

2020 Census Disability Community Toolkit

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# Presented by:

* Ditas Katague, California Complete Count Census 2020

**Moderator:**

* Tho Vinh Banh, Supervising Attorney-Multicultural Affairs Outreach Unit, Disability Rights California. Advisory Panel, California Complete Count Committee.

# Speakers:

* Margaret Jakobson-Johnson. Immediate Past Advocacy Director, Disability Rights California.
* Sheri Farinha. CEO, NORCAL, and Chair, California Coalition Agency for the Deaf and Hard of Hearing.
* Jeff Thom. Immediate Past President, California Council of the Blind
* Judy Mark. Founder and President, Disability Voices United, Faculty Member, UCLA Disability Studies Department
* Leroy Moore. Founder, Krip-Hop Nation, Founder, National Black Disability Coalition and Board Member of Disability Voices United. Journalist with Poor Magazine
* Dawniell Zavala. Associate Director and General Counsel at Mental Health America of Northern California
* Christina Mills. Executive Director, California Foundation for Independent Living Centers (CFILC)

>> DITAS KATAGUE: Okay, well, good morning, everyone. Thank you for joining us today for this webinar. I'm Ditas Katague and I’m Director of the California Complete Count Census 2020 office. This is the third time I will be undertaking this role. I'm very pleased to have technology that can help us that we didn’t have in 2000 or in 2010. And we’re working through it, so we appreciate everybody’s patience.

So the purpose of today's webinar is to educate Census 2020 stakeholders about the importance of outreach to people with disabilities and how to encourage their participation in the centennial census. We also want to engage with disability advocates and leaders so that California Census outreach efforts are inclusive of people with disabilities. And finally to inform the disability community about the importance of responding to Census 2020.

So while the responsibility of the census enumeration operations and related data management rests solely with the U.S. Census Bureau, the state campaign supplements and seeks to increase outreach efforts that are done by the U.S. Census Bureau but also to reach all Californians to ensure that they respond.

The California Complete office will conduct a robust outreach campaign to reach and activate hard to count Californians. Including people with disabilities.

I’m pleased to open this first webinar on the critical importance, including people with disabilities, in the Census 2020. So I'd like to turn it over to Tho Vinh Banh who has led the discussions around disability inclusion at our California Complete Count committee.

>> THO VINH BANH: Thank you. I'm just going to wait a second while our camera person comes on.

Great. Good morning, everyone. And welcome to Census 2020 webinar, Inclusion of People with Disabilities. So I want to start off by saying it's coming April 2020 and the federal government is going to start counting every single person in California and the nation. So we do have challenges ahead.

People with disabilities in the past have been hard to count and have not counted in the numbers that they should be. Today, we’re fortunate to have the wonderful panelists that we will, that will speak about how we can improve that. How we can ensure that everybody with a disability is actually counted.

Why does it matter, right? We are here today and we're spending this time with you today to let you know that a lot is at stake. There are over $675 billion that is essentially doled out to the state and to different programs using census data. That includes a number of representatives. It includes Section 8 housing vouchers. It includes special education programs. There's a whole lot at stake.

With that said, we want to make sure that people with disabilities and the communities that are going to help count people with disabilities are aware what the issues are and hear the panelists speak about what some of the solutions may be.

I am very fortunate to first be able to introduce you to Margaret Jakobson-Johnson. She’s our immediate past advocacy director for Disability Rights California. And Kyla is going to be gone for a second while we will come around so we can see Margaret.

>> MARGARET JAKOBSON-JOHNSON: Hello, everyone. I'm Margaret Johnson as Tho Vinh pointed out. I'm going to talk this morning about a toolkit that we developed. We're calling it the 2020 Census Disability Community Toolkit. And I believe it's being made available to everyone that’s on the webinar.

We did that toolkit in collaboration with Disability Rights Education and Defense Fund in Berkeley. It was supported by a grant from the California Community Foundation. The purpose of the grant was to conduct focus groups and listening sessions to hear from people with disabilities about the US Census and how they participate and learn about their past experiences. Get their reactions to some outreach messages, and to help organizations be more inclusive of people with disabilities in their outreach for the 2020 Census. So, that was the point of what we did.

I'm going to go through a little bit about what we learned. And we have four focus groups of six people each, and four listening sessions with 44 participants. Participants had psychosocial disabilities, intellectual and developmental disabilities, and physical disabilities. Some people were blind, hearing impaired, and parents of children with disabilities. So we have a pretty robust group of people that we had in our groups.

Unfortunately, the funding was limited to Southern California. So the sessions were held in Riverside and Los Angeles Counties. So it was really specific to that area.

We had ethnic and socioeconomically diverse people participate. We had people that had been living on the streets and people who were previously institutionalized. So I think that we had a pretty broad group of people that participated in this.

We wanted to know what people with disabilities want to know about the Census. And people with disabilities generally want to know the same thing that other hard-to-reach communities want to know. They want to know what it is and why it's important.

So only a few of the people we talked to knew much about the census. About half of them had heard about it but only nine people knew that the results determined how many representatives we have in DC.

Each person we talked to became more engaged and interested once they heard of the things going forth, when in doubt earlier that the census determines how more than $600 billion's worth a year in important resources for all Americans including people with disabilities is distributed to the states.

They responded to the fact that the census determines funds for SNAP, children's health programs, special education, support for foster youth, and funding for Medicaid.

So those were important things that they were interested in knowing about the census that really got them more engaged in participating.

Of the people that we met with, only 13% of them had ever completed the US census. So this really shows they think that people with disabilities are really underrepresented in the census.

We also asked people why they don't complete the census, assuming they even got it. We asked “Have you ever completed it?” And this is what we heard: “I've never been asked. I don't think the census has an impact on my life. I have trouble completing forms.” and “I'm worried information will be used against me.” And the last one, I feel, needs a little explanation. A lot of times people with disabilities are really concerned that providing personal information might interfere with their ability to get Social Security, Medi-Cal, and other kinds of benefits. And that is particularly concerning for people who have waited for years, even to get an eligibility determination to receive these kinds of services or support.

We also asked why people would participate. And the reasons people will participate include, if surveys are conducted in partnership with a trusted group. So trusted community group will help people feel that they can actually participate and that there will be a trustworthy relationship. And that could be, like, community organizations, service providers or other kinds of advocacy groups.

The other thing is that people, if people can understand the census will be helpful for them and other people with disabilities. So really making the census bigger than just them. And, again, this goes back to the comments about making sure that people understand that it really helps with a lot of benefits and services that people need in order to participate and function in the society -- larger society.

People also wanted to complete surveys in a place where they feel comfortable. That might be an independent living center, a frequently visited community center or even a church.

People also wanted information in an accessible format. So that might include something that's readable by a screen reader program, Braille, or in American Sign Language.

Another reason people would participate is when information is provided in plain language.

And then finally, it could be that in-person or with the support of someone they trust when completing this survey on a computer or using a smart form app. That wasn't necessarily true for everyone, but some people felt like they really needed the help and support.

The preferred messages that we found. We tested, I don't know, maybe ten messages. And out of those, three resonated with people. And the first one that resonated was, "The 2020 Census: The Disability Community is Counting on You." That was one of the messages.

Another message that resonated was, "The 2020 Census and Disability: Everyone Deserves to be Counted."

And the third message that resonated was, "Why the Disability Community Matters When Counting the 2020 Census.”

We also tested hashtags and the one that resonated was #DisabilityCounts2020. When people are doing outreach to the community, you might want to try using one of these messages that resonated and use that hashtag.

And then we also looked at outreach factors for people to consider. And those included things like making sure to provide access when you're doing outreach, whether asked for or not. And then to be aware that not all people identify as disabled and the things that impact that include things like a person's age, their economic and cultural factors, and stigma. A lot of people feel like having a disability is stigmatizing and may not want to disclose they have a disability.

