

**Webinar Transcript:*****“Strengths-Based Planning for Worst Case Scenarios:
The Role of Person-Centered Planning in Disaster Preparedness”***

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SPEAKERS

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Bevin Croft

Okay, hello everyone my name is Bevin Croft, and I direct the National Center on Person-Centered Practices and Systems. I am a white woman with blonde hair and a pony tail, and I am in a room with bright pink walls and some bright colored art and plants behind me. I am very happy to invite you into to our April webinar “Strengths-Based Planning for Worst Case Scenarios: The Role of Disaster Planning in Disaster Preparedness.” This is our monthly webinar series hosted by NCAPPS. We are happy to be supported by the Administration for Community Living, and the centers for Medicare and Medicaid services. All of these webinars are free and open to the public, next couple of slides please Connor. The National Center on advancing Person-Centered practices is here to promote systems change to make person centered principles, not just an aspiration but a reality in the lives of people all across the lifespan. We provide technical assistance and support, and educational experiences like these to the whole community. Next slide please. A few housekeeping details before we get started this is a webinar, so you are all muted, but you are welcome to use the chat to pose questions to us and to the entire NCAPPS community. Were happy to have a lively chat discussion happening during this webinar. If you would like to post to the whole community. Please be sure to select all panelists, and attendees and that way your message will be shared out to the to the whole community. Towards the end, we will have a Question and Answer opportunity and we'll get to as many questions as possible. We also will provide some written answers to questions that we didn't get to this webinar is being live captioned in both English and Spanish, and to access those links, you can go to chat and Connor will post them in again periodically for folks who've joined late, and we have just one poll, and some evaluation questions at the end. And I believe we can pull up our first poll next and go to the next slide. We'd like to know who is here. Oh and Connor, you can go to the next slide after this one. All right, so we would like to know, of the, there are almost 700 people on today so where, what, what roles do you self-identify with, please select all that apply. I know we haven't covered every possible role but



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hopefully some of these will resonate with you. And we'll give folks, another moment. While you are self-identifying know that PDF version of the slides and the transcript and other resources, and the recording will be posted on our website ncapps.acl.gov after in a few weeks. Okay, so let's see who's here Connor. All right, so the majority of folks on our social workers, counselors or care managers that 55% good number of provider organization employees, good number of government employees, some peer specialists are here welcome self advocates, family members and people with disabilities. So welcome to all oh and a few researchers as well. My people, welcome to all, and we're so glad that you're here. And I will turn things over to my counterpart, Alixe Bonardi the other co director of NCAPPS to introduce our speakers

Alixé Bonardi

Greetings, everyone. My name is Alixe Bonardi, I am a white woman I am have shoulder length, brown and gray hair, and I'm sitting in a room in a wall, but with a wall of books behind me. We are really excited to be able to bring this discussion to you and particularly with the panelists that we have with us today. The events of 2020 in the early months of 2021 have up ended and disrupted, many many people's lives and the impact of the law on the lives of people with disabilities and older adults is particularly pronounced. We are very happy to be able to bring the wisdom of the panelists that we have assembled here to talk about their own perspective around, person centered planning in the context of disaster preparedness, and people with disabilities. I'd like to introduce the speakers that we have here today. To begin, we have Koko DeMont who DeMont Thomas was born and raised in Dallas, Texas, and identifies as Black Deaf Blind he earned a Bachelor of Social Work degree, specializing in HIV education and a Master of Public Administration, both at Gallaudet University and a master's degree in rehabilitation counseling from the University of North Texas. Koko has been an advocate of the deafblind community for more than 20 years. Next we have Marcie Roth. Marcie is the Executive Director and Chief Executive Officer for the World Institute on Disability. One of the first Global Disability Rights Organizations founded and continually led by people with disabilities. Marcie has been establishing and leading coalition's committed to operationalizing disability inclusion as an intersectional imperative for global social justice, since 1995. Marcie joined the World Institute on Disability and 2019, bringing her lifelong commitment to advancing the rights of over 1 billion people with disabilities, and expanding Disability Leadership locally, nationally, and globally. And our final speaker today, Marcia Montague, is a clinical assistant professor in special education at Texas a&m University. Marcia's research and service interests focus on equity in access for people with disabilities including family empowerment disaster preparation and disaster recovery, Marcia has nine years of special education experience teaching students with a wide range of disabilities, and her efforts support partnerships with surrounding school districts and work with many local areas, local authorities on intellectual and developmental disabilities in Texas. We are really



delighted to have all of you here with us today. And without further ado I would like to turn us over to our first speaker this afternoon, or this morning depending on where you are. Marcie Roth, will be beginning to give us some context and some foundational content around understanding disaster preparedness from her perspective. So with that, I would like to turn it over to Marcie, and we're really excited to have you all here. Thank you.

