties in fact somewhere between almost 26% and almost 33% in those counties are people with disabilities. So it's in our planning assumptions we're planning for 20% of the population but in your county in fact the population is much higher than you're going to have an unfortunate shortfall in your planning assumptions and that's going to have a very significant impact not just on people with disabilities but on the whole community and the ability to plan adequately for the needs of the whole community.

Next slide please. The role of my office, the Office of Disability Integration and Coordination is to not handle all aspects of disability but rather to work to integrate disabilities into what everybody else is working on. And this is particularly important because we want to be able to provide support so that as those planning assumptions are being taken into consideration that we can provide promising practices, tools, resources, guidance around how to adequately plan for the real community not just the easy approaches of the past.

Next slide please. We do have a Web site and I would encourage you to visit. We have a number of tools there. I'll be talking about some more of the tools in a little while. Our Web site is www.fema.gov/about/odic. That's the Office of Disability Integration and Coordination. And if I could summarize our motto very simply, next slide, is baking it in, not wearing it on. So what we're trying to do is rather than being an after thought, rather than being add on or annex or something separate or special, what we're trying to do is bake in planning that is inclusive of the access and functional needs of members of the community into the planning for the whole community.

Next slide please. There are a number of federal laws that prohibit discrimination in emergency programs on the basis of disability. And I have listed those federal laws. You'll also note that I've given the dates that those laws were first enacted. And it's important to point this out because many people have said recently that they're hearing that there are some new laws around disability inclusion. I point out that these are not new laws. But what is in fact new –

next slide please -- is that the Department of Justice (unintelligible) to states and governments in 2007 that addressed where the (unintelligible) and other laws apply. And the Department of Justice pointed out that those laws apply in separation. So physical, programmatic and communication access during preparedness activity, during notification making sure that alerts and warnings are accessible, during evacuation and transportation that people can receive the assistance that they need in order to be able to evacuate and be transported. During sheltering and I'll talk a little bit more about this further down. First aid and medical services, temporary lodging and housing, transition back to the community, cleanup and other emergency and disaster related programs, services and activities. There are a number of key considerations and you'll find them in your slides. Those key considerations -- next slide -- would include self-determination, no one size fits all, equal opportunity, inclusion, integration, physical access and

equal access, effective communication, program modifications and that all of these are provided at no charge.

Next slide. This is a favorite quote of mine from Winston Churchill. "However beautiful the strategy is, you should occasionally look at the results." We have been planning separately for people with disabilities. We've been looking at this as special needs for a very long time. But the result has been that there's a lack of clarity and outcomes have not been successful in maximizing, optimizing limited community resources when we fail to plan for the whole community.

So you'll notice -- next slide please -- we're not using the term special needs any longer because the term special needs is defined very differently by very many people. I found 67 different definitions of the term special needs. And my colleagues in Connecticut at the Protection Advocacy Agency said it very well when they said, "We hear it all the time, special needs and vulnerable." Both terms do damage. When people with disabilities are thought of as special, they're often thought of as marginal individuals who have needs and not rights. The word vulnerable has a similarly unfortunate affect. Vulnerable people must have things done for them. They are recipients, not participants. Don't think special or vulnerable. Think universal access. Integrate access into all aspects of emergency services, transportation, sheltering, education, evacuation, et cetera. And remember that access is a civil right, not a favor or amenity.

Next slide please. Some people might say well, you know, what's the difference, you know, language. We're just being PC. And I would argue that language drives behavior. And Mark Twain said it best when he said, "The difference between the right word and the almost right word is the difference between lightening and a lightening bug."

Next slide please. So we're taking a whole community approach. And this is across the Federal Government understanding in the true needs of the entire affected community, engaging the community and strengthening the existing assets, institutions and social processes. Next slide please. And so participation of the whole community requires that we provide equal access, that we meet the access and functional needs of all individuals and our consistent and active engagement and involvement is inclusive of all aspects of the community.

Next slide please. So I've provided some additional information about how meeting access and functional needs, how we define that and the value of that.

