

## **Gift of Caregiving December 13, 2017**

**Speakers: Derek Lamb, ACL/AoA and Mary Weston, Gila River  
Indian Community**

**Operator:** Welcome. And thank you for standing by. At this time, all participants are in a listen-only mode. During the question and answer session, please press star and 1. Today's conference is being recorded. If you have any objections, you may disconnect at this time. And we'll turn the meeting over to Ms. Tara Nokelby. You may go ahead.

**Tara Nokelby:** Thank you. Good afternoon. Thank you for joining us today. My name is Tara Nokelby, and I will be facilitating your webinar today. Today's webinar will be the gift of caregiving from our speakers Derek Lamb with ACL/AOA and Mary Weston with Gila River community. This presentation will be recorded and posted on Older Indians at a later date. We will be doing a question and answer session at the end of the presentation. At that time, you can press star 1 to open up your phone lines. And I will pass it off to Derek to begin.

**Derek:** Hey, thank you, Tara. And thank you everyone for joining, and caregiving is really dear and close to my heart. And for some of you who have attended the Region IX, Region X Title VI regional conference earlier this year, you have heard my story. And basically, I am a weekend caregiver of my 90-year-old mom who has been diagnosed with multi-infarct dementia, which is caused by multiple mini-strokes, and during the weekdays she is cared for by my sister who really spends hours and hours trying to provide the quality of care for her. So, the gift of caregiving is really crucial because, as caregivers, we want to make sure that we won't burn out. In the meantime, we want to make sure that the community really has enough resources, and so in a space of Title VI where we are providing resources for American Indians, for Alaska natives, and native Hawaiians, we are going to cover the caregiver support services. What are some of the required components? And why it started in the first place. So, this presentation will cover an overview. So, when my co-presenter, Mary, joins later and she will talk about the caregiver stress and how to deal with that during the holidays. So, when Title VI C was first added, it's...really you know...an odd kind of choice for funding because Title VI Elders programs for American Indians, and Alaska natives, and native Hawaiians are already underfunded, right? And the original intent was designed to serve elders and not the caregivers. And so, people wonder, American Indians have already cared for and held the elders in high regard. So, why do we need such a program? And they always think that, you know, that since the elders are already cared for, so just put the money in other Title VI programs. But this is not really the intent of our caregiver support services because there are always ways that we can help elders as far as to help the families to provide the best possible care. And also, we understand that nowadays many things have changed. Both parents work. Children go to daycare program, and caregivers are burning the candle at both ends, especially in the case of caregivers who have young ones, like in my case. A few years ago, when my two daughters are still going to middle school and high school, it was quite a chore to meet the needs of my mother and my two daughters. So, the difference that we are seeing right now is that the Title VI programs indeed really gather the elders together and we provide resources so that the elders can stay in the home safely and also tribal communities are renewing those traditional ways of doing things, and

there's also Indian Child Welfare Acts that allows the children to stay in the community so on and so forth. So, now we see really there's a need for effective caregiver programs. And one thing I want to highlight is because you get a [unintelligible] is that elders will end up doing better when caregivers are supported. The caregivers know what to do, and the caregivers will take a break every now and then. And so, what I am going to present to you are the required services under Title VI C and also some of the things that you need to pay attention.