In addition, some communities have impact from communication, like communication. So you want to make sure you're using plain language so people with intellectual or developmental disabilities can understand. You want to make sure you're using American Sign Language, real-time transcription at events, Braille, large-print, screen reader-friendly websites. Things like that.

So the other speakers here today will get into more detail, I’m sure, on some of that. But just generally in our document, we made sure to list some of these things so you can remember and then reach out to other sources to make sure that you understand that.

And then finally -- this one may not seem that obvious to people -- but use images of people with disabilities in your outreach materials. I think that showing a person with a disability when you're doing your outreach materials really lets people know that you're interested in hearing from people with disabilities. And we encourage you to use imagery that avoid using red flags like images that use standard un-customized hospital-issued wheelchairs, for example. Or scenes depict a victim in isolation or institutions. Instead, really try to use disability images that show people in real-life situations doing a variety of things alongside friends, family members or colleagues.

So those are some of the outreach factors that we identified.

The toolkit also includes some resources. Most of those are targeted towards Southern California. But some of the resources in the toolkit are statewide.

And I thought that we were putting together some resources that we’d be distributing to people generally as part of this webinar. I'm sure someone can say more about that, if she comes back.

So I'm kind of wrapped up on what my toolkit covers. I'm not sure if we were doing questions at the end of each thing or at the end end? I think we’re doing it at the end, end. I’ll turn it back to Tho Vinh and she can introduce the next speaker.

>> THO VINH BANH: Thank you so much Margaret. I see in the dialogue box that folks are asking about the slides. We are, because we have many speakers and we have a short amount of time, one screen's going to be dedicated to the ASL interpreters. The other will be roving around to ensure that everyone can see the speakers. All materials, including the toolkits that Margaret spoke about, including the PowerPoint she’s using and resources materials we’ll be providing to you will be provided to all attendees after the webinar. That is what we're doing to ensure everyone could have full access of this panel. So thank you so much to Margaret for that.

Next I'd like to introduce you to Sheri Farinha. Sheri is the CEO of NORCAL Services for Deaf and Hard of Hearing.

>> SHERI FARINHA: Hello, everyone. Again, my name is Sheri, Sheri Farinha. In addition to being the CEO of NORCAL, I’m also the chair of the California Coalition Agency for the Deaf and Hard of Hearing. So first I wanted to share some facts briefly about our Deaf community.

So the use of that word, that term "deaf," really people don't tend to use "hearing impaired" anymore. They will use the word deaf or hard of hearing to identify.

And deaf really encompasses a wide range of individuals with varying degrees of hearing loss and hearing levels and communication preferences and language for communication such as ASL, English, etc.

Studies have shown that deaf people face extraordinary challenges in finding and retaining their jobs. Despite the mandates with the Americans with Disabilities Act to strengthen the hiring process and the provision of reasonable accommodations for all individuals with disabilities, several studies have found that even with training, laws and increasing awareness of the needs of the employees who are deaf, the employment rate itself still for the deaf population is lower than the rate of, comparatively with the hearing population.

The reasons for that higher level of unemployment rate within the Deaf community varies but it can be contributed to the employers' hiring practices, misconceptions, and also just attitudes.

Our population is very diverse. There's a lot of different backgrounds, different cultures. And within each culture -- you know, within the Black community, Hispanic community, Latino, Asian, they have deaf people -- there are deaf people included.

So for the census, deaf people don't always identify themselves as disabled. A lot of times they're looking for where it says deaf or hard of hearing or other options. They place their culture of being Deaf before the identity of disability. They consider disability people are people with disabilities are in a wheelchair, not somebody who doesn't have the ability to hear.

Approximately 15% of the total population are individuals who are deaf and hard of hearing, deaf/blind, deaf-plus and that actually equates to roughly 5.9 million residents who are deaf or hard of hearing.

And 43% of that population live in a household where language is used from another country other than English. And with that number of individuals who are deaf or hard of hearing, those are residents who are from linguistically isolated households.

The education background is another factor as well. About 90% of Deaf or hard of hearing individuals are born to a hearing family with hearing parents who might not be aware of what to do and oftentimes won’t introduce language until later.

And we know that it’s a very critical period for learning from age zero to five for children to acquire language. So if they aren't acquiring that language acquisition at that time, then oftentimes there is a language deprivation and the language barrier that ensues and that's the reason why with the census it's important to use English sentences very clearly on the survey. But that can be a barrier for some deaf and hard of hearing individuals who maybe, weren't able to read or understand the question.

We recommend for people who are involved with the census in every county to make sure that they include the -- same with the government offices -- that they include ASL on the menu, as an option, so that people can see that and pick that option for accessibility.

That way they can access all the information for the survey and have that split screen with the question and another screen with the question signed in American Sign Language.

We should caption all media, all media materials. It's very important that hard of hearing and anyone who needs that access can see visually the sentences in the language in the census. In addition to someone signing or using a video… and if you're using a video it's important to pick someone themselves who actually is deaf to show them in the video so we can show the true representation of the language.

We also should use deaf people to be a part of the outreach in general. Especially if you're going to be going to approach people in homes that obviously if the deaf people don't understand your spoken language, maybe you could write back and forth and that's not always the best way to do it, either.

So we have eight sister agencies in California, in the state of California --

>> THO VINH BANH: I'm sorry to interrupt for a second. Sheri, is it okay if you don't voice? Because the caption is speaking your voice and her voice. So if you could just sign -- it just picks up her voice. The captioning is picking up both. So if you could just sign without voicing it can pick up just one voice.

>> SHERI FARINHA: oh, yes.

>> THO VINH BANH: Thank you so much.

>> SHERI FARINHA: Sorry, I didn't even realize that. So where was I?

So we have eight sister agencies throughout the state in different regions of California. And we all have contracts with DSS, Deaf Access Programs itself, DAP.

So if you feel stuck, you're not sure what to do, the best thing to do would be to contact the DAP Office itself, Deaf Access or me directly. And I can direct you to the most appropriate local Deaf agency in your area. And they can work with you or they can refer you to other people who might be able to go to your area or to another agency to help maybe to interpret or interpret documents, translate them into ASL if needed for them to respond to the survey.

And, again, my name is Sheri, you can contact me via email at SFarinha@norcalcenter.org or you can call me (916) 349-7500. And if you want information about the closest deaf agency to you and provide you with assistance, we are so happy to help. Thank you.

>> THO VINH BANH: Thank you so much, Sheri. You're a wonderful resource to the community and you're always willing and passionate advocacy for individuals from the Deaf and Deaf-plus community. The next speaker is Jeff Thom who is the immediate past-president of the California Council of the Blind. One moment, give me one second.

>> JEFF THOM: Okay, good morning, everyone. First I want to thank the Complete Count Committee and all of the organizations that help organize and arrange for this webinar.

For many complex and numerous reasons that I won't even mention today, I think that people with disabilities are certainly one of the largest under represents groups in the census and especially here in California.

So I want to focus my remarks in two areas. First, I want to mention three significant segments of the blindness community that I think we need to focus on in terms of getting effective census data. And secondly, the best ways to go about the outreach for those particular communities.

The first segment are K-12 students who are blind or have low vision. Many of these students also have other disabilities as well. And I'll come back to that. But disabilities include hearing impairments and intellectual disabilities especially.

The funding that is impacted includes many types of services, the provision of technology, the teaching of Braille or the ability to use low-vision aids and materials. The understanding and navigating in one’s environment which… or persons with vision loss is known as orientation and mobility. Independent living skills such as the ability to prepare meals, the ability to use a checkbook, dressing appropriately. Socialization such as learning about personal space, learning about dating and human sexuality and many, many more skill sets that blind children don't acquire as easily as sighted children do.

In addition, of course, teacher training funding is impacted by census data. And as with other segments in the teaching community there is a severe shortage of programs and teachers for the blind and vision impaired.