Next slide please. And when we talk about the whole, whole community, we need to make sure that we're not just simply talking about the people who provide services to people with disabilities but that in fact we are engaging the entire whole community. And Dr. Allweiss is going to talk a little bit more about this in a few minutes. I want to make the distinction between meeting functional needs and ask acute medical needs. When we talk about acute healthcare needs, those are the needs that many people have either because of a disaster or coincidental to the disaster but where they require the care of medical professionals. Most people with disabilities on a daily basis don't have acute medical needs. Most people with disabilities have access and functional needs. And those access needs would include physical access, programmatic access and communication access. And when we think about functional needs, the

- we're using the (seamless) framework, which thinks in terms of communication, maintaining health, independence, (KC) services and self-determination and transportation. When we are planning people often will ask me well don't people with disabilities have a responsibility to participate in their own planning? And the answer is absolutely, yes they do. But we need to make sure that when we're holding folks to participate in their own planning that we need to make sure that the educational outreach effort information and tools that we're providing are available, achievable and accessible to everyone.

Next slide please. I put up a favorite comic here and the speaker's making a presentation. He says - he's presenting on be prepared 101. And he says, "No doubt you're asking yourself what are hatchets and how the heck does one go about battening them down?" We need to be really careful that the information that we're giving folks is information that they understand and that they can access. When we tell people information isn't achievable, then it's difficult for them to continue to participate.

Next slide please. Among the many things that we're doing at FEMA would include our bringing onboard regional disability integration specialists. We have regional disability integration specialists in all ten regions.

Next slide please. We have committed in our workforce diversity to bring on folks who look like the communities we serve and that includes many people with disabilities.

Next slide. We are available to assist our partners across public, private in all aspects, all stakeholders. We are available to assist in finding subject matter experts on disability (unintelligible) practices and welcome the opportunity to work with you all on that.

Next slide please. We've provided a variety of tools, resources, guidance and many of those are listed here.

Next slide please. And we've also provided information about allowable grant expenditures that states might prioritize. And at the next round of Homeland Security grants about to be announced. This is yet another opportunity to - for states to prioritize in their planning for the coming year some of the resources that might make it possible to fully include people with disabilities as participants in all aspects of preparedness, response and recovery. We've recently published, about a year ago, guidance on planning for integration of functional needs, support services in general population shelters. And this guidance is helpful for states and shelter planners to be able to identify promising practices and to begin to work towards ways to make general population sheltering accessible to folks who don't require a higher level of acute medical care. And this requires that we engage people with disabilities and community leaders and typically we've thought about people with disabilities as liabilities in emergency management. And we need to move towards helping folks to become assets, to be active participants. And this requires -- next slide please -- that we engage in what the disability community talks about a lot, which is called nothing about us without us. And I've given you a link to the FEMA think tank, which is an activity under way right now in which we're engaging the whole community as partners in creating new ways for everyone to be involved.

Next slide please. I gave you our Web site and we have many promising practices in inclusive emergency management. We have videos. We have PowerPoint presentations from a recent conference that we held on promising practices. You'll find about 55 videos there. Next slide please. And when we are successful in engaging the whole community, when communities integrate, the access and functional needs of children and adults with and without disabilities in all cases of community wide emergency management to strengthen their ability to prepare for, protect against, respond to, recover from and mitigate all hazards, which is in fact our mission.

So I thank you and next slide please. Here's where you can reach me if you'd like more information or would like to be added to our distribution list. And I know we'll have a little bit of time for questions and answers at the end. I'm now going to turn over to Dr. Allweiss who's going to be providing the overview and impact of chronic disease patients in vulnerable populations during disasters and emergencies. So thank you very much.

Dr. Pamela Allweiss:
Thank you so much Marcie. And I'm going to kind of build on many of the concepts that you just spoke about. People with chronic conditions many times fall through the cracks because of these definitions of people who are at risk for problems after disasters. And we definitely have some critical challenges. And I'm going to talk about some ways to partner and some things on the horizon to help many of these folks. What do these terms really mean, preparedness and vulnerability and who is at risk? Marcie started to talk about this.