So, for those who are already providing caregiver services, you know that there are five required components: information assistance, individual counseling, caregiver training support groups, respite care, and supplemental services. So, note that on the respite care, we are not talking about in-home care at all, so out-of-home, including social daycare and all-day health, which we will cover later on. So, first of all, information for caregivers. So, what are we talking about? In this space, we are talking about, people will get the answers in terms of what they need for caregivers and also how to access needed services and support. And we can also provide information through signage or articles in the tribal papers, not necessarily face-to-face kind of services. In terms of assistance, we will provide the caregivers with the hands-on support to find the different resources, whether it's respite, whether it's in-home care, or whether it's adult day health, or whether it's something that they can join through a support group, so they get sharing with one another and learn from other people. That they're not really alone when it comes to caregiving. So, that's a really important kind of assistance for the caregivers. And then, we also want the Title VI grantees to provide training, provide counseling and support, and these services can look different in each community because the key thing is we definitely do not want to use a cookie-cutter approach and ask you to do everything the same because each tribal organization is unique in your own way. So, in terms of training, there are caregivers who are short-term caregivers, who are mid-term, and in that space their needs actually are very different from those who are providing long-term care. So, if you look at this slide, for those who are in the short-term and mid-term kind of caregiving phase, they might want to know more about wound care, transfer, bathing, how to look at a range of motion exercise. Whereas for those who are providing long-term care, they would need more information on Alzheimer's disease, Parkinson's disease, [unintelligible] for my case, my mom has been diagnosed with multi-infarcts dementia. So, I basically look up lot of information and I understand that her case is very different from those with Alzheimer's because with Alzheimer's disease the one being afflicted will deteriorate gradually over a course of maybe 15 to 20 years in most cases, and it may start as early as someone who is in their forties. But for multi-infarct dementia, it's basically caused by sudden mini-strokes and the conditions will basically get worse after the stroke happens. So, the key thing really is to maintain, in my case, the blood pressure of my mom, make sure that her cholesterol is being checked, make sure that her diabetes is being controlled, so on and so forth. So, different types of ailments or illness will cause us to pay attention and to provide care in a very different manner. And then in terms of caregiver training, we can say for some who develop or to borrow the ideas from other people, from other tribes, or even from your local area agency on aging, or some research institution. Of course, that will meet the needs of the caregivers, and many times it comes in forms of videos, classes, books, and so on and so forth. And in this space, we can develop a library of materials so that the caregivers can borrow. So, what we want to include in caregiver training, which Mary will address later, number one: stress, especially stress during holiday. You know, how to manage the danger signs, home safety, how to manage diabetes, so on and so forth. And also, we need to provide counseling because it's a major

component for people who have been caregivers for quite some time. They may not be able to take care of themselves, especially not only physically but psychologically, emotionally, mentally. So, counseling actually will need to be provided, and they can be provided by mental health professionals or peer counselors. These are individuals who actually have gone through the process. They can relate to what's going on with the caregivers, and they will be able to provide some kind of help.

So, this basically covers what I just talked about, and the key thing really is to match caregivers with other mentors, so they can call if they need and ask a question. Support groups would be another great tool, a great service that we need to provide because, again, these are not just one-on-one, but they say this is in a group setting, and so during the time when the caregivers are attending the support group and the tribal organizations can really learn from them what kind of services the elders need so that it is not basically coming from a cookie cutter approach. And it can happen, say for example, in the space of providing a caregiver conference and a special day to honor the caregivers. So, the next slide basically we talk about caregiver honor day because caregivers actually are very crucial in the service to the system, although the caregivers are volunteers, family members, neighbors, and so on and so forth. So, it is very important to recognize them and make sure that we know they are part of a team, part of a really whole aging network to make sure that the ones afflicted, either with dementia, with hypertension, so on and so forth, other chronic diseases, are well cared for. So, we can provide like a nice meal. We can issue certificates of honor. And we can have door prizes, so on and so forth, so that they feel being recognized and they feel beloved, they feel significant, and they feel loved. And then, we can also plan for caregiver conference. We need to pick a theme and then we can basically look at different topics, say for example addressing dementia behaviors, emotional support. And then in this space, we need to provide lunch because it is crucial for people, especially after they have sat in a conference room for a long time, I think food will be a good way to not only keep them going, but also to recognize they are part of the team. And then don't forget the grandparents. We need to talk about different things, internet safety, so on and so forth, so that they are aware of different issues as well.