The second segment are working-age adults. This used to be the 18 to 64 population. But now it has really expanded in two directions. First, due to federal law and other circumstances, we are putting much more emphasis on transition youth of high school age. Secondly, seniors with vision loss, like other seniors, want to remain in the workforce. With the proper training and sometimes modifications in their jobs, many can either perform the same job that they did before they lost their vision or change into a new job.

The final segment and the big elephant in the room as far as the blindness community is concerned is seniors themselves. Our 55 and older population comprises more than half of us. I'm proud to say since I'm one of them [Laughs]. And people 55 years and over who lose their vision need a variety of services. Including some of the ones that our children need like orientation and mobility, and independent living skills, but also including mental health and peer support. They have to fight the isolation and the sense of the absence of self-worth that they acquire when they first lose their vision. They also may be dealing with hearing impairments. A significant portion of the low-vision senior community does have a hearing impairment.

So, having looked a little bit at these segments, now how do we outreach to these particular groups?

Let's first look at the K-12 student population. And of course, with a few exceptions, there are a few adults in that population, most of them have to be reached through their parents. So how do we get there? I think that the best way that the census office can help to reach these parents is to work with both the California Department of Education and at the local level with County Office of Education, school districts, and special education local planning areas.

And even more than that, getting information into the teachers of the visually impaired and orientation and mobility specialists who really have the one-on-one relationships with parents.

Obviously, the materials have to be language-appropriate because we are dealing with many minority communities and culturally appropriate. And yes, as has been stressed before, there's definitely a problem with stigmatization. A lot of parents for a variety of reasons do not want their children labeled as blind or having other disabilities. They are scared and they think it in some ways will hurt their children and will even hurt themselves.

I think it's important that we deal with various organizations that California is lucky to have. For example, California has groups of educators of the visually impaired and has groups of orientation and mobility specialists. And some of these resources will be placed in the resource guide that you are going to be receiving.

And finally, let's turn to the two sets of adults. And I think I'm going to handle these as one: Working-age adults and seniors. Although there are some areas in which they have separate categories of outreach.

One of the senior categories in which we are very lucky in California is we have a series of approximately 20 agencies and some independent living centers as well that serve blind persons specifically. It is important that these entities receive their money through the Department of Rehabilitation.

So through that department and individually with these agencies, they have a very easy way to reach out to seniors who have low vision and/or blind.

Obviously, the materials must be in large print and Braille format. Large print will probably reach far more, but certainly there's still a significant number, like myself, who use Braille.

In terms of videos, just as you have captioning for those who are Deaf and hard of hearing, it is important to have audio description for videos that people who are blind or low vision are going to see. We want to know what is going on in that video and audio description… which is a method of basically of describing the dialogue and -- sorry, describing the visual aspects of the video is extremely important for our population.

There are -- it is also important that we use cultural organizations in the minority communities as well. Because oftentimes it is very hard to reach seniors in those communities except through those types of organizations.

And, you know, we have focused so much on high-tech solutions, I'm going to focus on a low-tech solution. A lot of times our seniors even though they have used technology before they lost their vision aren't yet trained to use technology after they lose it. But if they have a wide-tipped pen known as a “bravo pen” in many circles, they can oftentimes fill out that census questionnaire because they’re gonna know what they're writing and they may be far more at ease in desiring to filling it out.

So, these are just some of the ways to outreach to our community. I will give you my email and phone number as well because you can also do it through the advocacy organizations including mine, the California Council of the Blind and the other major advocacy organization the National Federation of the Blind of California. My email is jsthom@comcast.net and my phone number is (916) 995-3967. And I thank you very much and I hope that this information has been enlightening.

>> THO VINH BANH: Great. Thank you so much, Jeff. If you wouldn't mind repeating that phone number again?

>> JEFF THOM: Yes, (916) 995-3967.

>> THO VINH BANH: Great, thank you. Our next speakers is going to be tag teaming it. We have Leroy Moore who is a board member -- sorry, Leroy Moore, board member of Disability Voices United and also founder of Krip-Hop Nation. Along with him is Judy Mark who is president of Disability Voices United. And she's also a faculty member of UCLA Disability Studies Department.

>> LEROY MOORE: Hello, how’s everybody doing? So, I'm Leroy Franklin Moore Jr., founder of Krip-Hop Nation and board member of Disability Voices United. Also, a journalist with Poor Magazine and also a founder of the National Black Disability Coalition.

>> JUDY MARK: And I am Judy Mark. I am founder and president of Disability Voices United and as well as I teach in the Disability Studies Department at UCLA. Most importantly, I'm a parent of a 22-year-old young man with autism and I live in Los Angeles.

>> LEROY MOORE: Yea, I forgot. I live in Berkeley and am a person with a disability.

>> JUDY MARK: So I'm going to get started just to explain developmental disabilities to folks who may not be familiar with it. Developmental disabilities include people with autism, cerebral palsy, epilepsy and intellectual disabilities. As well as disabilities that are like those, including some rare syndromes that fall under this category.

So the way that people get assistance in the state of California if they have a developmental disability is become eligible for something called a regional center. Regional centers do not serve all people with developmental disabilities. There has to be a certain level of disability in which to receive services. But there are over 330,000 people in the state of California who receive services through regional centers.

There are 21 regional centers throughout the state of California and they're based by geography. There are, for example, 7 in Los Angeles County alone. So they are all over the place. And they are the resource for people with developmental disabilities that often people, children even babies get diagnosed with developmental disabilities at regional centers. And they receive case management over their lifetime and are entitled to services from birth to death.

Regional Centers have contact information for all 330,000 people they serve and I believe will be a great resource for the census.

>> LEROY MOORE: The U.S. Census in 1980 changed my life. Why? Because for the first time, it gave me a picture of Black disabled people in the US. The late Frank Bowe in 1980 did a statistical report drawn from census bureau data looked at Black, Hispanic and women with disabilities for the first time. And these reports, I carried around at school and at my volunteer jobs in disabled non-profits to show the status of Black disabled people.

Since the 1980's I see how important the US census for Black and Brown people with disabilities. And I always wanted to make sure my community will be a part of not only filling out but helping put it together and doing outreach to make sure my community is not only fill it out but understand how the U.S. Census is so important for the community.

2019 is not 1980. With a growing population of Black and Brown elderly and young adults, that they make up a huge percentage of the houseless population because of gentrification and incarceration from schools and prisons pipeline to more cities passing anti-homeless laws like the California Conservatorship law will and have increased Black and Brown poor disabled people being incarcerated and in nursing homes. It's important that the U.S. Census not only reach these populations but include us as workers to spread the U.S. Census to these populations.

Lastly, we all know that the U.S. Census has a huge impact on future funding. As a Black disabled activist who works and has my own nonprofit, this is huge for my Black and Brown disabled community in California to nationally to implement programs with stable funding!

So how can we make sure that the U.S. Census will get to people in congregate settings, such as group homes, institutions, hospitals, etc.? We have to realize that just like the U.S. Presidential election is every four years, the U.S. Census comes around every ten years comes with funding to help pass out and talk about the U.S. Census.

We all know that people with disabilities have the highest rate of unemployment. So it's another way to put money in people with disability's pockets and at the same time to make sure people with disabilities will fill out the census.

Go to the website, www.2020.gov/jobs. How many people with disabilities know about these jobs and the website? Is the website accessible?

My election poll is a nursing home. I think the U.S. Census can make one or more of their local places of distribution can be a hospital lobby, homeless shelter, non-profit, disabled organizations, etc.

The U.S. Census can make paid positions like disability outreach coordinators that would have knowledge of the local disabled community. Also, hooking up with Mayor’s and Governor's Council on Disability. Having an educational campaign a year out on mainstream media and in ethnic newspapers lead by people with disabilities using Frank Bowe’s history with the U.S. Census.

The most important in the above examples of getting the disabled community involved is creating or building on an ongoing trustful relationship with the disabled community with opportunities to be involved with the U.S. Census.

>> JUDY MARK: Thanks. I'm going to give the parents' perspective. So in many cases people with developmental disabilities have intense parent involvement. So it is to ensure that people with developmental disabilities are counted, we have to reach out to the parents as well.

