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# Transcript Webinar Training on Expanding California Long Term Services & Supports

**Date:** Friday, August 2, 2019, 12:30 PM – 2:00 PM (PST)

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>> ALLIE CANNINGTON: Hi everyone, um welcome to today's webinar. Um, this is Allie Cannington, uh, I'm the Statewide Community Organizer for The California Foundation for Independent Living Centers. Uh, I have the honor of working with advocates and organizers around the state to advance independent living, and uh disability rights. I run the Disability Organizing Network. Uh, and we are um proud members of the California, uh Aging and Disability Alliance, which you'll hear a little bit more about today. Um, I also uh use...I introduce myself with my gender pronouns, I use she and they pronouns. And I'm so happy that all of you have uh, joined us from uh wherever you are uh, in the state. So why are we here? Uh, we're here because uh, there are more than 8 million, uh people with disabilities and older adults in the state of California who uh, are in...we are like deep, rich, important parts of uh, our our space, our society, our communities. And yet, um still to this day, uh we have...we experience so many barriers regardless of different kinds of disabilities. Um, we experience barriers that prevent us from having the most choice and options for um, having what we need uh to live in the communities and uh, have the jobs, and the families, and the lives that we want. So uh, I just want to, and I'm sure all of you around the state um, joining us today, know about um, the current inequalities that we're facing...people with disabilities and older adults. Um and today, uh you have joined um the Disability Organizing Network, uh and uh and leading...a few other leading grassroots organizations uh, including Hand in Hand: The Domestic Employers Network as well as United Domestic Workers Union, um to uh talk. We're here to talk to you about, uh, some of the efforts that we are um, that we've launched to expand California's Long Term Supports and Services for people with disabilities and older adults. Uh so as you know, um there's more than 8 million of us around the state, and then even more millions of us who have a stake in our lives, uh who are deeply connected to um, the quality of our lives and uh, and you know...the deepest lesson in all of this is that we all need each other in order to, to live the most free um, lives that we want. So um, today's webinar is gonna be a conversation with a dynamic panel of folks that I have the honor of helping to facilitate today. And this panel is going to discuss one of the many um efforts to expand California's Long Term Supports and Services. You will also hear throughout today's webinar the acronym LTSS, and that just means Long Term Supports and Services. And we're going to go into a little bit about what that means in a few minutes. So by the end of today's webinar, we hope that you will learn about the, about what we mean when we say Long Term Supports and Services and how uh, the California Aging and Disability Alliance is working to expand uh, LTSS uh in, across the state. Uh, we also hope that you will... you will take away how the work that we are doing through the California Aging and Disability Alliance, how it connects to the broader efforts, uh to expand LTSS around the state. And lastly, we... we need each other, right? So we're hoping that today will be just the beginning of you joining us. Uh, whether it be joining us through sharing with your community or joining us to tell a story uh or attending our grassroots events around the state. We want to uh, share with you ways that you can plug in. So uh lastly, I want to do um, a few things. One is I want to describe the slide uh that, that is in front of you, if you are logged onto the computer. Uh we describe slides and images to ensure that our community members who uh, are blind or low vision can have access to, equal access to the webinar. So, the first slide that you have in front of you is um, it says Expanding Long Term Supports and Services. There are a variety of images uh that um are under the words, and there's images um that have different people with all kinds of disabilities. Some that you can visibly see, for instance wheelchair users, um as well as some that uh you can't see. So we have um, people also using different forms of um durable medical equipment or assistive technology uh ranging from a computer screen to a car um to a manual wheelchair, um a cane. Uh and then we also have the, the pictures below, um are uh...are the um, are range from people of all ages and all races. And lastly, underneath the photos we have um the logos of the leading grassroots organizations a part of CADA. Uh the California Aging and Disability Alliance. And that, that these are our...the cohosts for today. It's the logo for Disability Organizing Network, Hand in Hand: The Domestic Employers Network, and UDW, uh the United Domestic Workers fighting for workers in our communities AFSCME Local 3930. Uh, we have an amazing panel ahead. Uh it...we have today uh, Christina Mills from the California Foundation for Independent Living Centers. We have Amanda Ream from UDW Home Care Providers Union, AFSCME Local 3930. We have Monique Harris, uh with Hand in Hand: The Domestic Employers Network. And we have Eli Gelardin from the Marin Center for Independent Living. Before we start with Christina, uh who is going to uh give us really a foundation of what we mean when we say and talk about Long Term Services and Supports, or Supports and Services. Uh and, uh we would like everyone to participate in a poll. So, this will help us get an understanding of where folks, how you currently understand LTSS to be. Um, so the poll reads "I believe Long Term Services and Supports include:" and it says "Number 1) Caregiver/Personal Assistant Services 2) Assistive Technology 3) Home Modifications and 4) Care Coordination." So if you can, please fill this poll out and uh, Megan will read the results and then we'll pass it over to Christina Mills.

>> MEGAN COWDELL: Great, thank you Allie. And you guys are quick, the results are coming in. We've got 43, wow, 46 out of 69 people have sent in their answers. I'm going to give you a few more seconds. Okay, I'm going to go ahead and close the poll now. And our results are: the majority of you agree that LTSS includes caregiver and personal assistant services. 94% of you answered that. 90% of attendees answered that LTSS includes care coordination. 77% of attendees indicated that it includes home modifications, and 75% of respondents indicated it includes assistive technology. So I'm going to go ahead and turn it over now to Christina.