Early on, I talked about the required services, and respite is one of them. And I just want to highlight, caregivers who take breaks, like my sister during the weekend, will become better caregivers. They will be able to manage the stress better, and they will have time to care for themselves. We don't want someone to be a 24/7 caregiver, and then they get sick, not even physically, but emotionally. And it's not gonna help anyone, and especially the one that we try to care for. So, I think this is really an important part of the Title VI C program. Early on, I talked about the different types of respite. In-home respite is one of them. And, basically, we are providing care for elders in their own home. So, first of all, we need to assess the needs of the elders by looking at the daily schedule, by looking at the types and times of medication. Any special diet instructions and other issues. And then, you know, we pay someone to care for loved ones at home so that the primary caregiver can take a break. There are also special in-home respites. So, sometimes we need more than one person, not the whole village, but we need a team of helpers who can come and help in the space of bathing, foot care, meal preparation, and night watch for some [unintelligible] so on and so forth. Sometimes, when we can't provide care in our own home, we have to look for out-of-home respite. So, this is what we're talking about when we negotiate a special daily rate with a local nursing facility so that if, and when, a caregiver needs

an extended time away, we can have that option. And sometimes we find that local area agencies on aging will have the contracts that you may be able to use this service. So, for those of you who actually have local area agencies on aging in your area, please reach out to them because that's one of the things that ACL always, always has pushed for us to see how we can better coordinate Title III and Title VI programs.

Adult day services is another component, and that is something that my mom currently is using. It's not a social daycare because just going to a licensed facility called [unintelligible] and so let's first talk about social daycare. Actually, in many areas it's not licensed, and, even if it's licensed, the main difference is that it doesn't have the medical component. So, elders come to your center, pretty much like senior center, and then they will engage in music, different exercise, games, watch a movie, they dance, so on and so forth, and so this is really a good way for us, as caregivers, to get some time off, and whereas our loved ones are being taken care of by trained professionals in a very safe environment. And for those who don't know social daycare and basically operates about six hours per day. And so usually it's located at a senior center, and service actually can be qualified as part of the Medicaid waiver program. And we have someone actually from ACL who can address that question later if it is being asked later on. And then, adult day health program is very close and dear to my hearth because about twenty some years ago before I left the city and county of San Francis-sorry, before I lived in Non[unintelligible] actually I developed an adult day health care program for that agency. So, like social daycare, it includes everything that we mentioned before. It also includes therapies and treatments. So, say for example physical and occupational therapy, skilled nursing, social work, case management, transportation, so and so forth. Now, there are pluses and minuses because it's a medical model, so basically, we can provide a higher level of care for those who need such a service. It usually has a rehab component because we have the physical therapist and occupational therapist, reimbursable under Medicaid. So, say for example, in California adult day health actually got reimbursed by Medical. And after the social worker, finished the assessment of a senior and completed the treatment authorization request form, so-called TAR. It can also be operated via clinic, a hospital to take advantage of the professionals over there. The downside is it's very expensive to operate. We need to make sure that you have enough participants so that the average daily attendance, or so-called ADA, is not under a certain number because we definitely need to make sure that the program can break even, so that we are not losing money. We also need to make sure that all the charts, therapy, and skilled care are being properly done and completed because the licensing authority will come in and check it during the assessment. So, those are the things that people will have to consider if they decide to go and pursue the adult day healthcare license. We also talk about as part of the required services, is supplementary services. And these actually are only provided on a limited basis...transportation, a lending closet, and so on and so forth. And also, we can provide family care management. So, in some tribes, family meetings are being held so that the whole family will get together and [unintelligible] this care, and usually we have a social worker or case manager who will evaluate the elders to see what are the care needs. And since the whole family is here, that's why it's actually a good time for different members to iron out the differences in opinion. And trust me, even though only my sister and myself are the primary caregivers, we have differences in many ways in terms of how we should care for our mom. And so, I really appreciate when we can go and ask for help of the social worker, even though I am a professional already, I think there's also

space for other professions to help the professionals, especially when it comes to a care plan for our loved ones.