One of the challenges I think that we face is that parents are often unsupported and overwhelmed. And because of that, they're just living sometimes day-to-day, sometimes minute-to-minute in providing the caregiving for their son or daughter with developmental disabilities.

And so I think that we have to acknowledge that and that's something like filling out a census form may not be the highest priority in their day. Making sure that their child doesn’t have a seizure or making sure their child is safe are their priorities for every day that they live. We have to make it easy, we have to encourage them and obviously appeal to them in places where they frequent.

So I think it's important for us to reach out to those communities in which they have trust. That may be school districts, special education, the teachers who teach within special education. It may be therapists and doctors and clinics where they may go. It may also be parent support groups of which there are many. There are autism societies and Down Syndrome associations that are run by parents that are important to do outreach with and get them to buy in to this important work of the census.

And another big piece are the regional centers which I explained at the beginning. Regional centers have the contact information of 330,000 people with developmental disabilities and their family members. And I think it's really important to have them through their regular communication -- most of them communicate regularly with their clients and their clients' families -- and it's really important to have them understand and to be part of this campaign to ensure that every person with a developmental disability is counted. There are 21 regional centers and they do things 21 different ways and have 21 different bureaucracies. So, hence, there's another challenge there.

But I think that they would be open to this and I personally would commit to doing outreach to them.

But one of the things that's really important is that parents often listen more to other parents than they do to professionals in the field. I as a parent, I can tell you some of the best information I got to help my son is from other parents. And so therefore I think it's really critical that we gets to those peer support programs, parent support groups, and that the census becomes part of the everyday discussion that people have in the lives of families.

Now the questions are, you know, “Do you have a good speech therapist?” or “I need a dentist.” These are the questions that are asked. There are so many listservs for parents that we have to make sure that part of that conversation on those listservs is also, “Oh, the census just came out, did everybody fill out their form? If anybody needs some help. Does anybody need any encouragement?”

The other thing is to point out something that Margaret had found in her focus group and that is to keep things in plain language. I think it's important to keep things in plain language not just for people with intellectual or developmental disabilities but for everyone. I'm a big believer in plain language for all people.

If you're straightforward, if your communication is clear on why the census is important, what kinds of services are funded by the count of the census such as special education, regional centers themselves are funded 100% through government funds. So that is critical. Funding for Medi-Cal. These things that pay for behavioral therapy and for speech therapy and occupational therapy and physical therapy, these things are all funded by the census. And I think that we have to use plain language communication with these parents. Some of whom have varying levels of education. Obviously just like every other community represented here, we have a very diverse community of people with developmental disabilities. We have hundreds of languages. And so we have to make sure we're reaching out and making sure that we're in the language that people feel comfortable in.

In addition, I think it's important to understand the immigration concerns of some families. And I'm sure that at the census that's a big issue that people have been talking about in other webinars. But I think it plays a particularly important role for families who have children with developmental disabilities.

So one thing that we should note is that people who are undocumented who have developmental disabilities have a right to services just like any other person with a developmental disability in the state of California. They receive services funded through regional centers. So therefore we have a way to communicate with them. We have the ability to reach out to them.

But families who have either mixed immigration status or are undocumented, face additional fears because in many cases people with developmental disabilities children and adults are really dependent on their families as caregivers. And if one of their caregivers is undocumented and there’s that fear of making themselves known to the government. That fear is compounded when their child has a developmental disability.

I think we're going to figure out how to provide levels of security and comfort for those individuals with mixed immigration family so that we can ensure that this information is kept private and that there is no risk involved in filling out the census.

Finally, just piggybacking on what Leroy said about ensuring that we hire people or people know about jobs who have disabilities. I think hiring parents of people with developmental disabilities is a great way to do that peer-to-peer support. Having someone who’s working on the census who has a child with autism, for example, can go to other parents and say, “Yea, I know, I see it’s a big struggle. My time is very difficult and I'm constantly worried about caregiving. But I made this time, I understand. It just takes a few minutes.” And to really prioritize it.

I think we need to do outreach to a lot of parent organizations when the hiring is conducted to ensure that parents are also hired as well.

>> LEROY MOORE: I want to end that with, you know, it makes sense to hire people with disabilities. We suffer from extraordinarily high unemployment rate and need these jobs. We are great workers. You should want your census workers to truly reflect the community. And also it moves our state toward the inclusion of all kinds.

>> THO VINH BANH: Thank you so much, Leroy and Judy for all those wonderful informations. How many people with developmental disabilities live here in California?

>> JUDY MARK: 330,000 receive services from Regional Centers. Studies have said 800 or 900 thousand total. There’s a whole bunch who don’t use the services.

>> THO VINH BANH: California?

>> JUDY MARK: California alone.

>> THO VINH BANH: Okay. We are fortunate to have our next speaker, Dawniell Zavala. She’s the Associate Director and General Counsel for NorCal MHA, Mental Health America, Program Director for ACCESS California.

>> DAWNIELL ZAVALA: My name is Dawniell Zavala. I am the Associate Director and General Counsel at Mental Health America of Northern California. We go by NorCal MHA. I first want to start off by thanking the organizers for bringing us all together. I feel very honored to be a panelist among these amazing individuals who are out there doing the hard work, representing their communities. So I'm very proud to sit at this table with everyone.

I also want to thank the public participants for tuning in. And, you know, appreciate the interest in this subject matter because it is quite important.

So as I mentioned, my name is Dawniell Zavala. I'm the Associate Director and General Counsel at Mental Health America for Northern California. I'm also the Program Director for a statewide advocacy program of ours called ACCESS California which I’ll talk about a little while later.

So NorCal MHA is a nonprofit organization dedicated to improving the lives of residents in the diverse communities of California. Through advocacy, education, research and culturally relevant peer support services. In all of our programs we work with individuals and families with mental health challenges to promote wellness and recovery, prevention, and improved access to services and support.

So while our agency still has NorCal in our name, we're actually a statewide organization with advocacy and education programs operating throughout California for the better part of a decade.

I'm going to focus a little bit on the statistics of prevalence of mental health disorders amongst California populations. And talk about why that matters in the census and the types of programs that are affected for the individuals who are served in the public mental health system in California.

So according to the Substance Abuse and Mental Health Services Administration or SAMHSA, nearly one in five adults in California reported experiencing a mental illness, which is a diagnosable mental, behavioral or emotional disorder other than a developmental or substance abuse disorder. And this was in fiscal year 2016 to 2017. So during that same year, SAMHSA reports that nearly 4% of adults in the state experienced a serious mental illness which is defined as any mental health disorder resulting in a serious functional impairment.

All evidence indicates the prevalence of both any mental illness and severe mental illness in California, have continued to rise for at least a decade.

To compare SAMHSA’s data for California collected in fiscal years 2008 - 2009 and 2016 - 2017, it also supports this upward trend. The information reveals that the prevalence of serious mental illness among all adults in California rose from 3.2% in fiscal year 08-09 to 3.94%, or nearly 4%, in fiscal year 16-17. The greatest increase was found in young adults ages 18 to 25. This percentage is jumped in fiscal year 08-09 from 3.262% to 6.61% in fiscal year 16-17. So likewise incidence of any mental illness and not just severe mental illness for California adults also rose during this period from 17.44% in fiscal year 08-09 to 18.8% in fiscal year 16-17. Again, with the greatest increase amongst young adults ages 18-25, growing from 18.49% in 08-09 to 24.75% in 16-17.

So California's public mental health system, you might hear me say PMHS as an acronym, primarily serves non-ACA, or Affordable Care Act, Medi-Cal enrollees and indigent populations who lack any form of health insurance. In the 16-17 fiscal year, 6,313,485 California children and 8,220,974 adults were deemed Medi-Cal eligible. Meaning at least 14 million, over 14 million, Californians are eligible for public mental health services.