Marcie Roth

Hi everybody, I'm Marcie Roth, Executive Director of the World Institute on Disability. My pronouns are she, her and hers. I'm an older light skinned woman with curly COVID gray hair and red glasses. I'm wearing a black dress, and my background shows the logo of the World Institute on Disability, which is a purple and white globe with my name and job title underneath. Thank you so much to NCAPPS for the opportunity to speak with you today in my opening remarks, I will be speaking about disability rights, accessibility and inclusion before, during, and after disasters. Next slide please. So just to start, I'm, I'm going to give you just a little snapshot of the emergency management cycle, and I will be speaking about inclusion, accessibility and rights throughout the emergency management cycle, whether that's in the preparedness, or planning phases, whether that's throughout the response to an emergency or disaster. Throughout recovery, both immediate and long term. And in mitigating the potential disasters that could follow. Next slide please. And just to give us some context, the weather and climate disasters, Over the past four years from 2016 to 2020 have been catastrophic. In fact, there have been 66 disasters, federally declared that has each caused more than a billion dollars in damage. Many of them, far more than a billion dollars. So and the maps that I've put up are from the National Oceanic and Atmospheric agency, and it shows the frequency of or the, the, the number of disasters of this magnitude across the country over the past four years. Next slide please. I also want to point out that there are a number of federal laws that apply in disasters, and I'm going to talk about three in particular. The first one is, of course, the Americans with Disabilities Act, which is a over 30 year old law that prohibits discrimination on the basis of disability. And this includes before, during and after disasters. It requires program access, effective communication access and physical access throughout all programs and activities. And I want to specifically point out that the Supreme Court in 1999 in its Olmstead Decision determined that the Americans with Disabilities Act includes requiring provision of services to individuals with disabilities in the most integrated setting appropriate to their needs. And let me emphasize, this includes before during and after disasters, important to our discussion today. Next slide please. The. I want to point out that the additional disasters, certainly over the past year include, Of course, the COVID pandemic. And right now as we speak. All 50 states, the District of Columbia. All of the territories and 32 tribes are working with FEMA, under these emergency federal declarations. Next slide please. And what that means is that other laws have come into play as well, the Stafford Act, which requires that, that all activities are conducted in non discriminatory ways including all Disaster Assistance



Programs relief organizations, and I want to point out that disability is specified in the non discrimination. This includes distribution of supplies processing applications, and other relief and assistance activities. Next slide please. And the Rehabilitation Act of 1973 which is the oldest of the three laws, federal civil rights laws. It is important to note that the Rehabilitation Act requires that any recipient or sub recipient of federal funds is required to make their programs accessible to individuals with disabilities, and its protections apply to all programs, and businesses that receive any federal funds. And again, this applies to physical accessibility program accessibility and effective communication accessibility. Next slide please. And when there is a public health emergency, such as COVID. Again, these laws apply, and it's important to note that the protections under these authorities include that there needs to be. No unjustified institutionalization or segregation, and that transition services and case management, discharge planning would be required to be provided to individuals, if in fact, during the public health emergency, people were in fact institutionalized. Next slide please. And to frame. Some of my next comments in the next couple of minutes. I want to point out that there are over 2 million people with disabilities in congregate facilities. And as well, about another 2 million people with disabilities in carceral and other correctional facilities. So we're talking about a significant number of the population. Next slide please. And much too. I think everyone's shock and horror. During the COVID 19 pandemic, over the past 13 months, at least 200,000 people with disabilities have died in nursing homes and other congregate facilities. In fact, the CDC has pointed out that 94% of all US COVID deaths have been people with quote underlying conditions, which is in fact a euphemism for disability. And, you know, this means over half a million disabled people have died from COVID in the past 13 months. Next slide please. And this disproportionate impact, which was already felt in very significant ways over the years with people with disabilities, experiencing a disproportionate impact in disasters of two to four times greater than others with disability, then others without disabilities, obviously, in this public health emergency we've seen, even more so, how significant this is. Next slide please. And the United Nations Convention on the Rights of Persons with Disabilities takes us through and expands beyond the US in terms of the Rights of Persons with Disabilities. And next slide please. In fact, the Convention on the Rights of Persons with Disabilities is a treaty that has been signed by 175 countries who have ratified the Convention on the Rights, I'm sorry, has been signed by 190 countries, and 175 of those have ratified the Convention on the Rights of Persons with Disabilities. There are nine, who have not ratified. And those include Bhutan, Cameroon, Lebanon, Liechtenstein, Solomon Islands, Tajikistan, Tonga us Pakistan, And unfortunately the United States. Next slide please. So in wrapping up, I want to remind us all that, with the focus on community resilience, which is an ability to anticipate risk limited impact and bounce back rapidly. It also needs to be very clearly, inclusive of people with disabilities because true resilience is only achievable with a full commitment to equal access and whole community inclusion. Thank you very much, I will be back with you shortly.

**Alixé Bonardi**

This is Alixe. Thank you very much for Marcie for giving us that context, giving us the grounding and particularly for bringing us around to the notion around a true resilience being something that needs to be for community and for all, before we move to our next speaker, I just want to make a note. Unfortunately we are having a challenge with our English to Spanish captioning. For those of you who have been trying to, to access that captioning stream using the link that is something that we are aware of and we are troubleshooting that also a note to our English to Spanish captioner, just, we're trying to sort it out. So, so apologies for that. And please know that we are working on that, in the background. With that, I would like to turn, turn the session over to, to our next discussant Koko for, for some, some remarks that will, that he will be sharing in the context of his own experience and policies related to disaster preparedness and response. So greetings Koko thank you for joining us.

Korian "Koko" DeMont Thomas

Hi everybody, Big hugs to you. And that was just mentioned, my name is Korian DeMont Thomas I go by Koko, as the nickname. That's my nickname and it's just a nickname that I got growing up from my family. So I have a blue background today. I'm deaf blind individual who's black I'm bald, with a suit jacket on and a salmon colored button up shirt. I'm excited to be here with everybody today. Thank you so much for the invitation. I'm honored to be a part of the panelists. To begin with, I'd like to bring your attention to the interpreters that I have here on site with me, these two are what are referred to as Pro tactile interpreters, and please rest assured that they've taken appropriate precautions, such as obtaining their immunizations for COVID. We also have our hand sanitizer here. So please just find comfort in that. We do make sure that we take appropriate sanitisation sanitary precautions when interpreters come into my home. Now, with that being said, I'd like to give a little bit of background about myself. I'm currently in Salem, Oregon. I am a Texas boy. I have traveled quite a bit over the years. However, now I have moved west, I have gone west, and I've been in Oregon for two years, approaching two years now, prior to the onset of COVID. I was having some visual impairments, I had limited vision and one of my eyes. I was experiencing cataracts and so I went first surgery. This was just prior to when COVID hit, so back in February of 2021 of the issues that I ran into when experiencing my vision impairments, was that I wanted to go into see a provider, and however, I wasn't able to do to meeting pro tactile interpreters. After some advocacy and educating on my rights as an individual, we were able to come to an agreement, and get things worked out. So I'm glad that all came to fruition and like I mentioned I'm now vaccinated, so that's all good. So that was one of the issues I ran into with with COVID. Another issue that I ran into was when we had the wildfires here in Oregon. Historically wildfires in Oregon are usually located in the southern region of the states. It's not so often that they make their way central to the Salem where I'm located, the fires got so close to me,