Well I want you to talk about, the most important point is elders are precious. My mom is precious. Your parents are precious. Your grandmother and grandfather, they are precious. And they deserve our really best care. And so, we need to really support the caregivers, like in my case my sister who is the primary caregiver during the weekday, so that we support the needs of our loved ones. Keeping our loved ones at home means we can then, in the community where they can continue to provide leadership, wisdom. And even though my mom is 90 and she has multi-infarct dementia, she has lost a lot of her memories, but don't be surprised sometimes she will make a statement and really, really brighten our day because "Mom, you are so correct," because I never have thought about that. So, don't underestimate it, even though when people are having chronic illness, like dementia, because they really, really deserve our best care.

And then their grandchildren one day will become wise elders. So, this is like coming back to a full circle. So, with that I am not sure if Mary has come onboard. But I will entertain some questions before we turn to the next segment because we are going to focus on our holiday stress on caregivers.

**Mary:** I am onboard. I just wanted to say hello to everybody.

**Derek:** Hi Mary.

**Unidentified voice:** Hi Mary.

**Mary:** Hi, everyone.

**Derek:** So, if we have no questions, I am going to turn it over to Mary, and then I can help you advance those slides since I don't see your name actually on the list. Is it okay, Mary?

**Mary:** Of course. Thank you, Derek. I appreciate that.

**Derek:** Alright, so Mary. Please, take it away.

**Mary:** Alright, thank you so much. Hello, everyone. Good afternoon. I am glad to join you this afternoon. We thought it would be appropriate and a good time to focus a little bit on holiday stress for caregivers, talk a little bit about burnout for caregivers, some stress busters that you can use, and other activities. So, let's get started. I wanted to first, before we get started, can I just ask who is with us this afternoon?

**Tara:** Their lines are actually, they're closed so that they can't speak.

**Mary:** They can't answer. Is that you, Tara?

**Tara:** Yes, it is.

**Mary:** Okay, alright. Thank you. Alright we'll get started then. Welcome to everyone. Let's take a look at some reminders for caregiver burnout. In working with caregivers, working with family members, we want to make sure that we're looking for some of these signs: withdrawal from friends, family, and other loved ones, a loss of interest in activities that they previously enjoyed, feeling a little bit out of it, feeling blue, perhaps a little bit depressed, irritable, not feeling like they can do things like they used to do them, changes in appetite, weight or both, changes in sleep patterns, and that would be not being able to get to sleep, waking up early, sleeping too long, getting sick more often, feelings of wanting to hurt yourself as a caregiver or the person that they're caring for. And that's certainly something that we want to listen for and keep in mind in working with family caregivers. Can that happen? Absolutely, it can come up where a caregiver gets to the point of having those feelings. So, it's important to listen for that and keep that in mind if it comes up that that person does need to get help right away. Counseling support and probably a new care plan or some help with their own caregiving. Emotional and physical exhaustion, being exhausted all the time, not having the stamina that they used to have to do things that they used to enjoy as caregivers, and that could be exercising or just getting outside and doing things for themselves. And then, the irritability again, certainly something to look for when it comes to stress.

Let's take a look at some of the causes of caregiver burnout. And that would be keeping in mind a caregiver who actually is showing, who has unrealistic expectations. And what are we talking about when we say "unrealistic expectations"? It's something that we hear a lot in working with caregivers, where their expectations for themselves is that they can do it all, feeling like the super-mom syndrome-the super-caregiver syndrome, where I can do it all. I don't need help. I don't need to ask for help. It could be that they really think they can do it. It might be that there is some pride involved or they simply really believe they can do it. Many times, before we get into caregiving, we don't realize the extent of some of the needs of the person that we're caring for. Perhaps that changes along the way. Lack of control of situations with caregiving can be stressful and very frustrating for caregivers. And that is where they don't have perhaps a say-so in the caregiving plan. It also may mean that they don't have control over who is helping them, the resources that they need or they feel like they don't have the right resources. Perhaps there hasn't been a care planning meeting with the family or with others where they can hear about resources and actually put a care plan in place and get some help. Or perhaps they just feel like they aren't in control of the situation because family is not offering to help and there's not others that are there for them. Also, depending on the need of the care recipient, the person that they're taking care of, or the loved one they're caring for, they may feel that they don't have control as a caregiver because of their illnesses, because of how the illness is progressing, or if it's a grandparent raising grandchildren perhaps the needs of the children, getting them settled in or special needs of the children they're caring for.