According to California's Department of Health Care Services, again, sorry another acronym, DHCS, adults and children… nearly 605,000 people, adults and children combined in California receive specialty mental health services in the public mental health system in fiscal year 16-17. So this does not include the 605,000 people, it does not include ACA insured or fee-for-service clients that are also served in the public mental health system.

DHCS predicts the number of Medi-Cal eligible individuals served in the public mental health system will continue to increase in the immediate future. Their forecast for fiscal year 18-19 will be over 686,000 people served in the public mental health system and for 19-20 over 720,000 individuals served in the public mental health system.

So chronic mental illness is highly correlated with poverty, unemployment and homelessness. This is not to mention co-morbidity with other disabilities such as physical health conditions, developmental disabilities, intellectual disabilities and co-occurring disorders where you have a mental health condition co-occurring with an alcohol or substance abuse disorder.

Poverty, first of all. According to SAMHSA’s 2015 national survey of drug use and heath, an estimated 9.8 million adults aged 18 or over in the United States had a serious mental illness, including 2.5 million adults living below the poverty line. Essentially, 25% of individuals living with a severe mental illness are also living below the poverty line.

The relationship between mental illness and poverty is complicated because poverty can intensify the experience of mental illness. It can also increase the likelihood of onset of mental illness. But at the same time, experiencing a severe mental illness can increase the chances of living in poverty.

Unemployment. Again, back to SAMHSA’s statistics. In 2012, among adults served in California’s public mental health system only 10% reported being employed with 15% unemployed and 75% not participating in the labor force. That was in 2012. Unfortunately these statistics are getting worse, not better. So if we fast forward to three years later in 2015, among adults served in California’s public mental health system only 8.3% reported being employed with 12.3% unemployed and 79.4% not participating in the labor force.

Finally, homelessness. Homelessness affects a sizable portion of persons living with serious mental illness. People who have severe mental illness are also at greater risk for homelessness than in the general population. Back in January of 2018, California’s point of time homeless population count revealed that 130,000 individuals were experiencing homelessness in the state at that time, representing a quarter of the entire nation’s homeless population. SAMHSA estimates that 20% to 25% of all homeless populations in the United States live with some form of severe mental illness. If we take those numbers as correct, that means of the 130,000 homeless individuals in California, between 26,000 and 32,500 of them are living with a severe mental illness. So we looked at prevalence of severe mental illness in homelessness population but now What about the prevalence of homelessness in public mental health system client?

A 2005 study of individuals served in the California’s public mental health system, found that 15% were homeless at least once in a one year period. If this finding still holds true, then in fiscal year 16-17 90,731 individuals, or 15% of all those served in the public mental health system were homeless at some point during that year. So since 2016, though, California has experienced a larger increase in homeless than any other state. Nearly 70% of the state's homeless population is unsheltered. Meaning that they're not utilizing temporary living arrangements provided either by charitable organizations or government programs. Rather, they're living on the streets, in parks or other places that are not intended for human habitation.

So given all the data and statistics that I've cited, individuals living with mental health conditions and particularly those living with severe mental illness are highly dependent upon programs that rely on federal funding, such as Medicaid, Section 8 housing vouchers, Supplemental Nutrition Assistance Program or SNAP, state children's health insurance program, supplemental insurance for women, infants and children, special education. Just to name a few. Counting everyone living with chronic mental health conditions especially those who are difficult to find is critical to secure the necessary federal funding to serve California's growing population experiencing both homelessness and severe mental illness.

There are barriers unfortunately, to not just to locating the individuals but also ensuring they're counted. Primarily individuals experiencing mental illness can be hard to locate. As I mentioned, they may be homeless, they may be transient or experience other unstable living conditions. They might be in an inpatient hospitalization clinics both short term and long term. They might be living in a board and care, supported housing, crisis residential or they may be under conservatorship. There are some barriers that are unique also to the mental health community. The first being that a great number of individuals are residing in state prisons and county jails.

So a Stanford University study from 2016 concluded that in the past decade the percentage of state prisoners with mental illness has increased by 77%. The same study found over 30% of California prisoners currently receive treatment for a serious mental disorder which is an increase of 150% since 2000. So in total numbers, in 2016, 37,907 inmates received treatment for a serious mental illness. And it's estimated that these figures are actually lower than the actual numbers and they continue to climb.

Now as far as county jails are concerned in fiscal year 2016-2017, over 76,000 individuals residing in a county jail received mental health services. Many of them involuntary but most of them voluntary outpatient treatment services within the jail system themselves. If you look at both the prison population and the jail population, it's almost 114,000 Californians living with severe mental illness who are incarcerated.

Individuals with severe mental illness are also subject to other involuntary detention. So, going back to the data. In 2016-2017, DHCS reports that 191,346 adults experienced an involuntary detention which could be a 72-hour hold, 14-day intensive treatment, 30-day intensive treatment, 180-day post certification intensive treatment program, okay? Also in fiscal year 16-17 over 7,000 adults in California were under temporary or permanent conservatorship for a serious mental illness.

As with other communities, stigma is a big problem with the mental health community because mental illness is wrongfully associated with violence, criminality, substance abuse, homelessness and obviously NIMBYism pushes people with severe mental illness to the margins of society limiting their public participation and community inclusion.

So that’s from the outside, in. But also, from the inside out, there's a strong mistrust of authority within the mental health consumer culture. Because we have to remember that the consumer movement was founded during the civil rights movement of the 1960’s as a responsive measure to the harsh and uncivil practices… Psychiatric treatments were imposing upon individuals with mental illness. This miss trust of authority stems from being subject to involuntary treatment. Even in voluntary programs there are also compliance conditions that are frequently placed on individuals who are receiving services. For instance, individuals don't want to receive medications, then they get cut off from all over services. There's also a strong incidence of criminalization of behaviors and circumstances that are associated with their illness like anti-camping or anti-homelessness ordinances, law enforcement interaction. This is huge because in most communities in California, someone cannot just walk in and receive crisis mental health services; they either have to go to an ER or they have to be taken to an inpatient treatment unit by law enforcement which is extremely traumatizing.

So some of the solutions that I have and recommendations to ensure that individuals with mental illness are counted are to work with state prisons, county jails, county mental health systems, county conservators in actually locating the individuals who are receiving services within their program.

Also, wellness and recovery centers, community centers, and community engagement campaigns will go a long way. Especially if you are able to locate liaisons from the mental health and also diverse cultural communities to establish trust and credibility and help and support individuals in completing the census.

To locate those individuals, NorCal MHA, my organization, our ACCESS California program has over 20 ACCESS ambassadors. These are all individuals located throughout the state. They all have experience with the public mental health system. They know how it works. Most of them have received services in the public mental health system. And their goal is to engage the community and build advocacy networks within their local to ensure that people are participating in the mental health planning process. So they already have established routes with in the community and they have credibility to establish that trust with individuals receiving services.

You can also rely on connecting with other statewide mental health advocacy organizations. So like NAMI, California Youth Connection, veterans associations, United Parents, and Health Access Foundation. County-designated consumer advocates. Many county mental health systems have individuals who are working within their system who have received services in the system who represent the consumer voice. So they know the community very well and they are able to connect individuals with resources and providers who can help get people to respond to the census. County patient’s rights advocates may be also a good avenue in locating individuals to complete the census. Community mental health workers and local mental health advocacy organizations.

So, Mental Health America has several chapters throughout California and NAMI has numerous chapters throughout many communities in California.

So I appreciate all of that. I thank you for hearing me out. My contact information, should you wish to reach out to me, is my first initial and last name dzavala@norcalmha.org. Or you can call me. My telephone number is 916-366-4600. I will provide a copy of my statement to the organizers. So if individuals are interested in where I found these numbers and what the actual statistics are. I’m going to update my comments and provide that information for dissemination to all of the participants. I may not be around after everyone is presenting because I have to run to another meeting. But again, I really appreciate the opportunity. It is very much an honor to be here today. Thank you so much.