But let's say that you have a person who has Type I Diabetes, 25 years old who does not have any quote disabilities or any complications. That person is a functional person but without medication that person then quote becomes vulnerable and may not be able to have as good outcomes post disaster as somebody else. Who has the expertise to serve these specific populations? It's a mindset and it's - and we have different definitions and we have to tackle these definitions so that when we do whole community planning we aren't bound by these definitions. When we look at vulnerable or at risk for special populations, many times we will think about people who might have hearing problems, vision problems, who may not have - who may not speak English as their native tongue. These are all folks who fall into these vulnerable or at risk populations. But we have to look at many different ways. We want to know our populations. As Marcie said, know your population, locate and enumerate the populations in your area. And I'll talk about ways to do this in a minute. We need to look at functionally based. And just because whatever program you're working on says this - these are the folks included in your vulnerable or at risk for poor outcomes because of a disaster, think about the whole community. Think about folks who do have preexisting medical conditions such as asthma, heart disease, hypertension and diabetes. Over 130 million people have one of these chronic conditions. I put this slide up just to show you all the lists of people who in many different definitions have fallen into the bucket of vulnerable populations from pregnant women to the elderly, people who do have chronic conditions. Many people can become vulnerable under different circumstances. It's just we have so many people who do have chronic medical conditions and we do not want to forget about them. And as I said, they sometimes fall through the cracks using our formal definitions. When we look at disasters, we have a lot of environmental destruction and certainly we don't have power, food, clothing or shelter. And what we do have - we have destruction of everything

from the environment and we also see that we have the infrastructure has been absolutely destroyed. And people who do have medical preexisting conditions may have exacerbations of these medical conditions. So what have we learned from past disasters? I'd like to use diabetes as an example but we'll talk about other chronic conditions such as heart disease and asthma.

We do have some documentation that diabetes control can decrease after disasters. And we do have some recommendations in the literature that anti-disaster programs, (peerness) programs should address the psychological interventions in people of chronic conditions as well. Many people, who have a chronic medical condition such as diabetes, high blood pressure, et cetera, also are at increased risk of having psychological comorbidities. And then of course you add on the stress of having a disaster and we need to address all of these problems.

Some examples. In the California heat wave, they saw over 16,000 excess hospitalizations were due to chronic conditions. The emergency room visits showed an increase number of visits for people who had renal failure, kidney disease, cardiovascular disease, diabetes, nephritis, inflammation of the kidneys, et cetera. These are all chronic conditions that became exacerbated after the heat wave. Certainly Katrina brought a face of people with chronic condition. People were saying how they couldn't get their insulin, their heart medicine, their asthma medication. And certainly we saw in that loss of over 6,000 health professionals; people lost their medications and supplies. Many of the pharmacies were destroyed.

One study showed that in the Katrina evacuees about 50% had chronic conditions. That's a huge number of folks. And when they - when we look at other papers, we saw that before 9% of the people in the area had diabetes, 25% of the adults had at least one chronic condition such as heart disease, stroke or diabetes. And these data were based on BRFSS data in New Orleans before Katrina happened so that we knew that this area had a huge burden of chronic conditions. When we looked at folks in the evacuation centers, we saw that high blood pressure, diabetes, preexisting psychiatric conditions, asthma were the top diagnostic (coats) that were found in the evacuation centers. But we knew the burden before.

