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American Public Health Association
Protecting the Health of People With Disabilities
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>> TIA WILLIAMS: Hello. Welcome to the American Public Health Association webinar, protecting the health of people with disabilities. My name is Tia Williams. I am the director of the center for public health policy at APHA, and I will be your moderator today.

For visual reference, I'm a Black women with black and clear framed eyeglasses.

Attacks on diversity, equity, and inclusion efforts and attempts to drastically reduce or eliminate Medicaid and the Department of Education threaten the health and well-being of the over 70 million adults and millions of children with disabilities.

These actions have the potential to devastate and further widen health disparities for people with disabilities, especially those who are low income and/or who have multiple intersections of identity by race, ethnicity, gender, geography, or LGBTQ.

In today's webinar we will review recent executive orders and other federal actions that impact people with disabilities. We will hear more about what it means to be in public health in this moment, and identify what we can all do in our professional and personal lives to be better advocates and allies to the disabled community.

Before we get started with the presentations, I have a few housekeeping notes. Closed captioning is available by clicking the CC at the bottom of the player.

There is a chat feature to the right of the video player. We encourage you to introduce yourself and share your thoughts during the event.

We will be taking audience questions. Type your questions into the Q&A tab next to the chat.

Please note that there is a different tab for questions versus the chat. You may add your questions as they come to you, but we will take questions toward the end of the presentation.

This webinar will be recorded and made available within three business days.

With that I would like to introduce our speakers.

First, we will have Dr. David Hutt, General Counsel. He will provide an overview of recent federal actions and their impact on people with disabilities.

He will be followed by Dr. Mai Pham, president of IEC, the institute for exceptional care, who will provide perspective on leading an organization that centers the needs of people with intellectual and developmental disabilities in the current polarized environment.

Mai will be followed by Yolanda Vargas, self-advocate and intellectual and developmental disabilities specialist. She will provide her perspective and insights to navigating this time as a person with multiple disabilities and several marginalized identities.

All views expressed by the presenters are their own and do not necessarily reflect the views or opinions of any organizations with whom they are affiliated.

With that I will pass along to David to get us started.

>> DAVID HUTT: Thanks Tia, good afternoon or good morning everyone. I appreciate the opportunity to be here and just to reiterate a wall of work for the National Disability Rights Network, the views I am airing are in my personal capacity this afternoon to talk about the numerous executive orders and other actions and try to give as much as I can of an update to some of the major ones that are certainly of concern to members of the disability community as well as I am sure many in the public health community.

Let me go to the next slide, Tia.

Let me start off with this administration has unveiled a tremendous number of executive orders in the first two or three months of the administration. Many of those, as I will talk about, are currently being challenged.

And just as a reminder as folks are trying to navigate the number of executive orders, the injunctions issued by the courts, is on this slide the president is constrained. While presidents can always issue executive orders, and those executive orders to have a

binding effect on law, some other memorandum, or proclamations may or may not. Some may only affect the federal government itself.

However, the president is constrained by Congress and legislation and statutes that have been passed by Congress. So many of the challenges that have occurred in the executive orders so far have asserted, some successfully, that the president has exceeded either statutory authority or congressional authority.

This slide cites some of the cases and has some good language to remind folks that we have to follow the statute. The statute will take precedence as obviously the Constitution will as we go through some of these decisions and these executive orders.

The next slide.

Currently there have been 165 cases that have been challenged in the various executive orders. There is a website that I can later provide that is tracking the status of many of the cases for those that are interested. I wanted to give you that as a current update. The initial obviously cases went through the federal district courts and they are now working their way through the Court of Appeals in some cases, and as you may have seen in the news, there have been some cases that have made it now up to the Supreme Court.

Procedurally these cases will go through a restraining order and then they will go through a preliminary injunction, then there will be an appeal and it may be sent back to a lower court. So for a number of these cases we will not know the legal status of the Executive Order for several months as they make their way through the process. And keep in mind that this will be something that will be in flux for quite some time.

The next slide.

Talk about some of the executive orders that have come out that can have an impact on people with disabilities and those working in public health as well as mental health.

First of all, if you have come out related to health care specifically. I mentioned three here on the slide, one enabling making America healthy again which has been an initiative that we have heard that Health and Human Services is moving on.

