NCIL-Federal State of Emergency Ending Listening Session  
  
Live captioning by Ai-Media.   
  
JESSICA PODESVA:   
Hi, everyone. Thank you for joining. Please unmute yourself when you join. We will get started in just a couple minutes. If you could please mute yourself when you join, so we can have clear audio.   
  
SPEAKER:   
If you make me cohost, I can mute people as needed.   
  
JESSICA PODESVA:   
Sure, thanks, Theo. Everyone, we are going to get started in just another minute. We are letting folks trickle in. I still see a bunch of folks joining. I will just give it another minute.   
  
Ok, I think we are ready to go ahead and get started. Welcome, everyone, today's listening session on the ending of the public health emergency. Cohosting this listing session with me today is Marty Musser. Marty, do you want to introduce yourself?   
  
SPEAKER:   
  
Thank you, Jessica. I am Marty Musser. I am the region Board representative on the NCIL board and I work... I am a white woman in my 30s with wavy brown hair wearing a black top. You can see some bookshelves behind me in my home office. I use she/her pronouns.   
  
JESSICA PODESVA:   
For those who don't know me, my name is Jessica Podesta and I'm NCIL director of advocacy. I am a thirtysomething woman with brown hair and glasses sitting in the conference room of my workspace with a big TV behind me and white walls.   
  
We will dive into today's listening session. We are excited we have so many people here. We will go through some brief technology housekeeping and ground rules, and then we will give a very brief overview of the public health emergency, but really today, we want to hear from all of you. We want to hear about the work that you have been doing in your states and today's main focus is really to hear from you all.   
  
We will dive right into the comment period after that.   
  
Some housekeeping: we have captioning and ASL interpreters today. To view the ASL video, you can find the interpreters video in the gallery. Click the right corner of the interpreters video and click the ellipses, then you can click the "Pin video" option. This will keep the interpreter videos on your screen.   
  
To view CART captioning, you click the close caption button with the CC icon. And you can click and drag to move its positioning with the -- in the meeting window. We have a link to the captioning that will be put in the chat. It also is in the meeting materials that were sent out with today's meeting reminder.   
  
Alright. Marty?   
  
SPEAKER:   
Ok. So the key word here is a brief introduction to the public health emergency and the federal health emergency, PHE, and major disaster declaration, MDD, will end on May 11, 2023. This will and the temporary but significant changes made to Medicaid enrollment and eligibility rules as well as pandemic specific flexibilities. There are some links on the bottom of this slide for additional resources.   
  
The purpose of this testing session today is for us at NCIL to listen and hear from all of you. The administration for community living has asked NCIL to gather feedback from centers for independent living about how prepare you feel to help consumers. We know what has been -- you know what has been helpful so far, what you might need. NCIL has provided resources to help you assist consumers. Please reach out to Jessica if you have follow-up questions or need additional resources.   
  
JESSICA PODESVA:   
Thank you. Today, we have also invited folks from the administration on community living to listen. They will not be called on to answer individual questions, but they will be listening and taking your thoughts and questions back.   
  
We have Nikki (unknown name) from ACL as well as Erica McFadden the thing today. Thank you for joining. Without further ado, we will dive right on in.   
  
To share a comment or a question... Sorry. To indicate that you have a comment, please use Zooms raise hand feature located at the bottom of your screen. When you raise your hand, it will alert me that you would like to speak and share your comment. Then we will unmute attendees and spotlight you in the order of which you raise your hand. Raise your hand you go to reactions then raise hand. You can also hit alt plus Y on your keyboard. If you are joining on the phone, you can hit \*9 to raise your hand and stare six to unmute.   
  
Would anyone like to share some comments today?   
  
SPEAKER:   
Erika in the chat says thanks for having us. Vicki from ACL says we are taking notes on really want to hear from you.   
  
JESSICA PODESVA:   
Once again, hit \*nine to raise your hand. Jeff, Hughes. I will spotlight you.   
  
SPEAKER:   
His video is not on.   
  
SPEAKER:   
I'm surprised that people aren't jumping in on this. I don't mind being the first want to talk. As far as centers being prepared in Oklahoma, I think we were very prepared for when things started happening shutting down with COVID. The challenges that we have had here is that the state, there is a whole Medicaid war. Any of the state agencies just stopped. There wasn't much of anything.   
  
The information coming out right now is very little. Almost none. So for people being prepared for the services that are going to change, I don't believe that there is any way that people will be prepared at all. Because this information just is not getting out and centers are not engaged on this at all. I would love to hear about some other states as well.   
  