>> THO VINH BANH: Thank you so much Dawniell. And to add onto the list of services that individuals with mental health can benefit from that census data is using includes block grants, community mental health services. It includes supportive housing for people with disabilities, protection and advocacy of individuals with mental illness, supportive employment services to individuals with disabilities. The list goes on and on. I mean, we cannot emphasize enough why people with disabilities matter and we count -- this panel is helping us and helping those who are on this webinar to better and for effectively outreach to the disability community.

We have -- so excited to be able to share with you Christina. Christina Mills is the Executive Director of California Foundation for Independent Living Centers. Before she starts, I want to just make sure that everyone understands she had a big role and her team, Kyla, behind the camera, helping us put this webinar together. So thank you for that. So we are going to close with Christina, and the questions because we have limited time with the panelists, I'm going to concentrate more on the questions for the panelists because the census staff will be available all the time. And you can email the census staff questions related to census outreach. But I would request that questions from the attendees target, actually, the panelists because we have them here today. With that, Christina.

>> CHRISTINA MILLS: This is wonderful. Thank you Tho Vinh. I just want to start by first saying thank you to Tho Vinh and Disability Rights California as well as Yumi and the Complete Count staff who have made todays webinar possible. It's been our pleasure at the California Foundation for Independent Living Centers to work in partnership with both of them, and all of today's panelists to bring you this very informative webinar on how to include people with disabilities across the state of California.

And with that, before I launch into my formal presentation, I do want to point out that we are very fortunate, I feel, in California to be in a state where disability has been prioritized as another underserved community on top of what the federal government had put out to the states, initially. We wouldn't have been able to do that without an appointment of somebody representing the disability community. So again, thank you Tho Vinh for representing our community on the Governor’s Census Committee and making sure that our voices are heard.

While people with disabilities are certainly a part of every diverse, ethnic, religion, gender, group in the world, there are still a number of reasons why our community needs to be separated as its own underserved we community. And the Census is one of those.

I'm happy to be here today. And again, I'm with the California Foundation for Independent Living Centers, CFILC. We are a membership organization that is an association that represents 22 of California's 28 independent living centers.

Independent living centers are advocacy organizations that offer a wide variety of services to people of all ages and all types of disabilities across California.

In addition to being an association for our members, CFILC also provides seven statewide programs that increase independent living options for individuals while building the capacity of our independent living centers as well.

For over five years -- I want to say almost six years, CFILC has been working in collaboration with the California Emerging Technologies Fund and the World Institute on Disability to help close the digital divide for people with disabilities.

Through our Digital Access Project, CFILC has assisted over 3,200 individuals people with disabilities in getting connected to affordable Internet options. However, research indicates that 25% of disabled people still do not have internet access in their own home. Given that the upcoming census, the 2020 census is going to be primarily offered online, and for the first time, affordable Internet access is going to be much more critical part of making sure that people are counted, especially in our community.

CFILC’s Digital Access Project can assist individuals who want and need low-cost Internet in their homes. If you'd like to learn more about that program, please visit our website at DigitalAccessProject.org. Again, it’s www.DigitalAccessProject.org. In addition to Internet access, I'd like to encourage participants to engage with their local disability community partners. Independent Living Centers, Aging and Disability Resource Connection and Traumatic Brain Injury Centers can be disability outreach resources and assist you in creating accessible strategies to reach our community.

These are organizations are known and trusted service providers that can be a wealth of knowledge. Not to mention the fact that independent living centers have been around for 40 years. Of course, I'm going to tend to focus on our centers because that's what I know best. But they are very unique in the sense that we are run by and for people with disabilities. The funding we get to exist requires us to have 51% of our staff as well as our board to be people with disabilities across the span of disability communities.

People with disabilities are defined as hard to reach and underserved for a variety of reasons. Not everyone who has a disability looks “disabled”, but may need additional support when it comes to participating in the census process. Thinking about disability access from the beginning of a process instead of an end will benefit everyone.

When developing outreach strategies, think about how to make your virtual and in-person activities accessible. Something as simple as adding a reasonable accommodation statement such as, “For reasonable accommodations please contact so-and-so.” on your forms or material will let people with disabilities know that you’ve taken access into consideration and are proactively planning for people with disabilities to be included.

Statements like that make us feel invited as well. Of course, that means you also need to know how to offer accommodations and that can be a benefit of partnering with your local disability organization to make that happen.

Today, in fact, our partnership with Disability Rights California and Complete Count through our resources and joined network was able to provide you with the most accessible webinar that you're participating in today.

And the chances are when you make your event or your online virtual activities accessible from the beginning, you're making it more accessible for people that didn't even know that that was something that could be offered. So as an example of that, we work a lot in independent living especially this year with the aging community. And in those efforts we're finding that many people in the aging communities didn't know that they could request large print or that captioning could be something that could be provided. And they're finding that it's very useful and something that they wish they would have known about earlier. So, again, planning for those things in advance helps everyone, not just people with disabilities. Programmatic and physical access is important to all Census related activities. People with disabilities will want to feel like we’re included and we don’t want to feel like we’re an afterthought.

We've heard a lot of panelists speak about specific populations of our community today, but I want to leave you with five tips that will help you move forward in reaching people are disabilities across the lifespan. These are in addition to the local disability organizations that I’ve also encouraged you to partner with.

One. When creating materials, make them readable for a wide audience. Our rule of thumb at CFILC is to try and make our materials no more than a fifth-grade reading level so that anybody can participate and understand what we're saying.

Two. I mentioned this earlier -- but adding that accommodation statement to your website and materials, not to mention making your website accessible from the beginning is also key to being inviting for our community.

Three. Make sure that when you are providing a local activity or event for folks to be a part of, that you understand what the needs of the community are. So, for example, making sure that if you're going to invite people to speak at your event that use wheelchairs, that you have a stage -- you have a ramp for your stage. Or if you’re having one of the biggest misconceptions I see a lot, is folks will speak louder and say “I don't need a microphone” and often don't realize using a microphone is an access piece. And it might mean somebody in the room is hard of hearing or someone in the room isn’t willing to disclose that they’re hard-of-hearing or Deaf, but really rely on that microphone in order to understand what’s happening.

Four. Before you create an online registration form or subscribe to a service such as a webinar platform, today we're using Zoom, make sure it's accessible. Make sure that it can include captioning – that captioning can be embedded like we’re seeing today. And that it’s screen reader accessible. Are the slides accessible as well? When you’re viewing a PowerPoint, make sure that those slides are accessible for the screen reader who’s participating in the webinar too.

Ways to do that are to partner with your disability organizations, many of which who shared valuable information from their specific point of views of today.

Five. When hosting an outside event, outside of your organization or at a community center, make sure that the place is near a bus stop. Many people with disabilities rely on public transportation. Being able to get to a location because it’s near a bus stop, makes it much easier for us to participate. Also make sure that the space has an accessible restroom. Make sure that everyone will have equal access in the seating in the facility will be integrated. Meaning that not everybody with a disability will be pushed off to the side. That often happens for me as a wheelchair user. Wheelchair users will be in the back row and we’ll have a section for a small group of us but we can't get around anywhere else in the conference or the room.

So, making sure that integrated seating is also encompassed in your event.

Again, these are just some of the tips I wanted to bring to you today. There are many more that you can learn by partnering with our local disability organizations, both independent living centers and those that presented here today. Thank you again for inviting CFILC to be part of today’s presentation and I do look forward to partnering with many of you across the state as you reach out to people with disabilities and make sure that we’re counted.

>> THO VINH BANH: Great, thank you so much, Christina. We'll have to give people a moment to get back to their seats. We want to make sure -- we know that included and those who are attending are individuals who are tasked with outreaching to diverse communities including communities of people with disabilities. That said, we want to prioritize those questions so that we can maximize the use of the panelist's knowledge and resources. We also want to let those that are attending know that we're putting together a robust resource list that includes the different disability communities and how the contact information for those diverse organizations.