Keeping education accessible and ending Covid vaccines, and then making America healthy again by empowering patients with clear, accurate, and actionable health care pricing information.

Most of these -- the first one is generally directed at a commission that has been established with the focus of that commission to do first an assessment focused primarily on children, and then secondly a strategy. The assessment will be due 100 days in the Executive Order, so in the next several months they will be an assessment, and secondly there will be the strategy which will be due sometime during the summer.

It is focused on things such as obesity, mental health, chronic illness. And right now it is just discussing, as I said, and assessment and a strategy.

The disability community will be concerned of things come out of these assessment and strategies that tries to take us back to a medical model. It is a little too early to tell. There was language in there that could indicate that the government is going back to looking at a medical model as opposed to a rights based and social model. So this is what we are looking at and we will see what comes down on these, and obviously the disability community obviously would be very opposed to anything that comes out of this. If it looks like it is going toward a medical model approach to disabilities. We will keep an eye on that.

The ones related to the Covid vaccine essentially allows now schools do not have to follow the Covid vaccine mandates anymore which for some people with disabilities it is certainly concerning. Also if they start to take down masks -- prohibiting masks in public settings, that would be problematic for people with disabilities and would likely end up with an Americans With Disabilities Act challenge if they did not allow people with disabilities to have masking if they are concerned because of the disability about covert or other communicable diseases.

We can go to the next slide.

Okay, and then the Executive Order on DEI. That is the one that I think has been most concerning to the disability community, especially as some of the language of these executive orders had mentioned accessibility.

The DEI has been a concern because of intersectionality and the language, the pretty harsh language in some of these executive orders that don't have legal effect but are certainly troubling to the disability community when these executive orders came out as well as for intersectionality.

The impact of these, there are two orders. One directly went to the federal government, the second one impacted federal contractors and federal funding. Both were challenged and were under a preliminary injunction initially, but now an appeals court has lifted that preliminary injunction. So these executive orders are essentially back in effect, and we will see how they work their way through the court.

It does not mean that that is been a final decision on the legality or the constitutionality of these executive orders, but they at least can be implemented by the federal government.

These are also the basis for funding phrases that happened to a number of federal contractors, and those funding phrases however have been enjoined and the federal government has not been able to freeze federal funding based on these executive orders. But the other parts of the orders are still in effect.

What I can say is as long as you are complying with title VII of the Civil Rights Act and complying with the ADA and with title VI of the Civil Rights Act, that is where you want to look at. It is still unclear how the administration is going to be looking at DEI in terms of federal contracts and what they may be coming out with. But I think at least from a compliance, you want to make sure at a minimum that you're looking at title VII and title VI and feel confident that you are complying with those provisions.

We will see how other guidance that may come out under these executive orders and how they may end up being challenged as the government roles these executive orders out.

What the appeals court said, it's a little too early to determine how the government is going to practically implement these executive orders, and that is why they have lifted the preliminary injunction with the idea this will probably be back up to the courts at a later time.

We can go to the next slide.

And these are just some other ones that I wanted to go through a little bit that will have an impact, I think, on public health and on people with disabilities.

The one on the Department of Government efficiency, DOGE, there have been numerous challenges to that. Some have been successful and some have not. The sense is that DOGE may complete what it is doing before some of these issues are in there.

Probably what is most troubling is the 10 for 1 rule which requires federal agencies to take away 10 federal regulations for every new rule they want to issue. It was 2 for 1 in the first Trump administration, and this is significantly more restrictive. This could impact how agencies are going to be implementing various statutory requirements, how they are going to be implementing civil rights including disability rights statutes.

So we are unlikely to get much regulations out of this administration because of this 10 for 1 rule and what we will be watching closely is whether or not they are withdrawing critical regulations that would be required by statutes. So this is want to be aware of us the regulatory process moves through this administration.

The one on official language, right now that provision does not restrict federal agencies or federal contractors or grantees from putting out materials in other languages. It says it is not mandatory, but agencies can continue to put materials out in other languages. However, I do know of instances where government agencies have told grantees and contractors they will no longer pay for this. So I would be aware that if you are a federal government contractor or grantee, there may be provisions coming that may restrict your ability to charge putting materials in other languages using federal

money. So this is what we are a little concerned about based on some of the [can't understand] we have for that is being placed on federal money.