approximately about 20 minutes or so, from where I live, that I was in real fear. The State of Oregon doesn't offer what we refer to as SSPs which are support service providers. And, also known as co-navigators. So, unfortunately I had to reach out to some friends who were able to come in and lend a helping hand to give me a ride to escape the dangers of the wildfires. Situations like the wildfires are so layered, because not only were we experiencing the wildfires, we're experiencing COVID At the same time. So there are quite a few barriers that I encountered during these disasters. I wanted to touch base maybe explain a little bit on what disability is and the different perspectives on disability. Typically, a person with a disability is, meaning a person who experiences, barriers to everyday life. There's a different phrase that I prefer to use instead of disability, I prefer to use the term person with differing abilities. Now, when going out into the public, and requesting accommodations for services, there's oftentimes that the person that I'm making the request to is unfamiliar, and I dare to say I'm educated with accommodations. And just by being unfamiliar and unknowing with accommodations can be a disability in itself. Earlier was mentioned, the ADA, the Americans with Disabilities Act and several other laws. Title One of the ADA talks about employment. There's also the public sector. Title Three is public accommodations, title four is telecommunications of the ADA and Title Five is known as miscellaneous. With that being said, while there are these titles and laws in place, it's important that accommodations and what accommodations are provided are flexible and dependent on the individual. for example, captioning. Captioning isn't always accessible by people with disabilities. As a deafblind individual I request pro tactile interpreters for my disability. And it's important that the organizer, or the Accommodator be in tune with those that flexibility of meaning that, what often I want to touch on. So in regards to Title Five of the ADA miscellaneous. One of the accommodations that can be provided as a transcript, a transcript of what's being said and that can happen both live in a session like this, and then also post webinar posts meeting transcripts can be provided. That's usually for people who prefer to read what was said and review, and those transcripts can be provided in various formats, whether it be reversed text and reverse coloring and so forth. So that's pretty much what I wanted to touch on today were those laws and my experiences throughout the wildfires and COVID Thank you so much, I appreciate it.

Alixé Bonardi

This is Alixe um thank you very much. And thank you, particularly for bringing your own experience and wisdom. I think that it's really important for us to think about both the policy certainly Title Five, but also what it really means in real people's lives, and particularly what you brought forward around flexibility of accommodations. So thank you for that. We are going to continue to move forward with our presentation then and I would like to bring our third panelists into the discussion. Marcia, and I will introduce Marcia Montague who we've met in



the introductions and I'll be turning it over to you, Marcia for your remarks before we move to a bit of a panel discussion.

Marcia Montague

Hello everyone thank you for joining us today. So my name is Marcia Montague, and I am a white female with middling Brown and also green hair, and my virtual background is of the Texas bluebonnets that are blooming right now in our state. As has been alluded to by our previous two presenters disaster preparedness to support resilience involves multiple factors, and is essential. This includes actions like having an evacuation plan in place, having access to a shelter or knowing where shelters are in the surrounding areas. Preparedness also includes having a plan for transportation in different types of disasters and preparedness includes access to basic needs such as food, water, and medication for individuals who require extra support with mobility or different types of communication, a plan should be in place for how that individual will access the information they need. It's also helpful to think through how you want to manage your personal information like your social security number, phone number, and banking account number, other components of disaster preparedness include things like life sustaining, durable medical equipment or DME DME cannot just be left behind. A plan needs to be in place for how and who will ensure that the equipment is transported along with the individual. Additionally, the social relationships that individuals rely upon, and the education that they have access to are key pieces to consider when engaging in disaster preparedness activities. And finally, when we think about disaster preparedness. We can't forget that pets are a big part of many people's lives, and having a plan for pet care and pet transportation is essential as well. Next slide please. Individuals and families are strongly encouraged to stay informed and know how. And excuse me and know those essential informational resources that can give them accurate and up to date information, individual persons and families can plan for how they will be prepared for different types of disasters, they can build a kit that helps them be ready at a moment's notice if disaster is impending. The Texasready.gov website is a great resource that provides a list of commonly needed items in a disaster preparedness kit, and also being added to the ready.tamu.edu website is a resource that gives additional information for individuals with disabilities as they prepare for disaster. In addition to preparedness being the work of an individual or family. There's also a need for provider and community preparedness for providers, prevent preparedness can look like advocacy, and helping to ensure that our community is prepared for different types of disasters, with the knowledge of the needs of the individuals within their community providers also have a preparedness responsibility in terms of advocacy for both family and personal preparedness. This means that their individual preparedness that they are individually prepared, but also supporting those that they work with to be prepared for potential disasters. Communities have a responsibility to be prepared for those who live within their geographical area community preparedness should include the identification of local partners, and the