That said, let's go ahead and open it up for questions. Again, we have Sheri… we’re lucky to have all the panelists we have here today. Sheri has a wealth of knowledge and connections to the Deaf, Deaf/blind, hard-of-hearing communities. So if you have questions related to that community I would welcome those questions. Of course, Margaret and all the knowledge that she’s gained through the toolkit, she knows what messages work, at least for the population that was.. What's the word I'm looking for?

>> MARGARET JAKOBSON-JOHNSON Tested. Surveyed. [ laughter ]

>> THO VINH BANH: So there's a lot of good information that's here around the table. Jeff Thom has been a leader in the Blind communities and has great knowledge around all the issues that may come about. So we want to maximize his knowledge. And, of course, Judy and Leroy with all the years of involvement in the developmental disability communities. Christina and all your knowledge, I mean – protest including, right? Ensure that people with disabilities have rights that they need. We have a lots of resources around the room that I'm encouraging those in attendance to make use of.

The question we have is, “How do you suggest an individual with a physical disability who has limited ability to write or the inability to write, fill out the census material?”

>> CHRISTINA MILLS: This is Christina from CFILC. I think that there's positive and I don't want to say negative but maybe challenges in the fact that the census is going to be offered online for the first time in 2020. And so it's not just going to be about a pen and paper, it's also going to be about computer access.

And through the outreach and census processes that are currently being planned to make sure that folks who don't have computer access have computer access and are able to take it electronically in the future will really make a significant difference for those that have limited dexterity. So even if somebody doesn't have Internet in their home, I know that through my work and research so far with some of my census partners that there's going to be, what I’m referring to as census hub sites where folks that don't have Internet access or don’t have accessibility in their own home to use a computer to do the census online, could go to an organization such as an Independent Living Center that might become a Census hub sites, to use their free equipment and their consumer workstations which majority of them have with software and accessible features to take the census at a hub site rather than individually in their own home or maybe at a facility that doesn’t have height adjustable tables or screen reader software and other forms of technology that will make it more accessible for you to take the Census online.

While we're really pushing for a lot of people to get Internet access and do it independently because we know that that's certainly a choice many of us have, we also want to make sure that when that's not possible because of fixed incomes and, you know, living off of let's say SSI and $920 a month, it's probably really challenging to be able to get Internet in your own home, even at an affordable rate. So in those instances, we really want to make sure that we have partnering organizations that are offering computers and sites where you can come in and get support, whether that be using the computer, doing it in writing, that's some of the services that Independent Living Centers have historically offered and that’s part of what we would consider individual advocacy support.

>> THO VINH BANH: There was a comment that says, “This is the most accessible webinar I’ve ever been part of. Access as well.” So we want to ensure that people with disabilities are counted. There's too much at stake. To ensure that we get the message to as wide an audience as possible we did all we could to make sure this is the most accessible so we could reach as many folks out there as possible.

“What about people under conservatorship? Do they get to be counted? How do we ensure that they are counted?” I know for a fact it is in the Constitution that every body is counted, does not matter. Every person is counted. It doesn’t matter where you are, who you are, documented or undocumented, in prison or out of prison, without or with a disability, conserved or not conserved, transgender or cisgender, everybody is counted. So all questions relating to “Will this person be counted because they are in this institution? Will that person be counted because they’re this particular status?” The answer is always going to be “Yes!” The answer is yes because it's required under the Constitution that everybody be counted.

And we have to give even greater efforts because there's going to be barriers in the way. There's access barriers, attitudinal barriers. With that, if I can have Margaret, if you can share again those messages, I think there were three that resonated the most with people with disabilities. If you can…

>> MARGARET JAKOBSON-JOHNSON: Sure, let me find them again. I don't have them memorized.

The first one was “The 2020 Census, the disability community is counting on you.” The second one was “The 2020 Census and disability -- everyone deserves to be counted.” And the third one was “Why the disability community matters when counting the 2020 Census.” And, again, the hashtag was #DisabilityCounts2020.

>> THO VINH BANH: Excellent. So we've done some work with folks around this table even to make the jobs of those who have been tasked with outreach to diverse communities a lot easier for you. So, for sure we're going to have the PowerPoint that Margaret used to present. We’re also going to have the toolkit that has all the information and all the wealth of knowledge that came from the surveys and testing that’s been done. And of course the resource list that will include everyone’s materials including any speeches that were presented today.

>> JUDY MARK: Do you mind if I just go back to that question about conservatorship real quick? Just because it’s a little obsession of mine. I think what’s important to think about with conservatorship is that many people who are conserved are conserved… well the court conserves them, but the court appointed conservator is a family member. And so we have to reach out to that family member like we would reach out to any family member of a person with a disability. Many of the people who are conserved are people with intellectual disabilities which is why Leroy and I have a lot of concerns about this. The area that I think we have to really focus on are those people who are conserved by professionals or people other than their family members and to ensure that that individual gets counted even if they don't have a family member who's speaking for them.

And I think that there are some ways we can think about that. And I'm really glad the question came up because I hadn't thought about it until the question came up. Because there are obligations of conservators and there are probate courts that work with professional conservators that I think are really important to reach out to, to ensure that the thousands and thousands of people who have professional conservators are counted as well. One of the issues is that we're not sure how seriously they're going to take them as professional conservators. So, next I think there's going to be an education that we’re going to be needing to do with them. Do you have anything you wanted to add?

>> LEROY MOORE: I wanted to add, nothing about the conservatorship, but having an advocate in institutions to deal with incidences. You know, like nursing home and other places that need that push some advocacy to just to do it. Like I said, it like feeds on… you could have a teach-in at the nursing home or at a hospital there could be a way.

>> THO VINH BANH: So Leroy, since we have you, one of the questions that we needs peers from the disability community to be part of the outreach, the training and the actual work for the 2020 Census. Could you share why that would be important and how they could best ensure that they involve peers?

>> LEROY MOORE: Yeah, peers is so important. Like I said, when I saw the U.S. Census in 1980, I saw that report. It looked like the beginning of something. Because of that, I wanted to get involved. It's really important now because our peers can really educate the U.S. Census on how to really build up the trust factor in the disabled community.

>> MARGARET JAKOBSON-JOHNSON: Can I add about conservator?

>> Tho Vinh BANH: Sure, yes. We’ll have Margaret and then Sheri will go next.

>> MARGARET JAKOBSON-JOHNSON: A lot of people with mental health disabilities are also under some conservatorship. I’m not sure who the person that asked the question was. Whether they were talking about people with developmental disabilities or mental health disabilities. Some people on conservatorships are often in facilities or in state hospitals. So, I think that when we’re thinking about how to do that outreach, we need to give you all resources on who to contact generally about reaching out to state hospitals or who generally to reach out to about facilities where people with mental health facilities are living. I like the idea of reaching out to nursing homes as well because there may be people with dementia or other kinds of disabilities that are under conservatorships that might be living in nursing homes on conservatorships as well. So, um, we are trying to put together this resource thing, so I'm thinking another component of that might be giving some resources for people to actually reach out and be able to ensure that those folks are counted as well.

>> THO VINH BANH: What does it mean to be under conservatorship?

>> MARGARET JAKOBSON-JOHNSON: It means your rights are taken away and someone else makes decisions for you. And it also depends on the type of conservatorship, of course.

>> THO VINH BANH: It happens sometimes to individuals with developmental disabilities?

[ Crosstalk ]

>> Judy Mark: It’s very common. Unfortunately too common, but very common.

>> THO VINH BANH: Part of what we're speaking here is to ensure that regardless of whether a person is conserved or not, their right to be counted should not be discounted. We should count everyone and make greater efforts to count individuals who are conserved so that they know that regardless of their status, they are to be counted and can be involved in the process. Alright, Sheri, I want to turn…

>> SHERI FARINHA: Yes, definitely. I just want to also remind people that online is one thing, but it's still -- they do have surveys that are on paper that people can fill out with an individual who can assist them with different documentation such as translation or some people -- and some people are very concerned about the system being hacked.