Next slide.

Many of you probably know of the cap that went into effect. I want spend a lot of time on this one. The National Institutes of Health change the indirect cost rate and capped it at 15 percent as opposed to individual rates for various grantees.

This one has been subject to a number of lawsuits that are working their way through the courts now. So I wanted to point that out.

More recently, within the last week the Department of Health and Human Services is dismantling or indicated it would dismantle the Administration for Community Living. That has held a number of important disability programs as well as programs for the aging population.

They essentially got rid of the policy offices, the contract offices at the Administration for Community Living, and also by moving these programs to other areas of HHS there is very strong concern that the focus on disability that those departments at HHS had is going to be lost within Health and Human Services.

So there is a lot of concern, though subsequently it did not change any specific rights or programs, there is a big concern that disability related programs will be delayed, funding will be delayed, and the emphasis on disability programs in HHS will be reduced by this move. So this is very concerning.

And I would note that as part of this back in February the Health and Human Services department had reduced where they are going to allow for notice and comment. Under federal law the administration procedure act, certain things have to go through notice and comment giving the public the opportunity to comment on a proposed rule.

The Health and Human Services took away what was known as the Richardson waiver where they would allow notice and comment for things like agency management, loans, grants, benefits, contracts, and it would put some of those rules and regulations out for public comment.

HHS has gotten rid of that waiver which means there are certain actions they will take without getting notice and comment and for grants and agent personnel, grants and loans, they will not open us up to public comment.

The waiver that was issued back in 1971, so it has been over 50 years, this is a bit precedent-setting over the last 50 years by not allowing the public to have as much comment into some of the things that HHS is doing.

And I will finish up with a last slide and turn it over. Just some cases to be aware of. I mentioned some of these, the NIH funding case, these are the two cases funding that on the indirect cost rate.

The funding freeze and the DEI cases are listed there and there is a number of others that are listed on the slide that are the leading cases right now.

And just briefly another major concern for the disability community, even though this was not an administrative action, there is a lawsuit ongoing which is challenging Section 504 of the rehabilitation act filed by a number of state Attorneys General. The federal government is the defendant in this case and so the federal government would be tasked with defending regulations under Section 504 as well as Section 504 itself which if you don't know that provides additional protections for people with disabilities for any entity receiving federal funding.

So there is a constitutional challenge and other challenges to the regulations. We do not know how the Trump administration is going to respond at this point. The case has been stayed. But this is one the disability community is very concerned about and they will be following very closely to see how the government response to this as the case moves forward or if it will settle.

Let me stop there and turn it over to Mai.

>> MAI PHAM: Thank very much, David, for that incredibly comprehensive review.

Let me explain how we view the current administration threatening the work we are trying to accomplish, and then talk a little bit about how we and we hope other nonprofits can find opportunities in this climate to actually move forward and advance better health care for people with disabilities.

IEC is a nonprofit. We do work on both the international level and in individual communities. We do not do individual services and we are not an individual service organization, but we work with health care leaders such as insurance plants, state agencies, hospital leaders, clinical leaders as well as community members, people with intellectual and/or developmental disabilities and their caregivers.

We bring those different stakeholders together to focus on developing solutions to make health care better. That could be something as specific as improving emergency care in a certain community, or it can be something broader like creating training pathways for primary care clinicians to learn how to better serve people with I/DD.

So that is so IEC is and we really focus on focusing on how care is taught to clinicians, and how it is paid for.

What we have noticed in this current climate is that when everything I am about to tell you is going to be outdated in roughly 12 to 24 hours for all we know. And part of that is

that David gave us a great inventory of the actions that were announced. But there is a lot of detail about how those actions will play out in smaller more specific decisions at specific agencies, or what happens when these decisions roll downhill to state agencies and governor's offices that we are not sure of yet.

So there was a lot of uncertainty. But I can give you some examples of how recent decisions threaten health care for people with I/DD.

The Administration for Community Living that David mentioned is being divided and also reduced in scope and then dispersed across other HHS agencies. ACL typically would give out \$1 billion or over \$1 billion for grants and contracts to direct service organizations as well as contractors and state agencies and local agencies to serve people with I/DD.