>> CHRISTINA MILLS: Hi everyone, thank you and uh, welcome to today's webinar. Again, Allie, thank you for setting the groundwork for today's webinar. And Megan for showing what the results of the poll are. I have to say that um, I'm finding it very useful um, and I think it serves the intention that we expected to see and why we're doing today's presentation on uh, what is Long Term Services and Supports. So, Long Term Services and Supports, um, just a couple of weeks ago I was doing a presentation out in the community and we asked a similar question about uh, whether or not people thought Long Term Services and Supports was more than just care giving or personal assistant services. And uh, a lot of the folks in the room said no, they also believed that that was what LTSS is. And um, I had to challenge them for a moment and said uh, "Do you think that people that need care giving or personal assistants also, or a majority of the time need assistive technology or home modifications, or um maybe Meals on Wheels or care coordination, um, other types of services?". And they said "Yes". And I said, "So why wouldn't that be a part of Long Term Services and supports?", and I think there was a light bulb moment and people realized "you're right, if people need personal assistant services, they likely need some other form of long term services and supports as well". And so um, it brought me to, you know the foundation of what independent living is all about, and that is uh, personal choice and being able to live life as independently uh, as a person wants to. And a lot of that is because folks are choosing um, choosing and navigating the LTSS system to get those needs met. So about two years ago, or I guess a little over two years ago now, um CFILC was one of many, and I think we're now over 3 dozen different organizations a part of the um, California Aging and Disability Alliance. And we came together because, there's a need in California, and there's a need around the country, and fortunately, California is proactively looking for solutions. CADA is one of those groups looking to figure out what are the ways that we can help fill the gaps in long term services and supports for Californians with disabilities and those in the aging community? And quite frankly um, you know, if LTSS expands in the way that we'd like to see it expand, it might also uh provide a lot of services and supports to people in the middle class that don't necessarily have um, a disability or are in the aging population yet, but will be able to benefit from these services, um if we are successful in our community organizing and advocacy. So um, what I should start by saying is that um, there's a lot of myths out there around uh what the purpose of CADA is and what CADA hopes to accomplish. And one of the things that I've heard uh consumers say that I've uh hopefully been able to get them to understand is not true is that we're not trying to limit or um, get rid of In Home Support Services. In Home Support Services is a very critical program to many people with disabilities and the aging community in California and I know personally speaking, um, as a parent with disabilities and children with disabilities, the IHSS program has been very critical to my family. Um, so certainly we don't want to eliminate that, but we want to expand what is available and look at other ways to um, educate folks...the community, policy makers, and everyone as to uh, why LTSS services are so important and what are LTSS services. And so a lot of people will say well my Medicaid or my Medicare, um when you age into that system, covers long term services and supports. And that's another myth. Um, do you consider what Medicare or Medicaid provides as the um, utmost best opportunities for you to uh, be able to access long term services and support needs? Because I know that many people feel like, uh, what they're receiving under those programs is not enough and there's still a lot that needs to be done. In addition to that, uh there's a lot of folks, especially folks with disabilities, who are working that don't qualify for those services. Um, and, there's lots of folks that become disabled or become... age into the community, um, that don't qualify for those services unless they spend down their income. And really what CADA is trying to do is we are trying to figure out what are the LTSS needs in the community for folks who are aging and disabled, but also um, how do we make sure that those services can be available to people not just based on their socioeconomic status? So we want folks that um...I'll take myself as um, an example. If I um, for some reason had to stop working tomorrow and go onto benefits I would have to spend down in order to qualify. Would I then qualify for IHSS? Not necessarily. Um, but I could qualify for maybe some of the Medicaid services available. Now I uh, had been working and uh, making you know, above the um, what do you call it, the uh Social Security Gainful uh, Income Amount for quite some time. And yet, because I have a pre-existing condition, and I also can't purchase a long term care uh benefit for myself and for my needs in the long run, when I retire. Or uh hopefully get to retirement. So, uh I'm sort of one of many people in the community that is stuck between a rock and a hard place. And so we want to make sure that people, whether they work, don't work, um whatever their income level is, that there's LTSS services for an array of purposes and uh for a larger population. And so one of the successes of CADA, uh, just a couple months ago when the state budget was signed, is that we advocated for an actuarial study of 1 million dollars to be passed and signed by the Governor into the budget. And that was, uh, successful advocacy campaign that uh hopefully is going to help us understand what are the LTSS needs, including care giving, home modifications. What are the other services that people need in California that should be covered under a Long Term Services and Supports benefit? So, um. The other things that I want to talk briefly about is CADA isn't the only group really taking on this effort. I'd say that CADA is certainly the primary group uh, working towards figuring out um, maybe what the benefit should be, the structure of the benefit, and how to possibly finance the benefit. We have yet to get to that portion of our uh, campaign at this point. But there's also a lot of other um, stakeholders in the community that are working towards better and more robust Long Term Services and Supports. And some of that effort is being seen through um, what we've now uh, had the Governor put out through the Executive Order on the Master Plan for Aging, and seeing that people with disabilities were included in the language of the Master Plan was very important. Uh, CFILC and a number of other disability organizations played a role in making sure that disability was uh, one of the areas that the Master Plan did cover. Um, the California Collaborative is working towards also uh better LTSS services. So is um, the SCAN Foundation, uh, which held yesterday a briefing in the Capitol on what some of the priorities are uh, from a community, from individual's standpoint around the state and what they would like to see as uh, a better Long Term Services and Supports. And I'm not sure if they've published the survey results online yet, but I'm sure they'll be up shortly. Um it was not entirely surprising to see some of the priorities that individuals, um, consumers around the state really want to see as a part of LTSS, um in the future. Like affordable accessible housing, um those sorts of um opportunities to stay in California and be able to live a quality of life that um, includes dignity and uh, self-direction. Uh, there's a number of organizations that...that are also a part of CADA, I'm not going to go over each one of them, but I also want to point out that uh, the issue of LTSS today, um is so relevant and so important, and that advocacy and community organizing being done on this topic, um, could not be done at a better time. I've not heard in the Capitol, um I've...I've been working in Sacramento for over a decade now and never have I heard so much consistency from legislators and policy makers themselves saying "I don't know how to navigate the LTSS system for my...my parents who are aging and need services". Um or folks that are realizing that um, their children with disabilities are going to grow up and are transitioning, and what LTSS services might they need, or have available to them. So I really do feel like, um now is the time to really make a difference in this subject, and I think that when we see um, both consumers, legislatures, service providers, and organizers...organizers working towards a common goal to expand and provide better and more equipped LTSS uh, for the future. We're headed in the right direction. And I hope that that, uh helped lay the ground work for what we believe Long Term Services and Supports is. And um, I will end with just saying that Independent Living Centers, um have been around for over 40 years, and many of you know that the first Center for Independent Living was established here in California, and many, um, if not all provide LTSS services. So, um, think about what services Independent Living Centers provide and how those systems um, have pro...how those services have helped folks, uh, maybe even some of you, um get the Long Term Services and Supports needed to live in your own community and home. Thank you.