And as you are aware, that issue regarding the election. So, what's not to say it's going to happen again in the census collection?

People feel that sometimes paper data has a stronger effect, whether that's accurate or not, we're not sure. But it's easier to – Internet for the access for people, we do understand that. The rural areas, quite often they don't have the Internet access. If they do, it's not as reliable. So we have to take that into consideration that regardless of where or who, it is important that there are different ways and different opportunities to make sure that you are counted.

>> THO VINH BANH: Right. This is Tho Vinh speaking. The reason why this panel is so important is that the state doesn’t control the enumeration, the counting process, in giving out the Census. The federal government controls that. Their decision, on their part, to make it electronic is very problematic for many groups, poor communities, language communities, disability communities who we’re speaking about today who may have limited access or no access to Internet. And so the outreach that the state itself has to do in these communities knowing they're going to have those challenges is going to be why -- it's going to be that much more important. We know that it's coming. We know that they're going to lean more towards do it electronically. I think they’re going to try do it… If there's not a response to the electronic process, there's still the paper process. But that’s a second process. That’s not how they’re going to target it first. So it’s going to be a barrier for a lot of our diverse intersectional communities. Someone had stated that they appreciate those distinctions, and whether they can be repeated. Transgendered or sex-gendered… yes. Anyone regarding your status, whether you’re transgendered, whether you’re gay, lesbian, straight, bisexual, questioning, your status still doesn’t matter. Everyone is counted. Whether you're a person with a disability or without, whether you're a parent, a child. Oftentimes who also gets uncounted are children, children and babies.

Everyone is counted, I cannot stress enough. Everyone counts. Regardless of what institutions you're in, if you're homeless, you're counted. If you're housed, you're counted. If you're under a bridge, in a hospital, in prison, in jail, I mean, any institution, under conservatorship, in a group home, in a supported living situation, regardless of any status, any situation, if you live in California, you will be and you should be counted. And the reason why we are all here today is to share what is at stake. There's too much at stake not to be counted. And this information, the data that's going to be used for the census is going to help shape and determine finances and resources and structures where hospitals are going to be built. Where schools are going to be built for the next ten years. And we're not having this again till 2030.

I think, Jeff, you may have -- you were at a point to make.

>> JEFF THOM: Yes, I just want to say that obviously we will -- we hope to have many organizations who would assist people filling out questionnaires for a variety of reasons.

But I think it's important when you perform that function to be a scribe and not to -- not to sort of use that subconscious willingness to suggest what the person with a disability should put on the form. That tends to happen far more than you realize. And, you know, it is not -- it is not intentional oftentimes. It is an effort to help, but it is a misplaced effort. It is the person with the disability's form, not the person who’s filling it out. It's important that person understands that.

>> THO VINH BANH: Thank you for that, Jeff. My understanding is that the federal government is going to be sending folks essentially a letter or a postcard that gives their identifier, and then they go on the website and fill out the census information. So it's not necessarily that they're sending it to you by email.

And one of the questions is in addition to Margaret's research through DREDF and through DRC with the generous funding from the foundation, are there any other that the panelists are aware that research – that documenting an under count of people with disabilities in the centennial census? And if the response is no, that also tells you there is a need.

The fact that the federal government did not designate people with disabilities as a part of count population tells you where we're at. As you can hear from the panelists, there are a lot of issues that may get in the way if not for the appropriate accommodations and group of thoughts to ensure people with disabilities are counted. So for all that are listening in the audience, I would put this out there as, there needs to be greater funding.

Margaret, can you share which foundation it was that provided the funding for the research that DRC and… ?

>> MARGARET JAKOBSON-JOHNSON: Yes, California Community Foundation.

>> THO VINH BANH: So we want to applaud California Community Foundation. We would encourage and challenge other foundations, other organizations, for-profit businesses to ensure that people with disabilities test the survey to see what their needs are to make sure they are counted. So we thank the California Foundation for their leadership and also for their generosity for the funding of the surveys.

>> CHRISTINA MILLS: Can I add something? I know we're close to closing and there's two things that I really think that are important about continuing this conversation after today among us and participants and as the work continues to grow as we hope it does. This webinar will be archived which will learn a bit more about.

But I think it's really important that we continue to use the hashtag #DisabilityCensus2020 to keep this conversation going and to make sure we're holding the census of process and those responsible accountable to making sure that they're including and becoming inclusive of our community through all of the different activities and the events that happen moving forward through 2020.

And secondly, I would be remiss if I did not bring up that the Disability Organizing Network, which is another program of CFILC, is doing community organizing work around census and we have many of our system change advocates from across the state and community organizers participating in today's webinar. I know that many of them have been working hard to partner with their local and regional census, organizations that were recently funded and identified. So I really do hope that all of you do get a chance to connect. And, again, just using that hashtag #DisabilityCounts2020 is going to be essential for us to making sure how our community is continuing to be involved as we move forward.

>> THO VINH BANH: And Christina, thank you for that. We'll make sure to include as part of the resource material, along with the toolkit, along with the PowerPoint. It will be in Word and PDF, along with the resource list. There are two others that want to share. As Christina mentioned, each county has its own census committee. We'll ensure each county's contact info… for those who are attending and want to be involved, we’ll share the contact information of those individuals as well so you can tap into your own county, to be involved. We need more people with disabilities in all facets of this, local, state, and all levels. The more we're visible, the more we’re seen, the more our voices are heard, the more we will be counted.

And the other resource I want to share also is, CPAN. Which is the Census Policy Advocacy Network also produced some materials including factsheets. And we will include that as part of the materials as well. Are there any other materials that we’re aware of that we think would be helpful for those who are reaching out to people with disabilities or want to ensure they count people with disabilities?

>> CHRISTINA MILLS: I’ll just briefly add that, Tho Vinh, you did a wonderful job of collecting a variety of different contact lists from each of us as panelists, I know that I mentioned a number of organizations in my presentation and that will be included in the toolkit that Tho Vinh will be making accessible to all of us. So while I mentioned a lot of them vaguely and broadly, that individual local organizations with contact information will be included in the toolkit.

>> MARGARET JAKOBSON-JOHNSON: Tho Vinh, did you also mention the 2020 census community outreach toolkit? That’s another place to look. I don't know if it's specific to people with disabilities, but it does have good information.

>> THO VINH BANH: Oh, Margaret, please speak about it!

>> MARGARET JAKOBSON-JOHNSON: I think it’s a great additional resource, that's all I know. 2020 Census Community Outreach toolkit. Our toolkit focused on disability and has a link to it. Under additional resources.

>> THO VINH BANH: Okay, great.

>> MARGARET JAKOBSON-JOHNSON: So once you get our toolkit, you’ll have access to that.

>> THO VINH BANH: Excellent. I want to thank the generosity of all the panelists here also who are willing to be the person that can help people connect to different diverse communities. I’ll put myself in the mix. My name is Tho Vinh Banh and my email is: ThoVinh.Banh@disablityrightsca.org. Everyone's been so generous with their time, with their information. The passion to ensure that people with disabilities are counted. I think with that, maybe this might be a nice place for closure. And I know we want to leave a little bit time for Kevin. Thank you Kevin for all your hard work and Laura. Laura and Kevin for all your hard work to ensure that this went smoothly. Kevin, I’m going to turn this to you to for closing remarks. Kevin… are you there?

>> JUDY MARK: Thank you, Tho Vinh. I just want to say that, thank you for organizing and being our voice on the Census Committee.

>> THO VINH BANH: Thank you, I'm more than honored.

>> Kevin: Thank you, everyone, for including today's 2020 Census presentation on Including People with Disabilities. We hoped you found this information presented helpful. And we'll reach out to any of the presenters or organizations mentioned in today's webinar.

Today's webinar will be archived on the Complete Count Disability Organizes Networking and Disability Rights California website within the next 10 for 14 days. Thank you, everybody, for attending and I hope you have a good day. Thank you.