As Marcie said, shelters can be an issue. And shelters certainly we've seen acute exacerbation of chronic medical problems especially because many of the folks were over 60 and had at least one chronic condition; 28 % had heart disease, almost 17% had diabetes.When we look at another disaster, the H1N1 outbreak, we saw that the folks who were at risk for developing flu related complications had preexisting chronic conditions such as asthma, diabetes or extreme obesity. Even the earthquake - even earthquakes can show some exacerbation of diabetes and other chronic conditions. And I'm talking about the 1995 earthquake, not the 2011 earthquake. When we looked at average blood sugar values, they went up after the earthquakes. And from lessons learned, teach people about appropriate diet during times of disaster before a disaster happens. It doesn't have to be an earthquake. It can be an ice storm in Kentucky. It can be an ice storm in Atlanta that we had last year. Everybody should have a medical information card and a small emergency medical supplies bag. And we will talk about medication barrier in a minute. Even when we look at Hurricanes Andrew and Charlie, many times people will come in to assess a situation. But in Andrew and Charlie many times it was 10 to 14 days that people were asked about their chronic condition. And one of the lessons learned was that they should have asked

people three to five days about their chronic conditions so that the appropriate medications could have been deployed because there were so many folks who did have chronic conditions.

A CDC study showed that it was very necessary to have a comprehensive understanding of the medical and chronic disease needs of the community and to use the BRFSS data as models. And that you need to work with the public health professionals with this information so that folks with chronic conditions are part of the preparedness programs. So we need to protect our folks who have a chronic condition. We need to protect children and adolescents. We need to protect the whole community and especially those who may need some more preparedness. We want to coordinate the educational planning with our state and local public health education. Many, many state health departments have programs that address the needs - the everyday needs and public health needs of people with chronic medical conditions such as diabetes, respiratory diseases and heart disease.

So we want to make use of these public health resources. We can partner with the Red Cross. We can partner with advocacy organizations such as the American Diabetes Association or the American Heart Association. The volunteers of the American Diabetes Association helped many folks during Hurricane Katrina because they had the expertise. I was just in New Orleans two weeks ago for a Region 4 and Region 6 Medical Reserve Corps training. And it turns out that many of the folks who had been very useful at times of emergency preparedness, they're trying to still keep these folks engaged and they are working with public health agencies on chronic conditions such as screening for high blood pressure, education about HIV, even trying to work with the let's move campaign with the White House. The bottom line is even though the Medical Reserve Corps folks were talking about emergency preparedness, it was also very important to work with these folks on chronic conditions. Each state also has the disaster preparedness team. Every state has diabetes prevention and control team and a cardiovascular team and these folks have to work together. As Marcie said, we have to teach everybody. And the challenge of teaching people to be prepared we will see similar barriers. And we're trying to teach people self-management skills for any chronic condition. Preparedness education is vital for healthcare providers and emergency responders. They have to teach each other. When we teach people with diabetes, asthma, whatever, about self-management skills, if we are teaching them about the proper diet, proper exercise, we need to teach them what to do at times of a disaster, pre, during and post.

The other thing is that we're now advocating competencies. So the public health emergency preparedness programs and the grantees now some of the competencies are to develop partnerships, to know their population before a disaster so that the (PF) community resilience workgroup for instance came up with some recommendations on how to identify folks that might have chronic preexisting conditions and know about the groups to partner with. Certainly like schools of public health, the Medical Reserve Corps and as I said, the state teams that deal with chronic conditions. CDC, the National Center for Chronic Disease Prevention and Health Promotion, is getting together to look at the needs and to develop tools for folks. There are models already. For instance, some CDC funded diabetes prevention and control programs have trained the state emergency preparedness teams on the ABCs, diabetes 101 and how to prepare folks with diabetes pre, during and post disasters. The surveillance needs are very, very

important. It's very important when you are preparing for your community to know the size, the functional status and the needs prior to a disaster.

You can go on the CDC Web site and look at small area estimates about the people who have diabetes, high blood pressure, cardiovascular disease. Then you can talk to your emergency preparedness planners so you know the burden of these chronic conditions in your community. Use the epidemiological data on chronic disease and share with your emergency preparedness teams. You can develop resources and lists of medications and supplies before the disaster happens.