>> ALLIE CANNINGTON: Thank you so much Christina. Uh, this is Allie again. Um, before we turn it over to Amanda Reams, uh from one of our partnering organizations, UDW, uh I just want to kind of summarize, you know, Christina I think that...you know I, I so appreciate you kind of dispelling some of the myths around uh, what we mean when we say Long Term Supports and Services. And for me as someone with multiple disabilities, um both physical disabilities and mental health disabilities, I...I didn't even realize that I rely on LTSS everyday in order to live the life that I have. Uh, and so as an overview, LTSS uh, and how we're envisioning it...it is really anything that people with disabilities and older adults need in order to live in the community and have choice around um, the ways that they want to live their lives. So that in...in summary can range from anything from personal care kind of services, care giving to durable medical equipment, home modifications, care coordination, um uh Meals on Wheels, support with paying bills, uh some com... complex care. Uh, and we think about um even that can range from support with transportation; anything that people need in order to live um in the community uh, with choice. So, with that I also want to say that with CADA, um the California Aging and Disability Alliance, I will share um you know, our members um, the members of CADA range from AARP California, Alzheimer's Association, California Alliance for Retired Americans, um CalPACE, Caring Across Generations, um, the list is long, it's about 20 organizations, and everyone who...who uh registered for this webinar, uh, I will send um uh...key um documents for you to review what CADA is and all of our members. Um, I want to...and of course our members include our co-hosts for today, uh Hand in Hand: The Domestic Employers Network and UDW. So, with that I'm going to pass it over to Amanda Ream with UDW to share how the work of CADA connects to in home supportive services.

>> AMANDA REAM: Alright, so thank you so much for inviting me to be part of this important webinar. Um, my name is Amanda Ream, and I'm the Research Director from the United Domestic Workers Union. We're a union that represents 100,000 caregivers, providers of IHSS services in California. And I'm going to speak briefly about the status of the IHSS Program right now in the state of California. Um, the primary uh goal of our union is to strengthen and expand the IHSS Program. We were part of the founding of the program, um, and I can say that it's um... when you travel the country talking about LTSS, all around the country people say "I'd like to have a program like IHSS". So we're very proud of it, we're very proud of um, what's offered in the program, and we know a lot needs to improve. We're part of the process of constantly trying to strengthen and improve the program. So, top item for us is securing consistent stable funding for the program. So I know many of the people who are participating today have been part of um, efforts to fight for year after year stable funding for the IHSS Program. We had an important victory this year with Governor Newsom. Governor Newsom restored the 7% cut to IHSS. There was a 7% cut, and he committed to restore those funds to the program. But this is a temporary fix. And I want to speak briefly about what the, uh, program looks like right now. And why Governor Newsom, we think, agreed only to a temporary fix. IHSS is a program that has grown dramatically since it was first started. Um, it's grown more than 30% in the last 10 years and we're expecting the program to double. Why will the IHSS program double, both in the number of people who participate in the program and in the cost of the program? It's because our state is facing a boom in the number of people who are becoming 65 and older. Uh, the number of seniors in our state uh, is expected to double by 2030. And so that means we have many more people facing aging in place, uh facing conditions... health conditions and other conditions where they want to access in home care. They want to access the IHSS Program. Now something that's a particular dynamic that we're trying to address with our policy efforts is there are many people in the state who uh, don't have the means to plan for that last year of their life when most of us need access to home care, so they end up spending down their resources. They end up taking whatever money they have and having to spend it down so that they can become eligible for the IHSS Program. Now of course we believe that IHSS and in home care should be available to everyone, but we're concerned about this group of people who might be able to afford some care, um for that year, two or three years that they might need towards the end of their life that by entering the IHSS Program, that's expanding the cost of the program. It's one of the fastest growing parts of the Medicaid Medi-Cal budget, and we want to address that group of people and provide more options for them. So while we know we need IHSS to be strengthened, and we need LTSS Supports and Services to be available to more people, we're specifically targeting coming up with a solution for that group of people who may be able to afford the access to some care, but right now, there's really no option for them to do so expect to take whatever resources they have and spend them down. So one of the goals of our work is to bring together the aging community and the disability community to take a hard look at the IHSS Program to protect the IHSS Program by creating more access to services for more people to alleviate some of those pressures that are being created on the IHSS program as we look to the next 10, 20, 30 years. We really want to stabilize the program. We really want to expand the program, and we want to make sure that its here to stay. And one of the chief ways that we think we can do that is by creating access to long term supports and services for more people. So the IHSS program doesn't end up being the last resort for so many people. So I hope that was helpful and I know we're going to have questions later, but I'll turn it back over to Allie.