JESSICA PODESVA:   
Thanks, Jeff. That is a great segue into one of our questions here. How is your estate working with your center for independent living on, specifically, the Medicaid unwinding as we have called it. Or starting the annual Medicaid reapplication process that will be up again, that has been on hold during the pandemic. We want to hear from you. What has been going on in your states?   
  
SPEAKER:   
We have a hand raised from Jane Johnson.   
  
JESSICA PODESVA:   
Jane.   
  
SPEAKER:   
My name is Jane Johnson and I'm the Executive Director for the Association of centers for independent living in Florida. We reached out to our Department of children and families, the agency in Florida that does Medicaid eligibility determination and redetermination. This was back in the summer, because at the end of the public health emergency it was forecasted to be... There is a rolling date that seem to keep moving forward.   
  
We asked how we could help and a couple of weeks ago hosted a webinar specifically for centers for independent living staff and consumers and walked through the process. I don't know if this is because our governor might be running for a national office in the future, they were conscious about not making negative headlines on this issue. But they were really accommodating to us. They not only hosted the webinar but took a lot of questions from me in advance, met with me personally.   
  
We had over 100 people on our webinar, they walked through the process, they explained exactly what they were going to do and they have tried to triage their outreach to people in terms of letting them know that their Medicaid will be expiring. Every month they are going to be taking another group of people based on their recertification date that was in place before the public health emergency was enacted. Whatever date they became enrolled.   
  
They are also escalating in advance, probably close to 1 million people may come off automatically either because they have not used Medicaid since... In the past year, or they haven't responded to any outreach. I thought they did a really good job educating the centers for independent living how to help consumers and what kinds of information to share with them.   
  
The other nice thing I think will be a long-term benefit, as people are getting reenrolled or recertified, they are matching up there snap expiration date with their Medicaid date so they will not have to have two recertification feature which is nice from a consumer standpoint. Some would have had to go and get there snap reauthorized at a different time. They are trying to get everybody all on the same calendar cycle so that things can be done with one interaction. That is the lead up. Leading up to it, they have been very accommodating.   
  
They shared a PowerPoint that walk through the process from the consumer side. This is what they will receive, this is what it will look like, this is what they will need to do. We don't know what reality will be until people start getting disenrolled, but right now, they are really helping out and they understand that they need the centers for independent living because they know the call centers will get bombed down and people will be able to get through.   
  
They want to be able to say somebody calls the center for independent living and they can walk you through the process online which can be an easier way to go.   
  
JESSICA PODESVA:   
That is great. Thank you, Jane.   
  
SPEAKER:   
before we move on to the next comment or question, I want to invite everybody to utilize the chat but answering this -- yes or no and say what your status regarding have you heard from anybody at the state level about how to prepare your consumers?   
  
JESSICA PODESVA:   
That's great.   
  
SPEAKER:   
That will help us get a good lay of the land.   
  
SPEAKER:   
I'm from Minnesota, southeastern Minnesota Center for Independent living. We have a collaborative contract for Metropolitan Center for Independent living and it's also honest with our department, of human services to provide a DRC call center resource. The things going through where there are CIL staff there, but our state has not approached Centers for Independent Living specifically.   
  
And in the legislature they are trying to pass right now the bill to help support the counties. We have 87 that are all individually doing the individual services in the eligibility renewals are on behalf of DHS. They are not getting a lot of information because our organization has taken it upon ourselves to contact the counties and try and connect with the local resources because we are not getting information at this point so we are trying to make sure people know we are there on the local level.   
  
JESSICA PODESVA:   
Thank you, Rosalie. He said you're from Minnesota?   
  
SPEAKER:   
Correct.   
  
JESSICA PODESVA:   
Noel? There we go.   
  
SPEAKER:   
I don't have much (indiscernible)   
  
JESSICA PODESVA:   
Your own good.   
  
SPEAKER:   
I am ready to rant. It's frustrating because I'm in Boston Massachusetts. It's hard because yes there has been some PR and according to some answers in the chat and grateful our state is even saying anything, but the PR has largely been concentrated on your state website or your hearing exclusively in the aisle space because you are a state agency providing benefits. You're not like, my neighbor was on ACO, does not know. I feel like it should be a thing or medical provider should be letting patients now in office, or at least posters, something like that. We're not really seeing that.   
  