No one knows how much of a budget cut those programs will see, but it will not be zero. And even if specific programs and grants and contracts are not zero doubt, there has been enough staffing changes at ACL and at other agencies such that the bureaucracy may not be able to release funds even if they have been committed.

So all of those impacts we are awaiting to see, but it will mean that a lot of nonprofits and other service providers on the ground may be facing some pretty significant challenges to covering their bills and delivering the services.

Another example is that the branch at the Centers for Disease Control and Prevention that was responsible for conducting surveillance of prevalence of Autism another developmental disabilities in children, which was a periodic regular process that they did through both chart reviews and through surveys, that entire branch has been eliminated.

So no one knows what happens with the surveillance work that had been done.

In addition, agency such as ACL and the CDC were collaborating with other parts of HHS to improve the data that we all have access to on people with I/DD. The quality of data on intellectual and developmental disabilities in this country is very, very poor. You also offer for that, people with I/DD suffer for that, insurance companies and clinicians suffer for that.

There had been a coordinated effort to try to improve that data. That is now in limbo and we have no idea what will happen next.

Many of the academic grants, research grants, and research centers that are under threat or have been put under threat both through the reduction in the indirect rate that is allowed, but also through Frank elimination of whole programs and grants and contracts, many of those focused on disability.

For example Vanderbilt university had a center on Autism and innovation. They saw some severe budget cuts.

There are entire grant programs on disability that may be at risk at NIH and through other grants that other agencies administer.

So those are just some examples of the impact of the funding cuts.

I think what people may not appreciate as much is that as these decisions firm up and they roll downhill, to the extent that there is work that absolutely must be done -- for example the delivery of services to people on the ground to help them stay in their homes -- governors are going to have to make some decisions. They are going to have to decide whether to fund that without federal partners or to not deliver the services and suffer the social and economic consequences of that.

You on the ground as public health officials and public health leaders will encounter that reality when it plays out. I suspect you will see it in things like sudden spikes in mental health crises or homelessness or other risks for public health and population health.

So what can we do under the circumstances? IEC is a small organization. We are only eight people trying to push against the windmill of the health care industry. So we can't change legislation. We can certainly collaborate with others to advocate for smart policy adoption.

But what we can do is we can organize ourselves and our peers. What we hope to do is to one, provide as much support to our community members as possible. IEC is a place where they can come and be empowered in contributing to projects that may change on the ground, whether or not their federal partners are allowed to be at the table.

But we also have other nonprofit sister organizations as well as state partners who want to continue this work. And what we hope to do is to pull them together and in a coordinated fashion taken inventory of what has been lost and/or is at risk, and then prioritize those things, those initiatives and workstreams and figure out what among them that is both mission-critical for people with I/DD, and that the private sector or state actors can at least help sustain or advance.

And we hope that that exercise will also create a map for rebuilding what has been lost, or at least the most important pieces of what has been lost when and if there is an opportunity to do that.

The point is just that the people who need us are too important for us to stay in a moment of confusion and reactivity, we want to be proactive in helping ghettos community members to help make that change.

With that I am honored to pass it to Yolanda Vargas was one of those amazing I/DD leaders and self advocates that power our work and provide the insights to make sure that we are making the right changes for the people we are trying to help.

>> YOLANDA VARGAS: Hello everyone, my name is Yolanda Vargas. I am a fat light-skinned Latina woman wearing glasses with dark hair, and currently on the screen we have a picture of my cat gummy bear reminding us all to breathe. Because we were just exposed to a lot of information that basically means people in our community are going to suffer. And that is hard to take because I am assuming if you are in the public health sphere, you did not take these jobs because they were not stressful and because they paid a lot. You most likely took them because you care about the people in your communities, and you wanted to make a world the better place.

Same.

My name again is Yolanda Vargas, disability is my life. I have been disabled since birth. I have cerebral palsy. Disabled people never need to disclose their disability. I just like getting it out there because it makes the context that I provide easier.

I have eight siblings. My dad emigrated to this country very early in his life. And so navigating health care was not something that he was used to in the sense of helping his children.

So basically the reason that I share this is because often times when we think of intellectual and developmental disabilities, we assume that people have access to a strong support system that can navigate the health care system. But I mean who among us can really navigate the health care system, especially in such uncertain times? It is a full-time job, and I started doing that job when I was 12 and my mother relapsed and it became my responsibility to take care of my brother who has Down syndrome.