building of a team that is representative of the diversity within a community. For example, at least one individual with a disability should play a large role on any team that engages in community disaster preparedness planning. Additionally, if there are different languages spoken within a community. We want to ensure that there's an individual on the team that speaks that same language. Next slide please. Now that we have a better understanding of preparedness for disasters. Let's talk a little bit about the intersection of disaster preparedness and Person Centered thinking, planning and practice with person centered planning, We want to be aware of the individuals profile, and we want that person to guide discussion or conversation related to their strengths, needs, interests, and what's both important to, and what's important for them. Further, we want to consider the environmental trends that are common in the area in which this individual lives. For example, if you live along the coast. We know that there's a greater threat of hurricanes than if you live in an inland area that's more prone to forest fires. So planning should take into consideration the needs of that individual, given their particular environmental context in which they live. Additionally, we want to consider the vision, what the vision is for that individual's personal well being during a disaster. What does wellbeing look like for that individual. We must consider the opportunities, and also the obstacles that could be present during a time of disaster. For example, if an individual relies on a ventilator for breathing and power goes out due to a winter storm. We know that the lack of power can really create an obstacle for continued life for that individual. An opportunity in that situation, would be to purchase a backup battery and or a generator. If access to funds for these purchases is problematic, we could collaborate with community organizations to see if we can get one donated to support that individual. We want to identify those strategies and action steps that need to be taken in the time of disaster in support of that person's well being. And the example of the need for a ventilator. This would require a plan in place for someone who knows how to start up that generator, and who would make a commitment to coming to do that if the power were to go out. Finally, we need to make sure that this person centered planning document is updated at regular intervals, as we all know that needs characteristics and interests change over time. Next slide please. Collaboration among entities, clearly is essential in order for communities and individuals within that community to be prepared for disasters. We must communicate and collaborate with one another, local communities planning for disasters need to think about how they can loop, disaster related organizations and community based organizations into their planning discussions, governmental agencies focusing on disaster preparedness can also consider what vo adds or volunteer Organizations Active in Disaster are present in their communities. These vo add should have a voice on the planning team as well. And then after a disaster happens, we want to make sure that long term recovery committees are also involved in the collaboration as they work to support the recovery of community members, post disaster. Next slide please. linked here are a number of resources that I encourage each of you to take a look at, and I want to spend just a moment talking through these different resources. So the first is [ready.gov](https://www.ready.gov) and this provides community



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preparedness toolkit, anyone who's looking to improve the preparedness that within their community is encouraged to click on that link and pursue further and bring that information into their community. The next link is the directory of community resources or DCR for people with disabilities, and this is produced out of the center for disability and development at Texas a&m University. Dr. Laura stelle heads, this work, which I'm a member of on that team. And this provide provides a number of resources, primarily for the Texas area, but there are some national resources as well, related to recovery from disaster with along with the DCR there is Project Red R E D D project read that provides information on disability and disaster. And I encourage you guys to take a look at that as well. The next resource is the effective communication toolkit, and this comes from our Texas disability taskforce on emergency management, and alongside that is the functional needs support services toolkit, also from the same task force. These two toolkits are helpful, as communities, think about how to support the functional needs of individuals with disabilities as they're communicating, during a disaster, as they are needing to set up shelters and maintain communication with individuals. Also on the NCAPPS website, there is a section on COVID-19 resources which is really useful as well as is the pacer.org website which has information on person centered planning. And then of course, FEMA has information on preparedness training for community based resources, excuse me, community based organizations. All right, thank you all and I'll turn it back over to our facilitators.

Alixé Bonardi

Thank you so much Marcia, for all of this content, and I would like to also thank you for bringing it around to the context of Person centered planning and how that all really fits in with all of this. All of this work and all of the discussion around disaster preparedness. My colleague Devin dropped a note into chat and a resource specific to to COVID-19 preparedness and you referenced it as well. Marcia, the, the person centered profile, which really gives an opportunity to focus in on what is important to the person and to do some preparedness and thinking ahead of time before we move into our panel discussion, I do want to say to, to everybody in attendance. The chat is the chat module is open, and we will have some time at the end, hopefully for some questions and answers. If there are questions that come up, please. You can put them into chat, and we can bring those forward. And if we don't have time to get to them, we can bring them forward to our panelists. After the discussion and get those out on the website, after the fact. So with that I'd like to take us over to our panel discussion and for that I would ask all of the panelists to join me in the room here is as that's possible so that would mean, turning your cameras on, and there we are, we're all here.

Korian "Koko" DeMont Thomas



This is Brandon. One of the pro-contact interpreters because our camera was turned off by the host we're unable to turn our camera on, would you please. Great, there we go, thank you so much.

Alixé Bonardi

Great. It looks, it looks like we've. Okay, fabulous. Glad you're here. Koko. Okay, so, um, so Marcia. Let us through a discussion about a number of entities that are responsible for planning for an emergency, to the extent they can. But of course, you all are the experts here and, and I want to ask a question to each of you. And I'll start with, with Marcie, actually, when, when you think about who or what entities are responsible to plan for an emergency. What is the first thing that comes to your mind about where the responsibility lies.