And taking on more than can be handled. Does that sound familiar? That can certainly be a situation that can happen for many family caregivers as I mentioned before, where they just take on too much. They really think that they can do it, and that burnout happens. That exhaustion, both physically and mentally. So, what can be done to prevent burnout? Let's take a look at that. Taking care of yourself is so important as caregivers. And many times, that's not the first priority. So, we want to make sure in working with caregivers that we really work with them to help to focus on taking care of themselves, how they can best do that for themselves. It's

important for caregivers to talk with someone that they can trust, to have someone available in their lives that they can talk with, whether it's family, maybe someone outside of the family, friends, professionals, someone through their church or other activities that they're involved with. Accepting that they may need help is very important and sometimes they need a little help with that. Sometimes the caregivers need to realize that first of all, it's okay to need help. Sometimes, it's so hard to admit that you need help. And they need to know that that's okay. And it's very important for them to get the help that's needed. And that level of help can change depending on the need of the individuals they're caring for. Taking advantage of respite services, and we certainly heard Derek speak on that earlier. That is so important to have that time away, getting out of the house, doing something for yourself. If you can't get out of the house as a caregiver, finding some way to relax or do something for yourself inside the house. But it's really a good thing to get out and do something that you really enjoy. Talking to a professional if needed. That could be a social worker, a counselor, those individuals available through the senior centers, caregiver coordinators. And there are many other resources that are available through the area agencies on aging. Lots of good resources to tap into for those caregivers.

The next one is so important. It's something that I find myself doing a lot of work with in working with caregivers. And that's knowing and setting your limits. Setting those boundaries of what you can do, and you can't do. Learning how to say no. Facing that it's okay to say no, or that you have to say no, and that you need some help, and speaking up and letting others know that you do need help. Accepting your feelings as caregivers. I do a lot of work with caregivers with their feelings. Just accepting that it's okay for them to have their own needs, that they may have some frustrations. They may have some anger at others that aren't helping in their life. Or they may have anger or frustration with the illness of the person that they're caring for. So, lots of different feelings that need to be dealt with. The most important thing is that caregivers realize how important it is for them to share those feelings and voice those feelings and have someone to talk with along the way, along their caregiving journey. And joining a caregiver support group can be a great way to do that. I highly recommend support groups for caregivers. That can be so helpful for them to express their feelings, hear about other caregivers that are going through similar situations and finding some ways to cope.

So, let's next take a look at holiday stress. Some stress busters that can be used by caregivers, and that you can work with them on. One of the most important things during the holiday season for all of us, and especially caregivers, is learning how to be flexible. And what does that mean? That means maybe not having such high expectations in so many areas that everything has to be perfect. The table, the food, the presents, the family gatherings. It's important to be flexible in how you do those things. Taking a look at your caregiving situation and the loved ones that you're caring for, what's going to work best for all of you? And then, once again, taking care of yourself is so important, especially around the holidays. Somehow managing to take that time, scheduling that time for yourself and taking care of yourself, even if it's getting a massage or getting someone to fill in for you trading off times with others in the family or working out a schedule where you can get some time for yourself around the holidays is so important. One of the ways of actually communicating with each other and coming up with a plan, and Derek mentioned this earlier too, is having that family meeting. And that's just so important to sit down, talking together and actually coming up with a plan that's going to work for the caregiver and how the others in the family can help, and what other outside resources can assist to help have a

viable care plan for everyone involved. And then simplifying the holiday activities. Encourage caregivers to take a look at simplifying things in their lives, the lives of those that they're caring for, and others so that the holiday spirit can be there, that the holiday activities can still be there. But some things could be changed to help simplify it, and everyone can still have a good time. A good time to bring that up is at the family meeting, and ask for some help from family members in how to change things where life could be a little more simpler for everyone around the holidays. Planning ahead can make a difference for everyone involved. Making time for family traditions is still so important and usually important for caregivers and many times important for those they're caring for. So, that also needs to be considered when talking with each other at the family meetings and for caregivers that you're working with. And saying yes to help from family, friends, and others. And I put that in there because many times caregivers don't want to say yes to help, and we need to encourage them every time we get a chance to do so.