And then the burden of letting people know, at a CIL we are taking it seriously, but it's mostly falling for people who are under coverage. 300,000 people in Massachusetts, the burden is falling on, what? 11 of us to let the information get out and let people know what that means.   
  
It's really confusing because obviously, for us, most benefits and April 1. When it comes to COVID even free testing sites are drying up, people are relying on those. We just kind of build community trust in the vaccines and a lot of our Black and brown neighborhoods and it feels like we just got people sitting with it for three years.   
  
Now it's hard to get to and it's just really a mess. But I think there is some language from healthcare for all. They are doing some campaigns. Anyone who has worked on campaigns knows mostly knocking on doors is PR. People don't answer, the information is not getting out.   
  
We are estimating anywhere from 50,000 people to over hundred thousand people are going to have huge interruptions. That's a huge range. Just seems like we won't know until it's too late. It's really frustrating and it's hard even just looking around in society and realizing this is because people don't value with people with disabilities who are largely affected by COVID and who need those protections.   
  
It's just this weird dissidence of everyone is excited that the world is getting back to "Normal" and things are opening. And at the same time your neighbors are getting sick. I have a lot of neighbors, I live in a residential neighborhood. My neighbor currently has COVID and he has pancreatic and melanoma skin cancer and he just got COVID this week. I've been trying to do my best to bring him food and it's like, it's just really frustrating just in the name of pulling back money we've been allocated, but we still have access to. Just decide it's not a priority to spend it even though it's just sitting there waiting to be used.   
  
I don't know. I'm curious to get some help from hearing what you all have to say. Seems like we're all a little hopeless. It seems like this is the place but will try.   
  
JESSICA PODESVA:   
Thank you. Looking at the chat I am seeing a lot of nos which is really concerning. So for the states that have no in the chat I'm curious if you wouldn't mind weighing in, what type of information would you find most beneficial to be getting from your states on this topic that can help you inform your consumers about this change, and if you could maybe talk about that a little bit.   
  
I'm also curious to hear why you think you haven't received, not why you think but why you think that is the cause. What you think has caused that.   
  
SPEAKER:   
I'm back 11 in orange county, California. Southern California. CFILC does a wonderful job of keeping us informed. I think I could use more information on anything state-level that would counteract the effects of the disenrollment of Medicaid because of the end of the pandemic marker thing on May 11.   
  
I know that Medi-Cal is already examining folks and diss enrolling them. But it would be helpful to find some information on things to counteract the diss enrolling. So if there's any spot programs or anything that would help to assist our consumers that would be great.   
  
JESSICA PODESVA:   
I'm seeing a lot of good stuff in the chat. Maybe while we wait for some more hands to raised you want to read through some of that? Let's see. Every time I start reading it moves on me (Laughs)   
  
I saw a comment from Gloria about PCAs. Gloria, do you want to expand on that a little bit?   
  
SPEAKER:   
Sure, Jessica. This is Gloria in North Carolina. I'm with the CIL. Other than reaching out to providers working with people with disabilities one of the things in a conversation yesterday I had is all of the organizations who received is funding to be advocating at the state level for more public service announcements so that people continue to know to go where to get COVID testing or access tickets.   
  
It's my understanding in North Carolina you have to go to your local Department of Publich Health. But a lot of people are not aware of that. Unless there's more information shared on a massive level I think there's good to be a lot of confusion about what to do if you think you have COVID, or you need to get the vaccine.   
  
JESSICA PODESVA:   
Thank you, Gloria. We've heard that a bit too. What has been the impact to access to COVID testing in your states as a result of this? Do you know? Are you seeing an increase of state testing sites closing without information on where you can get tested? Curious on that too.   
  
Anyone that could speak on that. Beth has her hand up.   
  
SPEAKER:   
Hi, everybody. I'm with the southern Illinois Center for Independent living in Carlinville Illinois. We are down south about south of Chicago. We serve the 13 most southern counties of Illinois. Two kind of combat the issue we've been seeing of testing sites closing and individuals not necessarily wanting to spend money on COVID tests and things like that I was able to have our center designated as a DHS, Department of Health Services test distribution center.   
  
In preparation for the end of, presciently-- prepping present-- preparation for May 11 I have 3200 tests currently. There are 4 in a box and I have 800 boxes.   
  
I ordered in mass because I'm worried what we will see in May is a trend toward a positivity's because it's going to come to the point where are individuals going to spend money on tests when they've been free for the past three years? Or will they put that $20 in their gas tank because they have things they need to do. I think with the economy and things like that we definitely see our consumers straps, especially with the deplete mint in SNAP benefits. Were trying to prepare to not only service our commuters-- community members the people who need access to testing so that we don't have a huge increase that affects consumers that benefit from the center and the staff.   
  