Marcie Roth

Well, this is Marcie speaking. And my answer is, everyone, and I have been part of too many conversations in which it is, first and foremost expected that people with disabilities need to take full responsibility for our preparedness. While certainly. Each of us has an important part to play in our own personal preparedness. If the information is not accessible. If the instructions are not achievable by people with disabilities. If the accessibility is not assured throughout. Then, individuals, all the personal responsibility in the world is not going to enable us to achieve the kind of preparedness, that is going to protect us in a disaster. And, you know, let me point out that, you know, typically, if you look at the resources that are provided for emergency preparedness, it will, it will tell you things like, you need to have 30 days of medication stored in order to, you know, prepare for, you know, a period in which you won't have access to your medication. Well, anybody who has any sort of insurance can tell you that having an extra 30 days of medication is an unrealistic expectation. And so, you know, when we start off saying things like that. It actually creates the you know the opposite effect, because people think, well, I can't achieve that, so why bother with any other part of it. And the other thing I wanted to point out, so, you know, each of us certainly can't count on the fact that anybody else is going to adequately plan to meet our needs. But there's an ongoing discussion in which the federal government says, you know, it is the state's responsibility, and states say it's local government's responsibility. And oftentimes we hear it's individual's responsibility. But, you know, circling back to what I talked about a little while ago, when it comes to the use of federal dollars, whether those federal dollars are spent by the federal government, or whether that federal financial assistance is provided to the state to local government or to any other entity, those federal dollars must be spent in compliance with physical accessibility program accessibility, effective communication accessibility. And so for that reason. When I think about who is responsible. I think first and foremost, that the federal government has an incredibly important responsibility to make sure that everyone who is spending federal dollars even one federal dollar needs to be ensuring accessibility. So individuals Absolutely. Locals absolutely



state, you betcha, and most particularly the federal government needs to be a good steward of our taxpayer dollars.

Alixé Bonardi

So So we heard this is Alixe so so we heard you say everyone is responsible and I think that that came through loud and clear. I'd like to turn the same question to you, Koko, when you think about who are the entities responsible to plan what first comes to your mind.

Korian "Koko" DeMont Thomas

Could we just rephrase the question I'm sorry just repeat the question for me please. This is Koko.

Alixé Bonardi

Absolutely. Um, as we, as we've been talking about the levels of responsibility and and Marcia laid out a number of levels of responsibility, including individuals and families, providers, state, state and local government, and as Marcie. Marcie pointed out, federal government. When you think about all these entities that could be responsible for planning, what, what is the the most important entity to be involved in in planning or what jumps to your mind first about where the planning needs to start.

Korian "Koko" DeMont Thomas

Okay, great, great, thank you for that this is Koko. So, I have to agree with what's been said thus far. If we think about the pandemic of COVID. Every single person has been impacted by this pandemic, and we have to think about communicating, and how to communicate during these emergencies. I know there's communication coming from the CDC in different entities different state agencies. We saw that with the forest fires as well. But with COVID. There were some in the beginning if you all remember many people were afraid to go to the hospital. Many people were afraid to even come into close contact or touch anybody and that was something that I struggled with in the beginning. But one of the biggest issues is the lack of communication. And so it's important that on the federal level that the federal level is putting out appropriate and clear communication, and that's being followed through and being pushed along within the different states and local agencies, you know, as if I were to need to go to the emergency room or to the hospital during the COVID pandemic, I would be concerned about the center about touch. However, I need protocol interpreting. And so that's a huge concern there for me it's it's really important that the federal government sets the standard there, and puts out clear communication. I know there's some individuals that don't have as much accessibility as I did. I had to fight for my rights. I'm a very self motivated self advocating individual. I often go grocery shopping, myself and often times would take a volunteer to go with me however because of COVID that was an issue. Now I'm having it to where groceries



are being delivered, because individuals don't want to have to touch me and that that, that some of that information and communication and how all that all works should be coming from a local and federal governments. Anytime I go anywhere, you've got to imagine that I depend so heavily on touch and in the beginning of the pandemic, it was just everybody was so afraid to do that. I think communication and an information has gotten much better over the last year and people understand it better. And I know we're all just really looking forward to getting back. Of course with respecting the new code violations. But getting back to normal.

Alixé Bonardi

Thank you, Koko and, and you've really brought it around to some of the person centered considerations as well which, which we will get to in a minute. Before we move on though I do want to ask Marcia if, if there are additional things you want to pick up as it relates to really what entities you see as being responsible or what the, what's the first thing that comes to your mind, I mean you've, you've laid out the whole context of essentially all entities have a role in in planning for emergencies but what's the thing that jumps to your mind first.

Marcia Montague

Yeah thanks Alixe. So I do you want to echo what Marcie and Koko have shared, you know, Marcie explained that this is everyone's responsibility and I completely agree with that disaster preparedness planning, and the response to that is a responsibility for all of us. One other thing that Marcie said and kind of Koko kind of alluded to here is that the individual person knows his or her needs and strengths, disability, better than anyone else. Right, and so advocacy is really, really important in that if an individual needs, durable medical equipment and needs that transported with them, then they, you know, need to speak up to that or have a plan in place with that, yes, local communities, cities, counties, state, federal government need to be inclusive and support equitable access to communication and resources. And we, we would hope, right, that that's universally implemented, but the reality is not everyone thinks about the needs of individuals with disabilities and the different types of needs because they haven't lived that they don't know necessarily exactly what is involved with that. And so, for me advocacy comes up, really importantly here in terms of planning for an emergency

Alixé Bonardi

hearing that comes through loud and clear. I am hearing, advocacy, we heard that both from you, Marcia, we heard that from Koko as well as, as Koko is, is getting set up, I just want to make sure that we move. We are thinking about the role of advocacy and self advocacy in the context of disaster planning and disaster preparedness. We also talked a little bit about the person centered approaches Koko, you talked a bit about how your own particular need to be close to people and have touch be important, is something that, that you've had to advocate for as well up. As we move to the next portion of portion of this panel discussion, Koko, I was



wondering if you could talk a little bit more about person centered approaches to disaster preparedness. How, how you have seen individuals Community Service Providers and Systems. Build person centeredness, into their disaster planning.