>> ALLIE CANNINGTON: Thank you so much, Amanda. Um, this is Allie again. Um I just want to go ahead, I'm going to describe your slide. Uh so the slide that uh, that Amanda was speaking um, about, is right in front on you and it has a um, a graph that um, a line graph that shows the growth of IHSS in uh, the past 20 years. And it says IHSS caseload has steadily increased over the past 20 years. Uh, there's also next to the graph, there are two statements. One is "IHSS is one of the fastest growing programs in the state and will likely double with the aging boom". And then below that it says "Governor Newsom restored the 7% cut to IHSS for next year. But as the fastest growing budget item in Medi-Cal, IHSS is likely to be targeted for cuts in the years ahead". So, and then below that, it says "Stop the Spend Down, Create Access to LTSS for the Middle Class". And UDW's logo is right next to that. Um now uh, thank you so much Amanda. We're going to, um, move to our next panelist, um, Monique Harris, who is representing Hand in Hand: The Domestic Employers Network, another really incredible partner with the grassroots, um work related to CADA uh and this effort. And so, uh I'm going to pass it over to Monique and uh Lindsay is going to be re-voicing. So uh, I will um, pass it along to you all and then I hope as everyone is sharing, um, all of the attendees, all of you are thinking about questions, uh, so that we can have uh, a dialogue after Monique and then Eli shares. Thank you.

[Monique Harris Speaking]

>> MONIQUE HARRIS (LINDSAY); Hello! At Hand in Hand, we believe that we have more to gain and can get much more done when people with disabilities, seniors, and unions and the broader worker community join together towards the common goals that we have for affordable LTSS that has fair conditions for workers.

[Monique Harris Speaking]

When we don't let politicians divide us, we are more powerful in our unity.

[Monique Harris Speaking]

So for example, in 2014 when senior and disability groups joined UDW and SEIU with the same demand, we were successful in pushing back against Governor Brown's um, cap on IHSS worker hours. And, in 2016, The California Domestic Workers Coalition with the support of senior and disability groups, UDW and other organizations, won the permanent right to overtime pay for private pay domestic workers, ending a racist and sexist exclusion.

[Monique Harris Speaking]

There will be those who will say that worker's rights and fair pay can only happen at the expense of seniors, people with disabilities, and our families. Or that we can only achieve accessible and affordable LTSS by keeping worker's wages low.

[Monique Harris Speaking]

But we all deserve an LTSS system that benefits us all. The worker and the consumer, and we can achieve it when we work together.

[Monique Harris Speaking]

And that is why I am, and Hand in Hand is excited to be working in partnership for an LTSS system where everyone can have their needs met, while workers are paid well and treated fairly. Thank you.

>> LINDSAY IMAI HONG: So what is being shown is a photo from I believe the 2014, uh, at the time Disability Capitol Action Day. And it shows, um, a lot of different kinds of people holding up signs and banners. Um, in fact Monique Harris who is speaking right now is in the lefthand corner, and includes uh, folks with disabilities, um older adults, members of various organizations and the California Domestic Workers Coalition, uh shows a banner from Senior Disability Action from San Francisco, Mujeres Unidas y Activas, and um um, there's different signs that have been written on, and one says "Unity makes us stronger", and the other one says the same thing in Spanish, La unidad nos hace más fuertes. Thank you. Thank you very much.

>> ALLIE CANNINGTON: Thank you so much, uh Monique uh and Lindsay, uh for um, just kind of also grounding us that in order to find solutions to expanding Long Term Supports and Services for our communities, we are...we have to be working with all of those who have a stake in this, including um, the workers and um. And it's just...I, as a disability advocate and organizer, I'm just so excited for our continued effort to look at these issues um, in partnerships and cause...we really do, um, depend on one another to have the kind of world that we want to see. Which is one where all of us, um have, um the pay that we need to live the lives that we, um, deserve as well as the care and support and services that we all need. Uh, so with that, um we're going to hear from Eli Gelardin now um, from the Marin Center for Independent Living uh and through CFILC uh has been active with CADA um in really, you know, looking at uh CADA's approach to um one piece of the puzzle that can help to provide more options, uh, more LTSS options for Californians with disabilities and Californians who are aging. Uh, so I will pass it over to Eli now who will, uh walk us through those steps and then we will launch into Q&A. Thank you.

>> ELI GELARDIN: Thank you Allie. Uh, hi everyone. Uh, so my task is gonna kind of give a deeper dive into uh, the California Aging and Disability Alliance's policy framework. And essentially, the analogy I'm going to use is how we're going to build this brand spanking new awesome accessible affordable home. Um, so...so when you're starting to build a home, you need to start with the foundation. And the foundation of this home is SB 512, which is the bill that will create the framework for our new long term service and supports benefit. It's a two year bill, uh, currently it's gone through the senate and I believe it's in the assembly um appropriations. Uh and we are going to continue to advocate it to move through the assembly and hopefully eventually get to the Governor's desk. Uh the bill, essentially calls for a new LTSS program financed by a sustainable funding source. It includes establishing a nine member, uh, committee that will provide ongoing advice and recommendations to the LTSS Board until January 1st 2025. This is what we're referring to as the LTSS Advisory Committee. Then as...as this bill moves forward and as we develop you know, the foundation is solid, we're establishing the LTSS Benefits Board, which is going to be a 10 member board that will implement and oversee the new program and manage and invest revenue deposited into the trust. And this will be created in the state treasury upon appropriations and finance long term services and supports for eligible individuals in the LTSS Benefits Trust. Now these are a lot of, um you know, complex concepts that I have a challenge uh, wrapping my head around. But again, using the uh house building analysis, you know we need to start with the foundation. We need to understand what the cost of building this home is going to be, and that's the, um appropriations we made for an actuarial study, which will determine exactly you know, what the scope of this LTSS benefit will look like. You know, what is the age of eligibility, um...support it will provide based on activities of daily living. Uh, will there be...you know. Essentially what is the determination process, and then, what will you know, this cash benefit um look like, uh in terms of daily benefit and the scope of uh LTSS services it will cover. And the LTSS Advisory Committee, um and then the LTSS Benefits Board will provide the foundation and oversight to craft this benefit, um, and and hopefully uh as we all anticipate, it will be in place. I'd like to talk a little bit about the time frame. Um so, 2019-2020, uh we would the actuarial study will provide guidance on the benefit: eligibility criteria, program costs. And then the legislative proposal, SB 512, as we discussed, will create the framework for the program and implementation. Between 2021 and 2022, anticipated legislation will define the program and benefit and design of the departmental oversight. And we anticipate an ongoing program design and finances. And then between 2023 and 2025, we anticipate to implement the program. Now this is, you know, a high level overview and there are a lot of elements that are going to drive um both SB 512 and the actuarial study. Uh, but essentially kind of using the housing analogy. We want to start with a solid foundation, understand our costs, and then use those two tools, which is the actuarial study and SB 512 to build the framing of our home. To build the roof, and eventually we'll have a brand spanking new accessible and affordable home by 2025. Um, so yeah. I think that covers it.