So I wanted to just give you some examples of resources and partnerships. We have CDC messages that you can find on the CDC preparedness Web site. We want people to have a plan. We want them to learn how to shelter in place. We want them to adapt their plan as needed. So let's say you have a family emergency plan and of course I want every single person after this call to go home and be sure that they do have an emergency kit with the essential elements to prepare for any disaster. But for instance for an emergency food kit, have the appropriate food. If a person does have congestive heart failure, you want to adapt that they might have some lower salt foods. If the person has diabetes, you might want to adapt for that as well; that people have some of their supplies and correct foods.

There's a Web site from the University of Louisville that has some tools for people who have chronic conditions and preparedness. So this is another resource. It's chronic disease preparedness.org that can give you ideas on how to prepare for your community.

The CDC Division of Diabetes Translation also has a lot of resources for folks with diabetes on their Web site. So if you just go to cdc.gov/diabetes, you can jut click on the information. Cancer and disasters. We also have recommendations for folks who have a history of cancer who may be on certain medications. For instance, things to think about; they may have to have voluntary quarantine if these folks are at higher risk developing infections in the shelter, et cetera. And certainly a consistent message that we hear is keep at least two weeks of medications available at all times; people with diabetes need to, high blood pressure, asthma, any chronic condition. There is going to be a toolkit coming out at the end of the month from the CDC aging program. It's cdc.gov/aging. And it's identifying vulnerable -- and there's that word again -- but older adults. And we want to increase their protection during public health emergencies. It's a template for planning for any community. Action options, developing plans, partnering, collaboration, just talks about make new friends, know your community, using data for action. We talked about using the BRFSS data; know your population and preparing the individuals and their caregivers as well. As I said, this toolkit will be available hopefully at the end of the month. When we're looking at strategies in general for preparedness, we want people to have access to their medications. Perhaps there has to be a resource for larger quantities. But many times people have mail delivery and that could be a problem. So perhaps one idea might be mobile meds to model after meals on wheels. Perhaps the special needs registry might be helpful to know where the vulnerable populations, the special populations whatever you want to call, people who might need a little extra care where they are. But we also need these folks to help us in our preparedness efforts. And you might want to partner with other agencies as well.

The big challenge however - one of the big challenges is having this quote two-weeks supply of extra medications. And indeed when we sent out the announcement about this COCA call, we did receive one question before the call. And it was well everybody is saying that people should have extra medications pre-disaster, but do you go about doing this? Certainly post-disaster there were plans made that people could go to a pharmacy without their medications and special dispensation would be given. But if people had a two-week supply, perhaps this would really keep a lot of people out of the emergency room. So the Office of Public Health Preparedness and Response actually has given the Chronic Disease Center a grant. And we're planning a consensus conference in early fall to talk about these issues of access. We're going to have a lot of partners from health plans to develop policies, distribution agents. We're going to have subject matter experts in the fields of asthma, epilepsy, diabetes, cardiovascular disease. We're going to talk to pharma manufacturers, et cetera, to see if we could come up with policies and a plan so that people can have access to medications for the chronic medical conditions before, during and after a disaster. So I will keep you posted.

So to summarize, disasters happen. We want everybody to be prepared. Please know your population. Know the folks who might have chronic medical conditions that the whole community needs to prepare. So please include these folks. Develop partnerships to teach others about disasters and chronic conditions and please don't lose the forest for the trees except in the case of hurricanes, tornadoes, earthquakes and tsunamis. Thank you. And we can turn it over to questions. Loretta.

Loretta Jackson Brown:
Thank you. Director Roth, are you there? Can you hear me?

Marcie Roth:
I can hear you.

Loretta Jackson Brown:
Okay. I'm sorry. I heard some noise in the background.

Marcie Roth:

Right.

Loretta Jackson Brown:
Thank you. Thank you Dr. Allweiss and Director Roth. We will now open up the lines for the question and answer session.

Coordinator:
(All right). Thank you. At this time if you'd like to ask a question, press star 1. Please un-mute your line and record your name to be introduced. Again for questions, press star 1. If you'd like to withdraw the request, you may press star 2. Thank you. One moment for your first

question.