Korian "Koko" DeMont Thomas

Hi, yes this is Koko. Definitely an individual and DeafBlind individuals across the, the United States that Petey is not known. I mean, her tactile ASL is not a common not known throughout the United States it's up and coming. And so, I mean, and people are protected, practicing protection as well. So, obviously, agencies need to plan. Interpreter agencies also need to. I mean, they obviously we have to follow the protocols of the Health Authority and have the systems in place like hospitals, said I said that I needed to do video relay interpreting. After I had eye surgery but my experience, I wasn't able to access that because I wasn't able to see clearly. So, that's something that needs to be considered. Just because one deafblind individual may be able to have access to VRI doesn't mean that all definitely individuals can, because it's the individuals preference and respecting that preference is what is needed, not to oppress them or forced them into a certain a certain box but to, to hear what their preferences is also advocacy is really important not to assume that the person is a specific way, and to that their square box and the need to fit into that box but to really know the individual and know their preferences. And again, I am a more of a leader in the deafblind community, I'm an educator and I'm a, I'm an advocate. Um, you know, I tried to encourage my, my fellow deaf blind friends to go get packed vaccinated to learn pro tactile or tactile communication. But, again, that comes with me, fighting for over 20 years and having that personality to be an advocate and to support the people and the deafblind community as needed.

Alixé Bonardi

This is Alixé and, and you've brought something forward Koko, which I think is really important. In addition to advocacy you also talked about how important it is to respect people's preferences, and that means having an expectation that you will ask what people's preferences are, even in the context of an emergency setting. And I, I'd like to carry that forward a bit, that that really does become part of the heart of Person centered planning, and how, how can we do that. So I'd like to turn that to to Marcia, to see what your perspective is in the context of Person Centered preparedness.

Korian "Koko" DeMont Thomas

Thanks Alixé.

Marcia Montague

So, some of the comments or thoughts that are running through my mind as we're having this discussion, are that being able to be prepared as a community for disaster requires that we



know who our community includes right in very large communities. It's much harder to do. Right. And in those types of situations, we need to anticipate that we have individuals who do need Spanish language translation we do have individuals who need ASL interpreter, interpreting, we do have individuals who need picture based demon descriptions or, you know, just images to help convey the message. My point being here is that if the way that we communicate, preparedness and disaster response and recovery response, recovery as well. If we only do that in the way that we as individuals communicate that is insufficient. Right, we need to keep in mind as Koko said the many different needs and preferences within our community. You know there's some very very rural areas, And in those areas you may have disaster planning committees that are fully aware of the needs of individuals within their community, but that requires again that that advocacy takes place so that they are, they're informed of what what those needs are. So, if I think back to what a person centered planning approach looks like for disaster prepper preparedness in individual, and in communities and in systems, it, it requires communication, right, and it requires advocacy. It requires that there are voices around those planning tables that can speak to different needs, write different experiences, so that we can be as prepared as possible.

Alixé Bonardi

Thank you, Marcia, thank you and this is Alixe, what I hear is the importance of advocacy in all levels of planning, to which, which is incredibly important to bring forward as it relates to making sure that people's preferences are monitored Marcie, Do you, do you have anything to add to this around just the person centered approach and, and how we can ensure that in disaster preparedness and planning.

Marcie Roth

Yeah, thank you. This is Marcie and I echo what the other panelists have said, and I want to raise an additional point and that is that it is so important that the people who come into our lives, and the, whether it's, you know, service providers, medical professionals, our friends and family. Everyone needs to have a culture of preparedness. And so, in order for people with disabilities, to, to be able to plan for our specific individual needs. We need the assistance of the people, whether it's, you know, in the, in the workplace or in, you know, in, in the transportation that we're using, or it's, you know, in the areas that we may be frequenting in the community, whether it's our medical professionals, you know, everyone has an opportunity to talk with each other about what it is that it's going to make each of us be able to take personal protective measures in a disaster. Some of the work that we're doing at the World Institute on Disability, includes focusing on the work that medical professionals are doing to support people with paralysis, to make sure that people who have mobility disabilities, people who may require some specific durable medical equipment or disability supplies that they work with us to make sure that people have access to those resources. In school, we need to be teaching everyone



about how to, you know, respect each other's individual preferences, and to make sure that we're taking into consideration what each person needs in order to maintain their health, their safety and their independence. So, you know, self direction requires that we have the tools, the resources and the support to operationalize our preferences, our, you know, the, the specific resources that we may need at any given time, and, and this is true, certainly for people with disabilities but this is true for everyone. You know, whether you've had your disability for 20 years, or whether you were injured. Within the last few minutes. Building evacuation is going to be an issue that may or may not affect you so this is not just planning for people with disabilities. This is a whole community effort. And when people with disabilities are at the table, you know, the, the adage is nothing about us without us. We are particularly good at, anticipating and brainstorming. two important skills needed in disasters.

Alixé Bonardi

Absolutely and so many layers to consider, particularly, but starting with nothing about us without us as we as we move to the next session of our, of our panel discussion, the last question I want to bring us around to is, is, is then a discussion about institutional based supports Marcie you you mentioned in your opening remarks that on any given day roughly 2 million people are living in institutions. And in the context of an emergency. We have heard both anecdotally and, and, and has been described to us that in many cases, people who are living in the community, don't have options, or it's described that people who live in the community don't have options other than a more institutional congregate setting, or that could be even a shelter kind of situation, which without proper preparedness can actually lead to a number of personal disasters, any number of them. So, so starting, starting with that premise and knowing that we can't plan for everything but how do we plan to avoid, and an institutional response. I'm going to start with Marcia. What are your thoughts about how best to avoid a facility or institutional base response when when disaster arrives.