I'm also on an advisory committee for the University of Indiana's disability vaccine committee. We are trying to work on getting plain language documentation so. That assess reading level of like 1/7 grade comprehension, just trying to get things that are visible because I actually run the COVID program here at our center. I am the program developer and it initially started as a group. Now it has drifted more into case management because I noticed consumers that have long-haul COVID really need that assistance.   
  
Social Security, disability, snap benefits, Medicaid. Those things they were able to receive or could fill out themselves prior to the diagnosis I assist them with. Luckily because I am slowly working in the atmosphere of COVID I am able to procure these things for my center but I know that's not the case at every center. I know there's not just a COVID specialist running around. I could potentially take a look at these emails that got us to be a distribution center but I thought it was kind of imperative for us to become one because where we live we are southern Illinois. When people say Illinois they think Chicago and the northern regions, but there's 13 counties down here with people. We're just not as popular as up north.-- Populace is up north.   
  
We have a high poverty rate and a low education rate. We see increases in cases and unfortunately I think we've seen COVID become politicized and that has really affected us here in the heartland.   
  
I think we are trying to be as proactive as we can but just kind of some ideas. Seeing if your center can be established as a point of distribution for testing. We don't do the tests but we will provide them for anybody who needs them because we do not want our consumers to fall victim to the community rise in COVID.   
  
JESSICA PODESVA:   
Thank you, Beth. I see we have another hand up from Deborah. Deborah?   
  
SPEAKER:   
Hello, everybody. I am also on that same panel so I look forward to chatting with you on the panels as we get the vaccine committee up and going.   
  
They recently did a webinar on March 15 on the end of the public health emergency with a lot of great information. I was trying to date up the recording or any of the slides but for some reason I'm having trouble finding. I was going to go ahead and share them but I can't find them at this point. But I wanted to put out there that if you want to reach out to myself and help us get information to that group is a funded organization. They are asking a lot for how can they collaborate, how can they work with other organizations. I think they should be working closely with the CILs to see if-- what we can put together to help educate folks as quickly as possible. I have a number of concerns myself, especially regarding the Medicare/Medicaid are going to continue it looks like with providing test kits, but other insurances are not.   
  
For example, the insurance I have a cannot order test kits, those types of things. So I think there's a lot to be done and a lot to learn. I'm also from Minnesota. Hi, Rosie. I will let you guys go now but I wanted to put that out there.   
  
JESSICA PODESVA:   
To piggyback off that and some the stuff about PCAs, we know we are in a significant workforce crisis right now, and the number of states, this will affect the PCA programs and the flexibilities those programs have been able to offer.   
  
Has there been any talk about that in your states? What are some of the concerns you are hearing from consumers around the PCA and the direct workforce crisis? Alex?   
  
SPEAKER:   
Hi. Thank you for taking my question. With Medicaid eligibility possibly ending for many people, many of our folks are very worried, because they are only paid for by Medicaid. Having insurance is very complicated to get an aide, so it's not just a question of my going to have (indiscernible) when I get a prescription but am I going to be able to get out of bed?   
  
And stuff that needs their aid in order to get up in order to come to work so that impacts (indiscernible) as well. Just, what state --   
  
JESSICA PODESVA:   
What state are you from?   
  
SPEAKER:   
Upstate New York where there are more cows than people.   
  
JESSICA PODESVA:   
I'm from Saratoga so I know upstate New York well. Thanks for joining.   
  
MARTY MUSSER:   
I am seeing a real need for plain language documentation to use with our consumers. I will put this out there. If Arturo CIL you feel like you are -- at your CIL you feel like you have done a good job that you are willing to share, if you want to send that to myself or Jessica, perhaps we can work on a way to make some of those good examples available for the rest of us trying to crack that nut to use.   
  
SPEAKER:   
This is Gloria from Chicago, Illinois. I am the information and housing resource person. I accumulate information and pass it on to our consumers. So when our consumers are calling us about healthcare, I received an email from the Illinois Department of Public health about the changes that are about to come. And how they are going to affect a lot of people that live in our community.   
  