I don't share my Dickensian childhood because it is fun or I want anyone to feel bad. I share it because again it provides context with the reality that people have to face. We are not in silos. I do not just deal with injustice issues involved around my disability. I am also queer, I am Latina, I am fat, and all of these things add up to the reality that I face.

So when I say I'm a specialist it is because I put in hours working with people who have a variety of disabilities and conditions and views of the world and I carry them with me and bring them all to you.

And right now what is happening is we are all screaming and afraid and doing our best to get through the day just as a community. And a big part of what is keeping many of us together and keeping us focused on our mission is something that I'm going to share with you.

Tia, next slide please.

So we have here the 10 principles of disability justice, not to be confused with disability rights. Disability justice is something that was created from the perspectives of multiply marginalized racially oppressed People of Color that are also disabled and proudly disabled. And they looked at the world and they were like we have to approach things differently. We have to empower our own people.

So we have intersectionality, and a wonderful quote to start us off by Audre Lorde. And I want you all to look over this. I am not going to read the slides verbatim because I only have so much time with you and I like to think of you locked in here with me and me not locked in here with you. So I would love to get as much information as possible.

And also to provide you kind of guidelines on how to approach intellectual and developmental disabilities that are away from the medical model and more the social model, and just seeing us as people and not children or people that need to be saved, but people that can do this work with you.

So what is important to recognize that the leadership in these situations should be the people that have the most to lose. And as David has so amazingly stated, we stand to lose a lot. Our lives are about to get so much harder even before things are finalized. Waiting and seeing is not something that you can do well when your basic needs might not be met and your health could get worse, and seeing the people you love suffer and potentially languish and perish is always in the back of your mind, which is not something new for the disability community. Death is always akin to disability just naturally, but it is another thing when the situation is being made worse by callous and unfair choices.

Just to be clear I am speaking as an individual and I want to reiterate that because I am going to be very honest with you all.

Anti-capitalist in politics. That is not to say that if you are a Black woman that gets an amazing job that lifts your family out of generational poverty that you can't go work at Amazon, good for you and do what you need to do to survive. But it should not deter you from the mission of helping others, and money should not be used to curb the revolution basically.

Next slide please.

Commitment to cross movement organizing is another one that I wanted to focus on. Thank you for reaching out to me and having me in these conversations. But also please reach out to me in the future, any of the amazing people working here, if you want to be in more disability spaces and if you want the opportunity to share your work.

It should be reciprocal. We need to be going back and forth, we need to be having these conversations, we need to be open and honest and raw about our realities and what we are facing and what our people are feeling. I think often times when people reach out to disabled folks it is kind of in the sense of hey, we will give them a little

space at the table, but we are not really legitimizing their struggles in the sense that we recognize them as an equally important movement. Which is funny because if you are working to better the health of any marginalized community, disability is there. There is no community that we are not a part of, so you should be engaging it on every level.

Again, recognizing wholeness. People have inherent worth. Oftentimes to get people to connect to disability, we use kind of emotional manipulation for the better, like this is your mother, your son, your loved one, to paint this idea of this is why you should care.

You should care because we are all people. That is why you should care. We should not have to validate our existence because it is more efficient or synergistic or whatever terms that might be pressed for us to adopt.

And again language is very fluid. I don't like to police other people's language. If you like the term people with disabilities, great. I prefer disabled. To each of their own. But the idea of having forced language changes is something we do not endorse and it will ultimately make it harder for people to communicate what they need just because they are afraid of getting in trouble.

Growing up with a mother that had addiction issues and that often saw me as an embodiment of her poor choices, I was not a stranger to violence. And wildly changing moods. So I know that many people out there feel the need to maybe make themselves smaller, to be less of a target.

That doesn't really work at least in my experience. If someone has power over you that they feel that they want to wield, they will wield it no matter how well behaved you are.

Sustainability. We place ourselves. This is not something that is going to be over in a couple of months. Even if everything legally goes how we wanted to go, there will still be changes in ideology and in the greater sense of the world community that we are still going to have to reckon with.

This is going to be for the rest of our lives. And that means that you can't burn yourself down, you can't expand everything just in the hope that you can solve these problems. Please take care of yourselves and your loved ones and let your loved ones take care of you.