>> ALLIE CANNINGTON: Thank you so much Eli. Um, this is Allie again. And uh, I just want to also thank uh, SEIU Local 2015 uh for uh their, these two slides, um that were created um from them. So I want to give one of the CADA members a shout out. Uh and um, Eli thank you for guiding us through um this framework that will help to create one of the many solutions that, that, California needs uh in order to create more options for uh people with disabilities and older adults to afford and access Long Term Supports and Services. So, I know there was a lot of information that was just shared, and what um, what we hope, um, you know Hand in Hand uh UDW and Disability Organizing Network, is that we can have, you know, this can be just the beginning of understanding how the policy framework in Sacramento can connect to uh, our lives on the ground. Um and how in order to really figure out how we can have more access to what we need, we need to hear from um, the experts on the ground, which are people with disabilities and older adults and workers who are living um you know, the current um barriers and inequalities on a daily basis. So with that, uh I...we're going to open it up for Q&A, and so I'm going to pass it over to Megan, uh to help logistically and then uh, the panelists will be um answering the questions. Uh and, I will kind of determine what panelist may make the most sense for answering the question, but panelists please feel free to um, chime in. And uh and, so let's get started. And then at the end, um, at about uh 1:45 - 1:50 uh, I will uh be able to share with all of you ways that you and your network can plug in. Because the only way that we can create um new, more options for all of us is by um utilizing the power of um, our communities on the ground. Uh so, Megan take it away.

>> MEGAN COWDELL: Great, thank you Allie and thank you to everyone that's been on our panel. Just a reminder, you guys can send questions to us through the Q&A Box, through the chat feature, or you can also raise your hand, uh, selecting the raise hand button or dialing \*9 if you'd like to uh, verbalize a question. Our first question um, I think is for you Allie, it says "Hi, my name is Eric. I'm wondering if we'll receive a certificate of attendance for today's webinar?".

>> ALLIE CANNINGTON: Hi Eric, um yeah, we can, no problem. Um, I'm happy to uh you know, develop some, a certificate for your attendance. Uh, if you could um please uh, in....if you could, I'm just thinking on the fly here, um...if you want to email me, uh and anyone is welcome to email me, but particularly you Eric, if you want to email me, [allie@cfilc.org](mailto:allie@cfilc.org). Thank you Megan for putting it in the chat box. Uh and we can for sure get you, um, a proof certificate that you attended this webinar. So thank you.

>> MEGAN COWDELL: Perfect! We have a few questions regarding uh CADA. Um, I know somebody asked how many members are in CADA, I'm going to go ahead and share that list in the chat. Uh, but we also have a question asking "Can CBOs or organizations like an ILC become a member of CADA?".

>> ALLIE CANNINGTON: Um, I will. This is Allie. Uh, I will pass it over uh to Christina.

>> CHRISTINA MILLS: Hi. Uh, that's a great question. But I'm actually not sure about the answer. In reviewing the list of coalition partners, they are all statewide organizations that represent uh local entities. So I'm just not sure um, but I can certainly find out and uh get that person back that information.

>> ALLIE CANNINGTON: Thank you so much, Christina. I appreciate that. Yeah. I, and I can make sure that um that that information, that we go back to um CADA and determine that answer, and then uh we will get back to that person. Thank you.

>> MEGAN COWDELL: Great. Um it looks like in our Q&A box, Caroline wants to know uh, "What is the senate bill again? And is it in California or Federal?".

>> ALLIE CANNINGTON: I will uh, pass it over uh, to Eli.

>> ELI GELARDIN: Hi! So, it's senate bill 512, uh it's the Cal...in the California legislature and I believe is currently over in uh the assembly, so it's gone through the senate. It's in the assembly. Uh, in appropriations. It's a two-year bill. And um if you Google uh, California Legislative Tracker, you can follow the um, process that the bill is taking. So uh, I would check out that link as well.

>> MEGAN COWDELL: Great, thank you Eli and Allie. Um, we have another question it's about the graph that was on the UDW slide. Um and they want to know "It, it looks like from 2012 to 2013, there was a decrease in California's IHSS caseload, do you know the reason for this decrease?"

>> AMANDA REAM: I do, yeah. This is Amanda from UDW. And, I just checked in on this, and it's because unfortunately the state began requiring a letter from a doctor. So, that certification meant that many people who had been eligible for IHSS and needed IHSS were then not able to get it. Um, when we asked the state the reason for this, they said it was an anti-fraud policy. So needless to say, this is something that we're pushing back against and we don't agree with. But I wanted everyone to have the information.

>> MEGAN COWDELL: Great, thank you Amanda. Um, we have another question here from Brenda. "Where will the money come from to fund these services?"