I kind of change the wording. I didn't change the wording. I kind of brought... I kind of changed everything to layman's terms so it won't be so... There would not be big words. For people, maybe third grade and up, could understand what I was explaining to them. I have a list server that I sent to our consumers that will -- reach out to us. I think there are close to 1500 people that I sent information to in the Chicagoland area period that includes some of the suburbs. I have people calling me from Tennessee, Florida, New York. People are calling me because they need help. I sent all the information that I had on a weekly basis to them so that they know about hiding -- housing resources, health resources, whatever we have available during that week.   
  
That is how we kind of send out our information for our people. We have all kinds, if you want to volunteer, I will send that out. I send out a lot of emails. I am the email queen. (Laughs)   
  
JESSICA PODESVA:   
Thank you very much, Gloria. Dan in Alabama says I cannot say whether state agency has reached out. It seems they are engaging around the issue of appendix K. For example, waving the requirement etc. this is an area where I'll may want to get involved to see what is happening when the COVID precisions -- provisions go away. Thank you, Dan. I thought that was a really good comment. I wanted to make sure we highlighted that.   
  
Does anyone else have comments? I am trying to sift through the chapter. If folks want to say some of what they put in the chat.   
  
SPEAKER:   
Let me chime in with the suggestion from Jeff Hughes. In an effort to capture the situation, if you would like to email myself or Jessica with that yes or no for whether you have heard from your state at all, that would be helpful. Please do that if you don't mind.   
  
JESSICA PODESVA:   
Yep. We also will be saving the chat as well.   
  
SPEAKER:   
Another question I can put the group to keep the wheels turning. If you are fortunate to be able to answer yes to the question that you have heard from the state, do you feel that the information or resources you have been provided has been enough information for you to actually help your consumers with this change? If not, what are some specific things that you need that would be helpful to you?   
  
JESSICA PODESVA:   
Once again, if you would like to speak, you can hit the raise hand buttoned above the reactions. If you are joining us by phone you can click \*9 to raise your hand and\*6 to and mute.   
  
SPEAKER:   
Nicole Davis in Virginia. We received from... Medicaid also received it from rehabilitation services to let us know they would do town hall listening sessions. They did seven about the whole unwinding session. The first session was for providers, the second was for advocates and community levers -- leaders, home health Associates. They were fairly good and had helpful information. They sent out flowers and posters enter information. That has been good to have in our centers to put some of it in our newsletters and on our website.   
  
So having the opportunity to ask them questions during those town halls was helpful. But also listing. I do not know... The thing I wish we could get back on with some of the questions that were posed in those. The answers have not come back period there were questions about people who couldn't get to social services or they would not answer the phone. What were the next steps? They took all the comments down and we have not heard back from all of them yet.   
  
I think they had a great start with what could become -- done and hope they continue to follow up with it.   
  
JESSICA PODESVA:   
Thank you, Nicole. Any other concerns around Medicaid or access to home and community-based services? We really want to hear from you. I know we have got a lot of good stuff in the chat.   
  
JENNY SICHEL:   
I think Jane Johnson potentially had her hand up as well.   
  
SPEAKER:   
This is Jane Johnson from Florida. I cannot work out how to make my raise handwork. It's my fault it's not working or impressing the wrong button. I wanted to just make an observation that when we were trying to work with our Department of children and families about doing some kind of outreach and education for centers for Independent living consumers on staff, it quickly became apparent how important the centers for independent living are to them.   
  
When I asked if we could have an ASL interpreter for the webinar, they got kind of scared because they did not know how to do that. One of our centers supplied the interpreter and we had to do a walk-through to explain how to spotlight the Zoom window.   
  
Rather than get angry with them, it made me realize that they want to do the right thing, they just didn't know how. It showed me the power of partnership when the centers for independent living can step into the knowledge For these bureaucratic agencies that are responsible for huge programs that impact billions of lives.   
  
What we did in the process of working together with them is let them realize we are friends. We can be allies. It is better to reach out in advance and let us know what you do not know so that we can help you.   
  
That was really important. It can be frustrating, but I think sometimes cities do not do the outreach because they are afraid to get it wrong and get their hands up for trying. We were trying to be a nonconfrontational partner.   
  
I hope that this developed a relationship of trust between them and the center -- centers for independent living period we capture consumers every day, and your consumers cannot access your information because it's not accessible. We can help with that. Obviously, I was jockeying for a more formal role in some of these processes because I think it is something that they should be paid to do as agents of the state, but anyway. That is an observation.   
  
We didn't hear... We knocked on the door and requested a meeting back in the summertime. We were very persistent. That shouldn't have to be the case, but to us, the webinar was worth it because we were able to share the information with a lot of people who could help a lot of people.   
  