Marcia Montague

Right, thanks Alixe for that question. And, you know, we want to have individuals, as part of their community in community based settings with their family with their friends, living in, in places where they would prefer to live, right. And so we need to think about what does wellbeing look like for an individual. For you, for me, for your sibling for whomever, what does that wellbeing look like. Now, but also during a time of disaster. So if a hurricane were to strike, even in that situation what could wellbeing look like if we know we have to evacuate a flooded area, right, in a time of forest fire disaster. What could wellbeing look like for that person, if they had to leave their home. And so the planning and the preparedness for that needs to kind of think through in a strategic fashion, really, what would daily living, look like if I'm living well. Right, even amid a disaster. What would mobility, need to be like, and can I put plans in place, as an individual with my family, or in the community to have those plans that action ready to



go. What would housing look like, how would shelters, be set up, what would I need as an individual to have, you know, some level of personal well being so that I'm not in that place of exacerbating disaster by having individual disasters on top of this disaster that's already happening. It's thinking through medical needs, are there particular medicines that I take every single day that I need to continue to take even during a disaster. If I take multiple medications are there some that are must haves, right, and I need to talk to my doctor about what those might be. Are there supports mental health wise that I need to have in mind. Do I have someone that I rely on is there a way I'll be able to continue to talk with that person having those plans, kind of developed out. It's important, thinking about how you communicate as well. What does personal wellbeing look like in terms of communication Koko's mentioned just the need for accessing information, and that remains or is even more heightened during a disaster, the need for accurate, timely communication and transportation evacuation thinking through that as well, what could that look like for for the individual and for that community. So, going back to your question, Alixe of how do we ensure that continuity of supports and services. I think we need to think through those different types of supports and services that should be in place. It's not just shelter right there are more aspects to it there there's education there's food, there's communication there's transportation, there's pet care, there's durable medical equipment right there are a lot of aspects that we as individuals and families need to plan for that you all as case managers or social workers or whatever your role is as well to support that individual and that communities can plan for. I'll turn it back to you, Alixe.

Alixé Bonardi

This is Alixe they thank you Marcia and I keep taking away from this conversation that there's, there's so much to think about there's not something that can be managed probably even in one conversation at one planning conversation. Oh Marcie, did, did you have thoughts around ensuring continuity of supports, when facing disasters.

Marcie Roth

This is Marcie oh yes I do. So, on March, 5 of 2020, a group of disability advocates, put out a call to action. I believe we ultimately had almost 200 organizations, sign on. And in this call to action, we were raising concerns about what we knew already was probably going to be a devastating and disproportionately impactful pandemic for people with disabilities. And one of the things we focused on was the absolute need to ensure continuity of operations and continuity of services. Unfortunately, despite our best efforts, We were not able to get the kind of focus on continuity. That's so necessary. There are a couple of pieces of legislation that are soon to be introduced. One of those is the home and community based services Access Act, which will address a number of the important continuity issues, and in particular, we need to be sure that that the service providers, the, the DSPS the, The personal assistant service providers, the various folks who provide assistance to people with disabilities are able to do



what it is that they do in steady state or non disaster times, we also need and and and this legislation, talks about the need for exercises or simulations where we practice, you know, like the old fire drill. But in these simulations, we need to actually use them to identify where our where our gaps are, where the holes are right, so that we can plan for continuity of those services to other pieces of legislation I won't go into great detail but one is the real emergency access for aging and disability inclusion for disasters Act, which will be reintroduced for the third time, which will focus very specifically on a number of areas in which continuity of services for people with disabilities are, you know, a big part of the of the bill. And then the, the third bill is the disaster relief, Medicaid Act which is also about to be re introduced which will enable the portability of Medicaid. And the current waiver services to enable people to cross state lines if they need to, with their Medicaid and their Medicaid home and community based services in place so that there can be a continuity of services.

Alixé Bonardi

Marcie. Thank you, but this is Alixe and those, those pieces of legislation that you're describing seemed tremendously important important to be able to ensure continuity of people's supports in the community. And thank you for letting us know about them and we can get that information from you and we can put that as part of the resources that we share you the activists website. Website. Wonderful. I'd like to turn to you Koko, as, as being able to wrap up this final part of the panel conversation to get your perspective on how we can ensure community of supports and services for people, when, when facing disasters.

Korian "Koko" DeMont Thomas

This is Koko. I think it's important to have some supports without any type of labels if you will, or any myths, so there is an example that was mentioned earlier, where we talked about how to avoid institutionalized responses. And that's often based on on a, an old system of information that we have. Oftentimes in past times Deaf and DeafBlind individuals were Institute's that institutionalized at such high rates, and we were assessed as being individuals with GAF. And so over time, the mindset of that has, has changed. I grew up in a family that was insistent on teaching on getting me education and making me as independent as possible. But there are times where I'm questioned if people will ask me when I request an accommodation if I'm truly deaf blind. And I do, oftentimes explain that, yes I am deaf blind yes I am requesting an accommodation, but I also am an advocate, that's another hat that I wear in the mental health world. That's just an additional layer. I don't really get involved with the mental health advocacy. I try to keep a boundary with that. But in general I think it's important that everybody keep an open mind and stay optimistic. During these, these times. I think if everybody keeps the good mindset, then the proper places the proper things will fall into place.

Alixé Bonardi



This is Alixe, thank you and and I'm what you just said is, is ringing in my mind about everybody keeping a good mindset because that is one of the things we think about often at NCAPPS about making sure that people are using, person centered thinking, which really is what to me is, is a good mindset to approach, planning for and delivering supports for people with disabilities. You all have brought forward, a huge amount of information and also been very very willing to share your, your knowledge and expertise. I have seen some information coming, some questions coming through in chat and we are going to now transition to to the more unstructured part of our webinar for a few minutes to to bring forward some of the conversations that have been happening in chat for that my colleague Bevin Croft will be joining us to bring forward some of the questions, and we'll put it to any of you. So with that I'll turn it over to Bevin.