Next slide please.

Commitment to cross disability solidarity. This is another big one I am going to touch on because often times disability rights and other disability organizations can create a hierarchy of disability where it is like the least disabled should be in the front of the pack.

And it's like no, all people should be included equally. And that helps prevent isolation, bitterness, things that really break down a movement.

Interdependence. No one is completely independent. This is a lie that capitalism has created that we all seem to believe.

But just look back at your lives and think do you really ever get anything done by yourself? And the answer will be no.

Collective access. And this is something that is so important that David mentioned where we are losing the ability to have comments on things that directly affect our lives. That is something that is so against the principles of disability justice where we have to have the ability to communicate. We have to have the ability to have nuanced conversations beyond just hey, this is good, this is bad, this is more profit yielding. Whatever. It has to be that everyone gets a chance to at least think about and provide input on the things that are going to affect them.

And maybe it is uncomfortable because we are going beyond the basic of oh, aren't we great, look at as being just like you. Yes, we have our own histories and [can't understand] to cross and things to reckon with.

And again to also add collective liberation. No body or mind can be left behind. Only moving together can we accomplish the revolution we require. Because again I just cannot stress enough that there is no liberation in stages. It's not going to be like okay, women get the phone, then we will work on this group and then this group -- no. It should have all happened together.

I think that is what we know now being historians of the past and especially looking at public health history in detail so much. We have to recognize that our revolution needs to be all at once.

So yeah, that is kind of my big take away. I have thrown a lot at you. There are so many people doing this great work and so many things you can do to help foster that great work, and I will be sharing those later.

>> TIA WILLIAMS: Thank you to all of the speakers for painting such a broad picture of the current landscape from the perspectives of the law, public health practice, and from lived experience.

I would like to invite all the speakers to join me on screen, and I have a few questions for each of you before we turn to questions from the audience.

Just a reminder to the audience to use the Q&A function to submit your questions, and we will try to get to as many of them as possible in a few minutes.

So what advice would you give to public health organizations and agencies as we have acknowledged many of them are reliant on federal funding and who are unsure of what

they can and cannot do right now related to people with disabilities, and may be scaling back some of their efforts.

I will start with Yolanda on this one, and then we will pass it along to the other speakers.

>> YOLANDA VARGAS: Well, I would really suggest that people take a moment to look at other funders like the [can't understand] foundation, the Ford foundation, the Robert Wood Johnson Foundation who are actively making a commitment to stick to their principles and values despite the ever-changing landscape of our political times.

I think that disabled people notice those things. And right now we are feeling like we are all on our own. And in some ways that may be true. But even if all that we've got, we are a lot in the best way.

So just commitment to the values that you had before, using that same language that is being used in your communities and not changing it.

But also being open to including disabled people from the beginning in your planning, that needs to be imperative. Because we don't have time to go back and of course correct. We all need to be there in the beginning and we only to be on the same page.

And again that might mean having uncomfortable conversations about privilege and basic needs not being met and how that may manifest, and that people have limitations. And those limitations need to be respected because we are all just hanging on by a thread it feels like. So yeah.

>> TIA WILLIAMS: Thank you. Mai, do you have something to add?

>> MAI PHAM: Please take this by understanding that I am not a lawyer or a business leader. But I would have basic recommendations like, as David said, when you feel uncertain hue to established law as opposed to things that are still in flux.

Second, as a business leader I would advise conserving your cash. I would advise starting to think through now how you would prioritize if you suddenly experience budget shortfalls.

And also to Yolanda's point, in addition to private foundations, and local communities there are business leaders and there are civic organizations that may be willing to step up during these very unusual times. Reach out to them, educate them about what is likely coming down the pike so they can start thinking about how they can contribute. And you can all start thinking through okay, what is our community need for a second and third.

I can't emphasize enough I think prioritization is really, really important, so that if any of us have to pull back on the services and supports we offer, we do it in as smart and a

strategic a way as possible and it is not slapdash, because it is more likely to cause harm if it is not coordinated.

>> TIA WILLIAMS: David, do you have anything to add to this in response to this question from a legal perspective?

>> DAVID HUTT: Just a few things, and my apologies, I did not do a description. I'm a white middle-aged male with a gray beard and ever-growing gray hair which has been continuing in the last few months.