>> ALLIE CANNINGTON: Uh, so I. This is Allie. Um, I will uh pass it over uh to uh Amanda. Do you want to answer that and then Eli if there's anything else to add?

>> AMANDA REAM: Well we're lucky. This is Amanda from UDW. We're lucky that there was just a major victory in Washington state which took, it was many years in the making, but it took two years in the legislature where they passed an LTSS Benefit. Uh, Hawaii and Washington are the two states that have a benefit. And uh that in Washington state is funded with a payroll tax. We think to be successful, the benefit needs to be universal, which means it needs to be funded by everybody and eligible for everybody. Our eligibility needs to be opened to everybody. So those are the principles that we're working with right now.

>> ALLIE CANNINGTON: And Eli, would you like to add anything to that? Thank you, Amanda.

>> ELI GELARDIN: I, I think Amanda covered it. And, you know I would just, I guess the only thing I would add is you know, as as part of the building of the house, that is something we have to determine. And you know, as we move forward um it might be one source of funding, it might be multiple sources. Um, it will also depend on cost and that's why we want to really drill down and get solid data behind the actuarial study. So it can inform us on what revenues will be required to support this.

>> MEGAN COWDELL: Great, thank you guys. Our next question is "Will age be a factor regarding eligibility to receive resources funded by the LTSS Benefits Trust?"

>> ALLIE CANNINGTON: This is Allie. Um, Eli, do you want to uh elaborate on where we're at right now in relation to that question?

>> ELI GELARDIN: Sure, thank you Allie. Um, so, great question. You know we, currently we have a work group, a mechanics work group in CADA whose kind of looking at the um eligibility criteria and options for the actuarial study to look at. And yes, age um is one of the components uh that uh is being looked at. So are activities of daily living, um investing period and other components. And essentially we won't know till the numbers come in. Um, but uh you know, we're looking at a variety of different options and what costs will be related to let's call it the most generous plan, versus uh one that's more narrow. Um, and and determine comparing costs across the spectrum. Uh, between those two polar ends.

>> MEGAN COWDELL: Great, thank you Eli. Uh, our next question here is "Will these slides be available as a PDF after the webinar?".

>> ALLIE CANNINGTON: Uh, thank you. This is Allie. Um we yes, we can make them available uh and I'll just have to make sure um that uh the...all of the slides are accessible. Um, so that may um, we may need in to next week to send them out, but I will make sure that they are available. And in addition, this webinar will be um, archived uh on the Disability Organizing Network uh website. Uh and so I hope that um, that you all uh can share this archived webinar with your network uh when it is available. And I can make sure that uh, a notice is sent to all attendees when the uh webinar is uh up and live in it's archived form.

>> MEGAN COWDELL: Great, thank you guys. Thanks for all the questions. We have quite a few more to get through. Um, this one says "Can you comment on the complication of IHSS recipients with cognitive impairments? Particularly ones who are isolated and or at high risk for abuse or neglect".

>> ALLIE CANNINGTON: So um, this is Allie. Um I, I think. Thank you so much, that is such an important question. Um, I'm sure that we could probably spend hours and days talking about that. Um I'm wondering if um, Amanda, would want to touch on that briefly. Uh, and then anyone else um if you have additional comments.

>> AMANDA REAM: Yes. Um, this is Amanda from UDW. Um. I'm a policy person for a union, so I don't have a lot of expertise in this question. But I will say in working on the policy committee for this effort, that um one of the ways that we've been looking at how the benefit would potentially operate is we've been looking at like what is the IHSS standard around ADLs and IDLs, and we know that we need to increase um, services that are available around cognitive disabilities. So you can see in the list of organizations that are part of CADA, in particular the Alzheimer's Association and a number of other groups have been uh bringing a high level of expertise to the conversation. So that's what I know I can say about it. Definitely still learning about how to address the issues that you're raising.

>> CHRISTINA MILLS: Uh, this is Christina. This is certainly um, a very critical and important topic. And it's coming up in a variety of different venues recently. Um, if if you're not aware or a part of the uh Silence Equals Violence Network, a coalition of uh both state and nonprofit organizations working on subjects like abuse and neglect, I would encourage you to join and you're welcome to reach out to myself to get information about that. Those meetings are held um at CFILC at our office in Sacramento quarterly. Um, and we are one of the partners among many others at that table. Um, the other thing that I think um, I think some of us should consider exploring around this topic is how are we holding the managed care organizations accountable for some additional supports and services they might be able to provide, or, frankly, should be um providing in uh partnership and collaboration with those in the community that are providing or know how to provide services to those with cognitive or um intellectual or developmental disabilities that need this level of uh service and um self-management type coordinated care. Um, I would certainly like to see that be something of discussion by the state, possibly when the next managed care organization RFP goes out. Um, but again, you're welcome to contact me if you want to learn more about Silence Equals Violence as well.

>> ALLIE CANNINGTON: Thank you, Christina. Uh, this is Allie again. I just want to add, you know, um I. First of all, just for acronyms, RFP stands for Request for Proposal. Um and uh, I know that and if there's any other acronyms that we've said uh, please um type in the chat box. Let us know so that we can make sure that we're all on the same page. Uh, in terms of raising kind of the, the particular um communities that have been mentioned, uh including the intellectual and developmental disabilities community, it is so essential that as we elevate the stories of people on the ground experiencing inequalities related to LTSS, that we hear from our community members with all kinds of different disabilities including intellectual and developmental disabilities. And so I'm really excited for you know, in addition to the Alzheimer's Association that is uh a member of CADA, we also have the ARC of California which is also a member uh and so, uh with the grassroots work that we want to invite all of you into, I really want to encourage us to think about who are the people in our lives, who are the leaders who um, and the everyday folks who uh, live with different disabilities who use LTSS or need more access to it and...and that, you know, and that those individuals, how can we support them in sharing their story? Uh so that those decision makers uh and entities that um, you know, can help to create solutions uh, that they can be told um our truths. So that we, so our truths can then inform uh, how these, how this benefit and other services that exist um truly um, can can support our community. Back to you, Megan.