On the next slide, you'll see that we have some information, some structure for your family meeting. Perhaps this is something that you can share with those caregivers you're working with and help them even make up an agenda if that would be helpful for the caregiver and the family. And that's something that we do a lot of here at Elderly Services. The case managers do a lot of work with the family members to, and the caregivers, to help them do an agenda for their family meeting, help them even if they want help in having one of them attend a family meeting to help keep things on topic. That's very important too. So, taking a look at planning that family meeting ahead of time. Who is gonna attend? For those who can't attend, there might be somewhere else within the country or the United States. Perhaps they can join by phone. Everyone should be invited that can participate. Agreeing on appropriate location to meet to talk about the needs, setting clear goals for the meeting, that the meeting is specifically about the person, the individual that is being cared for and their needs, and that the meeting is about setting a care plan for that person, and all working together towards that care plan. And it's setting some ground rules, some basic ground rules about communication, giving each other a chance to speak, respecting everyone's opinion, staying on topic, and having someone that's designated to keep everyone focused. I highly recommend having that agenda in writing. That will help a lot to keep everyone focused also, and some basic rules. And then, assigning roles for everyone in the family. It's important for everyone that joins you to know what their role can be and for them to participate in some way, however they can participate, whether they are working or not working. What is the care plan gonna be? And how can that caregiver be helped, and also the person that is being cared for? It's important to use outside resources and to find out resources that can be helpful. And certainly, professionals can help with that so that we can get that information from the senior centers and area agencies on aging can be helpful with that. And knowing when outside help is needed also to run the meeting. Sometimes families need help in actually running the meeting, and they're not able to do it themselves. And, as I mentioned, we help here from Elderly Services, our case managers, our elderly liaisons help with that. But it can also be someone that the family is close to in the community, an elder in the community, someone from their church or other activities that they have joined that they're comfortable with. As long as it's someone who can help guide that meeting and that is respected by everyone.

So, some ideas for the family meeting. And then next, we're gonna take a look at ideas for the holidays. Actually, the next two slides are some ideas for the holidays that you may already be using in your community. But some things to keep in mind. If you have support groups that are



active in your community, you can look at doing some stress busters in the support groups and maybe create them around the holidays. That's always fun. You certainly want to leave time for your support group members to talk about their needs and their concerns. And it's always fun to have some other things to do at the support groups. A craft idea for the holidays, a thank you card to the caregiver. This is a neat one that we've done before where the caregivers actually do a thank you card to each other in the group and thank them for the many things that they do in their lives as caregivers. A caregiver wish list. What would they like for Christmas? Maybe it's a massage, maybe it's to get away for 24 hours, or maybe even for 2 hours. A caregiver wish list can be a great way for them to actually plan some ways for respite and ways to take care of themselves. A caregiver reward where they actually have someone in the family that agrees to give some time to give them some respite time. Perhaps they'd like to go out for a dinner for two, a movie and popcorn. We actually came up with the idea to have some of these things available for the caregivers through the support groups. Just tickets for the movies and a pass for popcorn. Perhaps they have a family member that could give them, put some time in where they can take a two-hour nap, grocery shopping, or maybe they'd like to get away for a walk in the park. Just some fun things that could be utilized for the caregiver reward. And then other activities that could be used or scheduled through the support group would be potluck with stressbuster activities. It doesn't have to be expensive activities for your support group. A Christmas party with Christmas bingo. That was a big hit that we did for several years, and the grandparents actually invited their grandchildren to the Christmas parties. Trips to local festive events and movie days with grandchildren. And that would be great to provide those passes for the, some giveaways for the passes for the caregivers if you can.