I would just add that if you are a grantee or a contractor, at this point wait and see what the new grants notice of awards come out, what your new contract might say, and to pick up on Yolanda's point, don't stop reaching out to people with disabilities no matter who they are. Continue to do that work. That is still something that outreach in general is going to be wildly important to get to find out what your priorities should be. So I would definitely not stop that.

There has to be a little bit of a caution in terms of some of the compliance issues. But until you get notices for specific changes in your awards, I would try not to overreact or to anticipate too much about what might be coming into you actually see what is in the language.

>> TIA WILLIAMS: Absolutely. Try not to overly comply in advance.

The next question is especially with the DEI Executive Order, and there is a long list of words and phrases that are so-called band and prohibited, but yet our mission in public health has not changed. And improving health and reducing health disparities, advancing equity are still values of ours and they are the foundation of public health.

What opportunities do you all see for public health to continue to advance on its mission to improve health and reduce health disparities for people with disabilities? Mai, we will start with you.

>> MAI PHAM: Yes, I would say that all of the same opportunities that we had three months ago are still there. I think it is a matter of being smart about how you comport yourself.

For example, on the language limitations, that can seem very stressful. But as I look at the list, and granted some things on there are just not doable, like you can't avoid the word warm and for example which is on the list, but it does encourage you -- and this may not work -- but I find it very helpful to actually say what I mean instead of using coded language, which is what many of the words on that list can be interpreted as.

So rather than saying, for example, what is a good one -- we are going to address intersectionality. We can say we want to make sure that our programs serve people who face different challenges and a range of different challenges in life. There you go.

You are being very honest but you are also being much more specific and clear about what you actually want to do rather than using coded words that may mean different things to different people.

But in terms of your ambition, I would not recommend that you pull back on your ambition. I know that may sound contradictory because I said you also should prepare to prioritize. You should always be prepared to prioritize and know what is second and third, but it does not mean you should not dream big.

>> TIA WILLIAMS: Yolanda, would you like to answer that question?

>> YOLANDA VARGAS: Yes, I think now is the time we prepare our people. We start being open and honest about the fact that we don't know what the future looks like. We need to get people to build connections within their community, to hopefully soften the blow of potentially losing services.

That can be something as simple as getting people to talk to their doctor about instead of getting a one month prescription for their meds, like three or a year-sized prescription, whatever is possible just in case they no longer have access to that assistance.

It could also be sharing that you are tired with friends and that maybe even if respite care no longer exists in your community, you could work something out with someone that you trust helps you with your disabled child, or whoever you are providing care for.

We are seeing a silver wave of people needing more support and care. That is not going to change anytime soon regardless again of the political situation.

So just start being creative and how we can get our people to build community with one another and support one another, because again there is a lot we don't know, but there is a lot that we do. And we know that hopefully we will be there for each other.

And while the social safety nets might not exist, we have the safety net of being social. So yeah, to start having those conversations on how to lessen the fallout.

>> TIA WILLIAMS: Thank you, Yolanda. And that actually dovetails nicely with my next question which is for you. You have given us a lot of gems already today, but I wanted to see if you had any final words about how public health professionals and advocates -- how we can be better advocates and allies to people with disabilities and the disabled community.

>> YOLANDA VARGAS: Get more comfortable with being uncomfortable. I have said it a million times and I will say it a million more. We are all flashbacks and our bodies are constantly changing. If you are not disabled now, you maybe in the future. Maybe you are disabled and you don't want to admit it and that is fine. You are on your own journey.

But disability is just a natural part of life, aging, existence. And so tried to distance yourself from what you may have been told, whether it is media or trainings from nondisabled people. Because those really can kind of be counterproductive to what we want in that it can be infantilizing, it can create a distance between disabled people and nondisabled people. It can reinforce hierarchies.

Try to enjoy spaces filled with disability joy. Go to disability film fests, go to community gatherings that include other forms of pain management. Work with your local dispensaries if you want to. Just figure out what people are actually using and respecting that and respecting them.

There are so many other things I can tell people. Please if you want to reach out, do. I am working again as myself and as an individual, and I do have a few slots of pro bono work.