>> MEGAN COWDELL: Great, thank you guys. Uh, so our next question us is "Can you share the statistics of how many years do most people need LTSS?".

>> AMANDA REAM: Allie, I can answer that. This is Amanda. Is that okay?

>> ALLIE CANNINGTON: Please, go for it. Thanks, Amanda!

>> AMANDA REAM: Um, that's a, that question is very broad, but I'll answer for the aging community for older adults. Um, the statistics is most people, more than 75% of people, will need access to at least one year of home care at the end of their lives. So that's the most sort of universal statistic that we use around aging. There are many many statistics for the other communities that are a part of the CADA effort. Um, so I'll go back to Allie to see if anyone else has anything to add.

>> ALLIE CANNINGTON: Thanks Amanda. Um. Christina, would you like to go ahead and share a little bit? I know I have thoughts um, from the community organizing perspective, but um, Christina or Monique or Eli, um, as it pertains to the disability community.

>> CHRISTINA MILLS: This is Christina. I'd love to give Monique an opportunity, um, to reflect on, on that. Um, and while she's putting together her thoughts, maybe Allie you could give your organizing perspective on it.

>> ALLIE CANNINGTON: Sure. So, um my. So my answer is that I think it depends on uh you know, so the question again was uh "How many, how many, what's the average number of years", I believe? Was that correct, Megan? That people need LTSS?

>> MEGAN COWDELL: Yes, that's correct.

>> ALLIE CANNINGTON: Okay. So, so I think for people with disabilities, um it depends on uh, it depends on the type of disability. But uh for uh, people who have their disabilities um when, from birth, uh, they could need LTSS uh, everyday for their whole life. Um uh, that. You know, I can speak for myself. Um, as someone who needs a wheelchair, so I need durable medical equipment, um I also for a number of years have needed um, long term mental healthcare. Uh and those are, those are LTSS services that I need. So, for instance, durable medical equipment has been something I've needed all my life. Uh and um, and then for my mental healthcare, that's been long term, uh it has been, you know, for the past twelve years. Um, so I think, with that being said, as we think about from a community organizing perspective, it is so essential that uh, that we get the spectrum of stories. Um, about not only what LTSS is, um, but also, uh the different kinds of LTSS and the levels of um, time. The different time lengths that people use them. Which is again why, um, the grassroots efforts that we are doing um and about to really full on launch through CADA, um and through our organizations. It's the diverse stories of LTSS, um, that will paint the picture of uh, of how LTSS is used for kids up until, and then, for their whole lives, it could happen at middle age with acquiring disabilities. Or it could be the last few years of peoples lives, like Amanda shared um around our aging community. Uh so uh, Monique and uh anyone else but Monique, do you have any thoughts that you would like to share?

[Monique Harris Speaking]

>> MONIQUE HARRIS (LINDSAY): Yes, Lindsay is going to say what I said. So we were just talking in the room here while you were talking and agree with what we've heard. Uh, but Monique wanted to add just from her personal experience, that her mother needs um, support in the home and is going to live...and need it a lot longer than just one year.

[Monique Harris Speaking]

Because she has cancer.

[Monique Harris Speaking]

And she has other friends who have cancer who need attendant care.

[Monique Harris Speaking]

So similar to what you were saying Allie, it really is going to vary based upon different individuals. Thanks.

>> ELI GELARDIN: This is Eli. Uh, I would just add a couple things, which is I think one of the real um, values and dynamic components of exploring this Long Term Services and Supports Benefit and the work that CADA, uh California Aging and Disability Alliance has embarked on is that it's giving the aging and disability uh, and workforce communities an opportunity to define or redefine these very kind of complex and broad topics. What does Long Term Services and Supports mean? What are activities of daily living? You know, traditionally we think of activities of daily living as, you know, kind of those basic um domestic activities like eating, bathing, dressing, toileting, and so on. Um, that support you in the home. But you know, when we talk about community activities of daily living, uh, we're going outside the home. You know, what does it take to pursue and maintain employment, um or vocational training? Uh, arranging and accessing public transportation. Um, keeping your and following through on your healthcare appointments. Participating in you know, social activities. I think some of the dynamic and and, what I find really exciting components of this work is that it's allowing us to have these broader discussions on you know defining, not just what this benefit will uh ultimately look like, but what are we talking about when we say Long Term Services and Support or activities of daily living.

>> ALLIE CANNINGTON: Thank you so much, Eli and Monique and everyone who shared. Uh, back to you Megan.

>> MEGAN COWDELL: Great, thank you Allie. Uh, we have a question here, it says "Is loneliness part of the current LTSS services? And if not, is there a plan to include it?".

>> ALLIE CANNINGTON: This is Allie. Um, I, thank you so much for that question. Uh, I...I definitely have some thoughts, but I would like to throw it out to any of the panelists who uh, would like to answer a piece of that question. Is loneliness part of the current LTSS services? And if not. Is there a plan to include it?

>> CHRISTINA MILLS: This is Christina from CFILC. Um, I haven't heard this specific topic come up under LTSS, um, in our SB 512 conversations. But that's not to say that it's not relevant and could be. I just don't think we're at a point yet of determining, um, how it would be covered and in what mechanism. What I will say though is it is certainly coming up, um, repeatedly in the discussions around um, the Master Plan, and how the Master Plan will create opportunities to decrease isolation and loneliness. And um, as a member of the California Collaborative Master Plan work group member, this is something that we've spent some time talking about. And um, what we're going to be asking of the, um, Master Plan Advisory Committee that the administration is uh, putting together. So thank you for bringing that question up, and it's certainly coming up in other um, other conversations, but not necessarily in the 512 conversation quite yet.