Loretta Jackson Brown:
And while we're waiting for the questions through the audio line, I want to remind you that you can submit questions through the Webinar by clicking on the Q&A tab at the top left of your screen.

Coordinator: All right. Thank...

Dr. Pamela Allweiss:
Loretta, if anybody wants to contact us, my email is on the first slide.

Coordinator:
Okay. Thank you. Our first question comes from Carol Rodman. Your line is open.

Carol Rodman:
Thank you. This is Carol Rodman. I'm at Uphams Corner Health Center in Dorchester, Massachusetts. And I was probably either the one or one of several that emailed you a couple of weeks ago about the issue of making medications accessible for people who have chronic medical conditions and normally take medications at least on a daily basis. I'm very glad to hear that you're addressing the issue in a very holistic way and being very inclusive about it. However, I want you to understand that first the way that this issue was raised was that I was training a group of our home health aides and homemakers about six years ago. And when I raised the issue of putting together family emergency kits, one of the staff stood up and said, "How can we do this? We can't even get enough medication or formula by prescription for those of our family members who need it at the end of the month. We have to wait until the prescription is almost used up before we can replenish." So please be aware that there are insurance requirements and rules that prohibit people with chronic medication needs from stockpiling at all. And if you have a condition like Type I Diabetes and take insulin, using the mail supply does not work. I have spoken with numerous pharmacists who say, "Don't have insulin go through the mail because there are too many times when the insulin is subjected to weather extremes and becomes non-functional." And I'm sure there are other medications like that as well. The issue as the disaster planner for our health center becomes will the strategic national stockpile or some other supply chain be able to have enough medications regionally and locally so that people who can't stockpile have another form of access so that they're not suffering in addition to the disaster event?

Dr. Pamela Allweiss:
I'm going to say bravo, because those are exactly the issues that we have brought to AHIP, America's Health Insurance Plan, okay. And we are inviting those folks - those exact issues are exactly the same. Okay. You expressed it wonderfully and that's exactly the point. Okay.

The mail order issue, that's one issue. But certainly if somebody gets a 30 day supply, well, some months we have 31 days, okay. Also let's say in the case of diabetes, sometimes when people are sick, they might need 10% more just as far as regular care. So those exact words are being brought to the players for this conference, that your plea is the exact plea that we are giving to them. I cannot guarantee anything, but at least they have heard and those are the exact issues that we are going to try to address.

Carol Rodman:
I'm delighted to hear that and frankly if there's an opportunity...

Dr. Pamela Allweiss:
It took me five years.

Carol Rodman:
.for a health center disaster planner to attend this conference and to raise some of them directly, I would really like to be invited because I've been doing it now for six or seven years. And yours is the first presentation when the issues have been understood and there's a response in the works.

Dr. Pamela Allweiss:
Okay. It took me five years to get it done.

Marcie Roth:
This is Marcie. And let me talk a little bit about some of the things that we can do while we're trying to address this systemic issue. And it is a - it is a very complicated systemic issue and one that I think a lot of people are thankfully paying a lot of attention to. But in the meanwhile as a person who takes many medications, one of the things that I do personally is I keep a week's worth of my medications with me at all times. Not an extra week's but this week's medication is with me at all times. And, you know, every day I add another so that I always have a week's worth with me at all times. Additionally, I keep a print and flash drive information about my medications with me at all times. I have a flash drive that I can put around my neck if I needed to evacuate. You know, that I might be able to have the information that way. Additionally, and probably most importantly in planning, we need to make sure that we have folks at the planning table who may be able to be helpful as we're addressing these issues. So in local communities making sure that the pharmacy association and some of the pharmacies in the community are part of the planning team.Your correctional folks often have a lot of resources in terms of medications that are on hand in a correctional facility. They might be great partners to bring to the table in addition to the more traditional medical providers there. So there are a number of things that we can be doing while we're addressing a very important issue that's been raised.

Carol Rodman:
Thank you.