Bevin Croft

Hi everyone, this is Bevin thank you for your insights. In chat. We've gotten some good questions. We've also gotten some awesome and thought provoking comments. We'll do our best to gather these up and produce a resource, after the webinar. Someone asked about that. We can certainly create a compilation for those of you who don't like to multitask on webinars and follow along with chat. We did get some questions and we have a little time so my first question would be for all three panelists it's it's a good one. What are your suggestions for states that may be lacking funding or running out of funding to support people with and without disabilities. During times of disasters.

Marcie Roth

This is Marcie and I'm happy to jump in and I have really really good news and that is, you don't have a shortage of funding to support people with disabilities, You're actually required to do that. And so it's really shifting priorities. I often will say, you know, as much as we love the shiny red things that make fumes. In fact, what we need to be doing is spending our money on meeting those accessibility requirements, and that's, that's your top priority. And I also want to make a secondary point and that is meeting the rights and meeting your obligations to people with disabilities must not be relegated to volunteers to charity to the kindness of strangers I often say, and that's not to say that we're not all big fans of volunteerism. But the rights of people with disabilities and disasters are not an opportunity for charity. As an alternative to providing what is obligated to be provided with the use of federal funds, and states get a tremendous amount of preparedness funding, every year. So, there's, there's plenty of money on the table.

Bevin Croft

Thank you, Marcie, Marcia or Koko, would you like to take a shot.

**Marcia Montague**

This is Marcia, thank you for, for asking that question, and I agree quite a bit with what Marcie has said there that this is a requirement or responsibility right if we receive federal dollars, We need to be complying with federal law, and accessibility is a part of that. Perhaps it's a shift in thinking rather than thinking that putting in place the accommodations or additional accessibility is an extra, maybe it's seeing it as just part of what is the task at hand. That might be, you know, an approach to that as well. Yeah, so I would just embrace the, the approach of serving all of our individuals as part of who we are as a community, as a state, etc. And perhaps that shift in thinking can free up additional dollars, or make those move over to a different column I don't know. Anyway, those are my thoughts.

Bevin Croft

Thanks Marcia, KoKo.

Korian "Koko" DeMont Thomas

This is Koko. I have to agree with what's been said thus far. Just to throw out this idea, or to talk about this if states aren't in a place where they have funding available, or organizations, there are specific state entities that do have funding. Sometimes we do see the response where people say that there's not money available to provide accommodations. And while that the truth may be that there may not be an overwhelming amount of money available. But it's important that we expect the unexpected. And so when we're working with people with disabilities. It's a whole new ballgame, at times. For example, when it comes to pro tactile ASL interpreters oftentimes I see a response that people have, are completely unfamiliar with it. And so I think it would be good for local entities to maybe make a list of the most common accommodations they see and while remaining flexible have monies attributed to that those most common accommodations requested.

Bevin Croft

This is Bevin. Thank you, Koko, um, in chat, we had a number of folks sharing about specific states, and some ways in which they were disappointed with their responses and others where they thought that state was strong in their responses. And I'm wondering if each of you might be able to share, particularly strong strategies or, you know, states that are doing a good job, or what, What makes for a strong state response keeping with the state theme and Marcie I see you going off mute.

Marcie Roth

This is Marcie actually I was off mute, and happy to jump in. But, you know there are a small number of states, who's actually hired a Disability Integration Specialist in their state emergency management agency, and, and that is one of the promising practices. Having



someone who has a full time responsibility for ensuring that the needs and rights of people with disabilities are integrated into what everybody else is doing. It's important though that the role of that specialist is not a replacement for everyone. Having a responsibility to be inclusive of, you know, 26% of the population, people with disabilities. So, the states that are doing especially well with this. And I can call out a couple of them, Colorado, California, North Carolina, several other states that are specifically investing their preparedness dollars in this sort of expertise.

Bevin Croft

Thank you, Marcie, this is Bevin, Marcia, or Koko, any other states you'd like to give props to or strategies, I will note Koko had shared one earlier that we think is pretty great, which is to just get started with a list of the most common accommodations requested. So those are at the ready in the event of preparedness, any others. Marcia,

Marcia Montague

I would just say you. In Texas we have T dem which is the Texas Department of Emergency Management, and there is a disability Task Force related to that and much work is being done to to be inclusive, and I would refer people to the red. Ready Project read at Texas a&m University as a potential resource as well for inclusive thinking in disaster preparedness and recovery.

Alixé Bonardi

Thanks Marcia and Koko, I would like to give you the last word.

Korian "Koko" DeMont Thomas

This is Koko speaking, I agree with the other panelists and I do agree that Texas is is very stressed strong advocate for people with disabilities, people who are Deaf, Deaf Blind I mean you name it. And I also like to state that if states are trying to start something new, not to be judgmental, but to support them and partner with them, so that we can get it right. And again, Texas does have a strong workforce work tasks delegated to this minute, Minnesota, or Maryland as well. There are specific states who have a strong depth and definitely population in those states are very strong, Tennessee, as well, Minnesota. And I think really it's, it relies on people who are within the states, those individuals to, to be a strong advocate, and also to provide partnership and support for the states while they're developing these guidelines that will come forward.

Bevin Croft

Thank you, Koko and thank you to Marcia and to Marcie for this discussion, very rich, very helpful. I would like to leave you all with one last evaluation poll, Connor if you could pull that



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up, please let us know how we did. We are a learning organization and caps, and we're always looking to improve so your feedback will be helpful for us to do that so a poll will be coming up shortly, you can scroll down, there are six questions and before you hop off if you could quickly give us some information that would be fantastic. So thanks again to our speakers. We appreciate you. And we are grateful for your wisdom, this afternoon. Bye everyone. We'll leave the poll up for another minute or two.