And then on the next slide, some training ideas for the holidays. You'll see are listed. Some of these you may already be utilizing: stress management, managing time during the holidays, finances during the holidays, effective communication is always good. There's always a need for effective communication around the holidays. It's so important. Coping with grief and loss. And certainly, keep in mind traditions and values of your community if you decide to do something with this. You can certainly reach out and pull in those in the community that can help in doing some type of activity or support group for grief and loss. Very important to focus on the traditional values for that. We have a lot of loss around the holidays, and we just want to keep that in mind and find ways to reach out or open doors for those that need to talk about their grief and loss. And then we wanted to take just a few minutes, see if you have any questions, but also share some ideas if we can. I'm not...Tara, are you still with us?

**Derek:** Yeah, I think Tara is aware that we need to open the lines. This is Derek.

**Mary:** Okay, alright, Derek. Can we...

**Tara:** [unintelligible] open up the lines.

**Mary:** Thank you. So, at this time, we certainly can...I'd like to see if anyone has some ideas to share. Some of the things that you might already be doing for caregivers during the holidays in your community.

**Operator:** All lines are open at this time. So, if you do have a question, you can speak up at any time. Again, if you have any questions, your lines are open and interactive at this time. So, you may ask your question at any time.

**Judy:** This is Judy with the Apache tribe. Can y'all hear me?

**Mary:** We can hear you.

**Judy:** ...question. What happens with my caregivers when they turn in extortion reports as far as the elders being concerned. And we've done our part. I do activities for my caregivers, and I do groups and sessions of that sort. But when they turn in reports that my elders or my patients are being extorted and we report it, nothing is being done. What else can we do?

**Mary:** Judy, this is Mary. And I'm sure that we both want to probably weigh in on this. When you say extortion, can you say exactly...I mean I know what extortion means. But can you explain that a little bit more?

**Judy:** When we come in and we relieve a family member, as caregivers do. And you go in and you know that the family is abusing the elder as far as extorting their money, taking things from them, and the elder doesn't say no because it's their family members. So, we reported it to the elder hotline. Nothing's being done as far as the care for the elder. So, what I mean by extortion is they're taking this elder's money and spending it elsewhere and the elder is going without food, medical supplies, hygiene items. The elder is going without. So, how do we help in that situation if we've already used all of our resources?

**Mary:** So, one of the most important things it sounds like you've done. Although, you said that you reported it to a hotline. Didn't you say? Would that be, was that report made to Adult Protective Services within your state or your region?

**Judy:** Yes.

**Mary:** Very good. So, that certainly would be the first step for any of us. And this is absolutely something that we can come across in working with caregivers and elders. Financial exploitation is one of the areas of abuse that we see the most. Or see a lot. So, if you have reported it, if you feel like that you need to report it again. I don't know if you have protocol through your agency. That is certainly something that you could look. Are you with an area agency on aging?

**Judy:** Yes, ma'am. I'm with the tribal government.

**Mary:** Okay, you're with tribal government also then. Okay, alright. So, for tribal government, you do have an APS. You have made that report to them. And the most important thing that you can continue to do is to support them. If you feel you need to make another report, do so. Sometimes it looks like APS isn't doing anything, but they are investigating. Sometimes it does take time.

**Judy:** Okay, thank you.

**Mary:** You're welcome. Does anybody else have any questions? That was a good one.

**Kimberly:** Hi, this is Kimberly Fr[unintelligible] from the Mashpee Wampanoag tribe, and I had a question about the Medicaid waiver program and getting reimbursed. Can you just explain that a little more?

**Mary:** Derek, do you want to explain that one?

**Derek:** Actually, I think I will defer that to my esteemed colleague Shelly from Region 10. She actually has a lot of experience dealing with Medicaid waivers, so Shelly would you mind taking this question?

**Shelly:** No, I'd like you to repeat it again because I only caught part of it.

**Kimberly:** Yes, so just when he was talking about the Medicaid waiver program. I just wanted a little bit more information. And he said it could be reimbursed. And I didn't know who could do the reimbursement, and did it have anything to do with somebody that was running the Title VI [unintelligible] of a program.