Dr. Pamela Allweiss:
Also, the other thing is many private practitioners have samples and they're - and certainly at times of disasters the sample closets have been a wonderful resource as well.

Carol Rodman:
Okay. Thank you both.

Coordinator:
All right. Thank you. Next question. Barbara Brookmyer, your line is open.

Barbara Brookmyer:
Yes. Hi. Thank you. This is Barbara Brookmyer. I'm a health officer in Frederic County, Maryland. And similar to the first person's comment is I was wondering if there was any consideration at the federal level about requiring insurance companies or let's say because Federal Government authority isn't there for requiring insurance companies. But putting in the health insurance exchange minimum benefits I know for the healthcare reform, the minimum benefits placing a requirement there that a 13th month of prescriptions be allowed to be filled. You know, not necessarily having to pay - have the insurance companies pay for it or allow it to be done through a co-pay like all the other months but to address the other caller's point about the restrictions on when you can refill it. If we were really serious about making the prescriptions available for people so they'd have enough on hand, I'd think at the federal level there'd be some interest in trying to incentivize or require that a 13th month provision be put into place. Thank you.

Dr. Pamela Allweiss:
Very helpful comment. We were talking about having like emergency kits that people could get, you know, of two weeks even having a formulary or whatever. But these are all wonderful suggestions that we will bring to the consensus conference.

Coordinator:
All right. Thank you. Next question. Michele Samarya-Timm, your line is open.

Michele Samarya-Timm:
Good afternoon. I'm calling from Somerset County Department of Health in Central New Jersey. I want to thank you for a timely topic. Our county is currently in the formative stages of addressing these emergency and public health challenges. I know both speakers had mentioned the word grants. Perked my ears up. Are these grants that you have received or that will be available for local public health to address our community's functional needs.

Marcie Roth:
This is Marcie. And the Homeland Security grants go to states and so you would be encouraged

to work with your state administrative agency and to find out what their priorities are for the coming year and for that next grant cycle.

Michele Samarya-Timm:
Thank you.

Marcie Roth:
Sure.

Coordinator:
All right. Thank you. Next question. Amy Wishner, your line is open.

Amy Wishner:
Hi. I'm from the Pennsylvania Chapter, American Academy of Pediatrics. And some of the issues about medication and the inability to stockpile due to insurance regulation, you know, restrictions apply also to the community pediatrician - ambulatory pediatrics world that on the one hand you want your local pediatrician to be able to stockpile, you know, to be able to have medications on hand, have excess capacity to store, you know, should there be a need for new vaccine or a new medication. And yet they're in the same position of limited physical space, limited storage capacity for medications, limited supplies because they can't afford - literally they can't afford to have excess capacity and things are being done in a just in time approach because that's the way the whole system works is that that's only what's paid for. And there isn't any sort of cushion anywhere along the way. And yet, you know, we would not hospitals to be overwhelmed. We want people to do as much as they can in their homes, to do as much as they can with their primary care provider and not overwhelm hospitals. So I wondered if you had thoughts about that about how to increase the ability of ambulatory peds and to primary care of family medicine docs to have the ability to have a cushion.

Dr. Pamela Allweiss:
That was not a - when we had our topics of - our discussion topics. But I will certainly include that because that certainly is timely. The supply chain adjustments can be adapted to include that as well. So I thank you for that. And I've written it down.

Amy Wishner:
I mean my - I mean my point is that it goes beyond medications.

Dr. Pamela Allweiss:
Yes.

Amy Wishner:
Yes, that's one aspect of it.

Dr. Pamela Allweiss:
Yes.

Amy Wishner:
But it really goes to everything into the goal that we want of trying to keep people from flocking to...

Dr. Pamela Allweiss:
Exactly.

Amy Wishner: ..
.you know, hospitals that would be overwhelmed. So thank you.

Dr. Pamela Allweiss:
Thank you.

Coordinator:
All right. Thank you. Next question. Jerome Gordon, your line is open.