>> ELI GELARDIN: Yeah, this is Eli. Uh, I would just add that you know, if you look at some of the components of uh, personal assistance or adult day health center services, um, uh, there are LTSS, you know, community based organizations and programs that really do touch on social isolation and the social determinants of health. Independent Living Centers, another one obviously. Um, so so while you know, we're in the early stages again of kind of building you know, this house and this foundation, I think looking at all of the social determinants of health and what it takes to support people in living safely and high quality lives in the community, definitely social isolation is a touch point across many of the LTSS services. Um, and you know, and intervention.

>> CHRISTINA MILLS: I just want to quickly add, but Eli said it, if you're not familiar with your local independent living center, I would encourage you to touch bases with them. Um, for their peer support services. And you might also find out during that um, meeting and process from your peers in that area what other services might be available to help prevent or limit loneliness and isolation and there's a lot of other services. Um, you know, community by community, it's a little bit different and eligibility might be a factor as well. But I think if you are in touch with your local ILC, they will also provide you some additional resources in that area.

>> ALLIE CANNINGTON: Thank you so much. And I just um, anyone else um, Monique did you also want to speak to, to this at all? If not, feel free to. Okay. It says no, Monique doesn't have anything to add. Alright well um, let's see if we have any other. I actually also see a comment here that I wanted to speak to. Um, that uh you know. Regarding the question around loneliness, I've heard this individual has said: "I've heard so many folks, so many Meals on Wheels folks, say that the visit is just as if not more needed than the meal." Um, and I think that when we. From the policy level down to the grassroots, when we think about um LTSS uh, it may not be explicitly uh, to um, meet the need of, of loneliness, but uh, but, in order, but for example, having access to Meals on Wheels, or having access to um durable medical equipment or home modification, that um creates a door to then um, have more access to community living, which inherently means uh, more access to connection. Uh, to relationship building. Us, so I just wanted to also share that piece. And then let's take um, one more question Megan, and then we'll move to uh, uh the um how folks can get involved.

>> MEGAN COWDELL: Great, thank you. Our last question here comes from David. Um, and he wants to know "Are spousal impoverishment rules, uh rules that allow IHSS applicants income and resources to be allocated to a community spouse so that the IHSS applicant can meet income and resource requirements still in effect? I've heard there might be a sunset date."

>> ALLIE CANNINGTON: This is Allie. Um, Amanda, are you able uh to touch on that?

>> AMANDA REAM: I you know. This is Amanda from UDW. That uh, I'm working on uh federally, we're working on this. Spousal Retirement eligibility issues around the IHSS program. Uh, for family caregivers. Um, but I can have. Megan, if you don't mind, if you could just email me that question, and I can get the answer for you on it. Thank you for that question.

>> ALLIE CANNINGTON: Alright, um. Thank you so much, uh, and I am just going to make sure that everyone can see. Okay. So, we are already almost at two o'clock. Uh, which means that uh, I want to thank each and every one of you for joining us today. Um, and for our panelists. Uh, Christina Mills, uh Monique Harris, Amanda Ream, and uh Eli Gerlardin. Uh, and of course Megan. Uh, for facilitating uh, the the um the logistics of Zoom and the, of course our captioner. Um, access is essential to um, all of the activities um that we do. So now what? Uh, we're here today because we wanted to connect you to the policy...we wanted to connect the policy to the grassroots. Uh because the real change um that we want to see in the world has to happen with us. So what now? We need each other, we need our stories, our relationships with other people with disabilities or folks living with chronic illnesses. However you identify. Folks who are aging. And then we need our collective, our communities. So the grassroots committee of the California Aging and Disability Alliance um, UDW, uh Disability Organizing Network, um and Hand in Hand and Caring Across Generations, and some of our other partners. We are um, launching a campaign that is really to elevate the stories of LTSS and the inequalities that exist. So that we can educate and inform the media, um our policy makers, decision makers, uh around the state. And so there's a few ways that you can do that. One way is, we need our stories. We need LTSS stories, um whether it be your own story or someone you care about who has had to either um, you know, spend down, spend all of their money in order to be on Medi-Cal to access um, what uh you need. Or that you are you know, deeply struggling right now um to afford the access um to afford and access the LTSS that you need. There's different stories that we need to elevate around the state uh and, we'd like you to join us. Uh, the other way that you can get involved, um, which connects to storytelling is uh, we will be hosting a series of Long Term Supports and Services uh, for expanding LTSS for all town halls around the state. Uh, there will be um, two in September and more down the line. Everyone who is on this, who has joined us today, you will receive an email with the details of the, of these town halls. The first one will be on September 16th uh in Valley Village California in the San Fernando Valley. And uh, the the after that on September 19th, we'll be uh a LTSS town hall in San Francisco. Uh, I also wanted to say that we are launching um, this element of the campaign to create more options for LTSS and we are um calling it The Care Agenda: Expanding LTSS For All. And uh, the care agenda, I just wanted to speak to for the last minute or two. Uh, as we look at this name, The Care Agenda, expanding LTSS For All, we want to re redefine and hold, take power over um, what we mean when we say care, um. We are talking about uh a campaign that is, that we want to invite every single Californian, policy maker or not, to care about the essential need for affordable and accessible long term supports and services for our, for aging and disability communities. And to ensure that we do this alongside our um, worker and union communities because the reality is that in order for it to create solutions that can um, you know, create more community living options for all of us, we need all of us at the table. And so please um, we invite you ah to join us in The Care Agenda: Expanding Long Term Supports and Services for all. Uh, your stories, your connections, and your um, your participation is essential. So again, thank you so much uh and let this just be the beginning.