**Shelly:** Ah, okay. The Medicaid waiver program is one that's really difficult to understand. And the reason I say that is because it's developed independently in each state in the nation. And so, every state has their own program which they designed. They have different services included. And there's different approaches to it. So, what the Medicaid waiver services are called are what we call HCBS. You may have seen that before. And it stands for Home and Community-Based Services. And so, these are services that we bring to the elders in their homes. In some states, respite care is included in their waiver. It's on the menu for the services that are provided. In other states, it is not included. And then, how you get to it. You can't just bill for it because you have to have a contract to bill for it. And that process is also different in every state in the nation. And so, probably the question needs to be answered in this way, if you are interested in this, I would say contact the person who is your regional contact person. For you it would be Rhonda Schwartz. And contact her and see if she can help walk you through how to find the people that you need to talk to and to get a contract to have those services provided and be paid for. Common services that are available to be paid underneath the Medicaid waiver include things that almost every tribe does, like home-delivered meals. But in order to get paid for those home-delivered meals, the person, you have to have a contract and the person that you're serving has to be on that particular program. So, although people light up saying, "Oh boy, that sounds like a real lucrative way to go about doing business." Sometimes what you have to recognize is that if you don't have any elders on the program, whatever it's called in your state, where they have a paid caregiver living in...not living in their home, but coming to their home to help take care of them, you will, there is no reimbursement for home-delivered meals unless the client is actually on the program. So, a good place to start is to get people on the program, and then move from there. And if people have questions and want to call me directly, my telephone number is 206-615-2299.

**Rhonda:** And this is Rhonda. I'm on the line, so call me.

**[unidentified speaker]:** Hi Rhonda.

**Rhonda:** Hi.

**[unidentified speaker]:** Let's talk separately offline.

**Rhonda:** Okay.

**[unidentified speaker]:** Thanks, Rhonda. I appreciate it.

**Derek:** And Shelly thank so much for your feedback.

**Shelly:** No problem.

**Tara:** Okay, do we have any additional questions?

**Anthony:** Yes, I have a question. Anthony Sebastian. Mashantucket Pequot in Connecticut. I was wondering could we get a [unintelligible] program discussed sent to us?

**Tara:** I can certainly send you the presentation that we have right here if you want to provide your email address. And that goes for everyone, if you would like the presentation, either of the PowerPoint presentations, please feel free to enter your email address in the chat button on the WebEx. And since the lines are open, if you are not speaking, if you could please put it on mute. Alright so it looks like we don't have any additional questions. You can certainly email me after if you do have some questions, and I can forward them on. And then again, if you would like the presentations, please put your email address in the chat button on WebEx. I want to give a big thank you to Derek and Mary for your presentations.

**Derek:** Thank you for having us here. Before we close, I would like to actually mention a quote from Candy Crowley who was the Chief Political Correspondent at CNN. Her mother actually has had Alzheimer's disease, and I think this might actually be something you can relate to or your elders can relate to. "I want to tell you how much I miss my mother. Bits of her are still there. I miss her most when I'm sitting across from her." I think that's the really something that we should bear in mind. Why our caregivers are having so much stress because part of the thing about chronic disease, especially in the space of dementia, is that we are seeing our loved ones not dying quickly, but slowly and being affected by memory loss and change in behavior and cognitive functioning. And those actually are hard to really accept. So, I'm really pleased that Mary covers the parts on caregiver stress and give you all some tips how to handle it. The holidays coming up and with that I want to wish each and every one of you a happy holidays. And so, with that I'm going to turn to Mary and see if she has any parting words for us.

**Mary:** Thank you, Derek. It was a pleasure to be a part of all of this today. And I just want to say Happy Holidays to everyone, and thank you for all that you do every day, all of the work that you do with the caregivers and the family members. Happy Holidays.

**[unidentified speaker]:** Thank you. Happy Holidays.

**[unidentified speaker]:** Thank you so much

**Operator:** Thank you. That concludes today's conference. You may disconnect at this time. Thank you, have a great day.