Marcie Roth:
This is Marcie Roth. And I'm going to have to leave the call. I'm very sorry but we're right at 12:00 and I have really appreciated the opportunity to be here. I'm happy to answer any additional questions via email.

Dr. Pamela Allweiss:
Thanks Marcie.

Marcie Roth:
Thank you.

Loretta Jackson Brown:
Thank you Director Roth.

Jerome Gordon:
Is my call still open?

Loretta Jackson Brown:
Yes.

Coordinator:
Yes.

Loretta Jackson Brown:
Operator, this will be our lat question.

Coordinator:
All right. Thank you. Go ahead sir.

Jerome Gordon:
I started to type it out. So often free clinics are completely ignored. I'm in St. Lucie County, Florida. We have a clinic called the HANDS. We treat all kinds of people without insurance, poverty level in disasters. Our facility is huge. And we feel like - I'm listening to your presentation and I feel it's neglected as a source for medications, treatment, et cetera, during – especially during disasters. (I'd like to know why).

Dr. Pamela Allweiss:
Have you - well, I think many times - and I think that's a very good point. I think many times people are looking at the federally funded health centers. Okay. Sometimes they've been involved. But the volunteer clinics may not have been. And I think that's a very good point.

And I think that when people are doing an inventory of all of the resources in the community, it would be great if you could get on the - in the planning and I mean not just your county but I think that's a very important thing to educate folks that it isn't just the traditional physician's offices, the traditional hospitals or even the federally funded clinics. There may be other resources out there like the free clinics. So certainly people just may not be aware. So that would be planning for the whole community. If you can match yourself up with some of the community folks to understand at least be in the loop possibly when we do have better supply chain things. I think that's a very good point of doing a very thorough inventory of a community because just like people's chronic conditions fall through the cracks, I think clinics like yours might fall through the cracks as well.

Jerome Gordon:
Yes. I think they really do. I was just curious. I noticed this OPHPR grants. Is that a...

Dr. Pamela Allweiss:
Oh that was grant that our center applied for to do the consensus conference. So we - I was just saying what the source of funding was for this and that was kind of like an internal CDC kind of funding type of thing.

Jerome Gordon:
Okay. So it wouldn't necessarily where our clinic - you know, often our clinics are dependent on funds from the community itself.

Dr. Pamela Allweiss:
Right.

Jerome Gordon:
And outside sources like governmental sources are not really - they're available but they just don't seem to be interested in doing...

Dr. Pamela Allweiss:
Right.

Jerome Gordon: ..
.they're rather pour tons of money that's usually ripped off some place else rather than in the community where it's doing the most good. Just a comment.

Dr. Pamela Allweiss: ...
as well.

Jerome Gordon:
Okay. All right. Thank you. I'd like, you know, we'd like to stay in touch and stay next times that these programs are available to be **(unintelligible).**

Dr. Pamela Allweiss:
Okay.

Loretta Jackson Brown:
Thank you. On behalf of COCA, I would like to thank everyone for joining us today with a special thank you to our presenters, Dr. Allweiss and Director Roth. If you have additional questions for today's presenters, please email us at coca@cdc.gov. Put Allweiss or Roth in the subject line of your email and we will ensure that your question is forwarded to them for a response. Again, that email address is coca@cdc.gov.We do want to apologize for the technical difficulty that some of you may have experienced when attempting to access the Webinar. We do thank you for joining us today.

The recording of this call and the transcript will be posted to the COCA Web site at emergency.cdc.gov/coca within the next few days. Free continuing education credits are available for this call. Those who participated in today's COCA Webinar and would like to receive continuing education credits - excuse me. Those who participated in today's COCA Webinar would like to receive continuing education should complete the online evaluation by March 13, 2012 using Course Code EC1648.For those who will complete the online evaluation between March 14, 2012 and February 13, 2013, use Course Code WD1648. All continuing education credits and contact hours for COCA Webinars are issued online through TCE online, the CDC training and continuing education online system at www the number 2 the letter A

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Coordinator:
Thank you. That does conclude today's conference. You may disconnect at this time.

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