Another big thing I want to say is if you are calling on disabled people, especially those with intellectual and developmental disabilities, please pay us. We need to get paid for that so we can make a decision about how we are using our time.

Another big thing is if you are working directly with disabled folks, try to have conversations where you always assume competence, but you also give them the opportunity to speak freely away from caregivers. We love to assume they have a positive support system, but maybe they want to ask you some questions that their mom or their PCA might not be comfortable with, especially around things like reproductive health, sexual health, mental health. Depending on the culture you come from, that might be a taboo subject to say in front of somebody.

Give them that space and respect that autonomy.

And a billion other things, but we only have so much time, but thank you so much again for having me today.

>> TIA WILLIAMS: Thank you, Yolanda. And we have a question from the audience. And I will throw this out and whoever wants to take it first, please feel free to come off mute and take the question.

As more folks are mobilizing in public action and just organizing in general, any thoughts and how they can make sure that they are holding accessible and safe events for everyone who wants to participate?

>> YOLANDA VARGAS: I will go first because I am very passionate about accessibility.

Recognize that if you are planning events and you are wanting to make things accessible, have disabled people on those planning committees from the beginning so you are not again course correcting which is the worst thing you can do because we all

know when you put a sad little ramp on a thing and it's all last minute and a hodgepodge mass, we can see it. And it does feel horrible to see.

We also know that funding is going to be hard to come by. If you were not able to get the funds to provide things like ASL interpretation out of pocket, there are some interpretation services that can be donated if you work with them.

But again that requires you to plan beforehand and to think about those things beforehand, to reach out way before the event happens.

But also if you have barriers to creating accessibility, let people know. Be transparent. Don't just not say anything and have people show up and have them wondering where do I go for what I need.

>> TIA WILLIAMS: Mai, did you want to add something? Okay.

I have one last question just to get all of your perspectives around what narratives should we be lifting up to counter some of the messaging that is coming out of the -- of this administration. Who are some of the leading voices in these spaces, and if you all had particular resources you would like to list, resources, organizations, or individuals you would like to lift up for our audience to look more into and to understand what other narratives that are more supportive for people with disabilities in this moment.

>> MAI PHAM: I can start and I am sure David and Yolanda have much longer lists to offer.

Every community -- I should not say every, but many, many communities of local chapters of national organizations that are great like The Arc and like Special Olympics. Many communities have local ACL centers on aging that also serve people with disabilities, Autism society has local chapters.

And those local chapters are great places to get to know and access the experts in your community who are often the most compelling to speak to what is needed in that community.

Reach out to any of us if you want to tap into voices of people with natural profiles in given areas. We are happy to redirect you to our I/DD sister organizations as necessary.

And I think keep in mind that there are a lot of online resources as well. Any of the organizations that I just named, the National Down syndrome Society, and even the agencies that I mentioned, well we have been concerned about the loss of resources on federal websites, we at IEC have scraped a lot of that data and reports and such and many other organizations have as well.

So if there is a particular program that you want to learn more about or that you are trying to track because you are actually involved in the program, reach out to us and again we can help redirect.

>> DAVID HUTT: I would add that a lot of the advocacy is now local, so as Mai mentioned, getting involved with Allstate chapters. I will give an example. When we were trying to get Attorneys General to get off of the Section 504 challenge case, and there has been a lot of great advocacy, we have not gotten anybody off yet but they were certainly feeling the pressure of allies in the disability community. So I think that is important to get the message is how important these laws are, how important the federal government is and even state and local government with enforcing this.

I think the narrative is sadly going about trying to devalue people with disabilities and that has got to stay at the forefront, just how important people with disabilities are in the community. And really we have worked for 50 years or more with the disability movement and we can't lose that and we've got to keep up the narrative about how important these laws are and how important people with disabilities are and how we may not leave them.

>> TIA WILLIAMS: Thank you, and with that we are at time. Thank you also much. Thank you to our panelists and thank you to everyone who joined us for the live event today. And thank you for your questions.

If you would like to learn more about people with intellectual and developmental disabilities especially, I encourage you to check out several resources we have on the APHA disability and health page including a primer on I/DD for public health professionals.

Just a reminder that this webinar was recorded and will be made available within three business days and we will also provide a transcript for the webinar.

Thank you so much for joining us today and have a great rest of your day.