I was kind of appalled at how inept they were. But we pulled it off thanks to center for independent living that provided the interpreter and make sure that the closed captioning was enabled.   
  
JESSICA PODESVA:   
Thank you, Jane. That brings up a really good point. For those of you who put in the chat that you have not heard from your states, have you reached out to their -- the state and what was their response when you did? If you did. Latoya?   
  
SPEAKER:   
Good afternoon. I missed the beginning part of this meeting, and I see it is recorded. I hope the recording is shared so I can watch it. My comment is I listened to a presentation last week. Josie Badger? I don't know what her position is off the top of my head.   
  
She did a presentation on (indiscernible)? There is another program starting for people with disabilities who are working and can save more than the $2000. You can have up to $100,000 of assets and your services will market changed or anything. I don't know how many CILs or people with disabilities know about that other program. I am trying to go through my emails to look for the name of that program, but an issue that I know we will run into... A lot of people with disabilities, because you are allowed to work from home, they sort out work and, I have to get switched over to (unknown term). I know when I started working I wasn't automatically switched over. I had to apply and get help.   
  
With talking to Josie, it seems like you are automatically supposed to be enrolled and the County assistance office are supposed to pride provide information and it's not necessarily being done. So the problem with that federal state emergency ending is an issue that a lot of people with disabilities might run into, not knowing how to apply or supposed to be getting automatically enrolled and thinking they will be enrolled and not being enrolled.   
  
It's a program where if you worked for over... Either a year or more years. It is a higher level. It is under (unknown term), but I do not know the name of the program. A lot of us want to work, we want to move up the ladder in our jobs, become supervisors, managers, CEOs, but we are fearing that our income increases and then we get kicked off of medical assistance and things like that. We don't want to lose our home and community-based services because we need them, like you said earlier. We need them to just get out of bed and get our basic needs met in the home before we even go to work and so forth throughout the day.   
  
JESSICA PODESVA:   
Thank you. What state are you in?   
  
SPEAKER:   
Pennsylvania. Philadelphia County. I work for liberty resources and we are the Centers for Independent Living for Chester, Montgomery, Delaware and Philadelphia County.   
  
  
  
JESSICA PODESVA:   
Thank you so much. Heidi?   
  
SPEAKER:   
I'm in New York, Center for independence and disabling New York. As far as we can tell our department is doing a really great job in trying to protect people is much as possible. They've been online and engaging with us a lot and all that. This is a bit of a different issue but it has to deal with the end of the public health emergency. It's something we are concerned about in New York.   
  
I haven't looked at all 160 people, but before the public health emergency began, or just in the beginning we adopted a restricted on eligibility for home care such that people would have to require assistance with maneuvering three activities of daily living or have dementia or Alzheimer's diagnosis requiring supervision for at least two activities of daily living.   
  
These have not been implemented during the public health emergency because as condition of receiving increased federal matching funds we were not allowed to mess with the benefit package for eligibility.   
  
When we finish spending the federal magic funds-- matching funds that we've got which they keep telling us may not happen until April 2024, it's on the books that it would be implemented. So this is probably a different part of CMS than what you deal with, but we are really concerned about that. We are trying to get repeal of these restrictions into this year's budget which is supposed to be passed by tomorrow and will probably be passed next week. We get them repealed event next year's budget it's just something to be concerned about because a lot of people are not going to be eligible for home care if these restrictions are implemented. There's going to be increased injuries, hospitalizations, deaths, people forced into nursing facilities that things will happen.   
  
We've been spending a lot of time educating our facilitators about what this would mean and we have to actually educate our entire congressional delegation two years ago because our previous governor, who was finally taken down by some women, but what he wanted, he tried to sneak something into an omnibus budget bill to allow him to implement these restrictions. We had to meet with 20 people in the congressional delegation to get that out, treated back when he was still powerful.   
  
It's something that we are concerned about how CMS would go about allowing us to implement, or them rather, not us, to implement these restrictions.   
  
So, if you know a person that could deal with this I'd love to be in touch with them, you know.   
  
JESSICA PODESVA:   
Thank you, Heidi. Kate?   
  
SPEAKER:   
Thank you. Kate LaRose from Vermont. This is a bit event aside but it's an important aside. In the chat and seeing a lot of comments regarding testing and people getting home-based testing kits, which is great, and I suspect that most of those test kits are rapid antigen tests. Which we've known don't work very effectively since the summer.   
  
I don't know how many folks are aware of the FDA's updated emergency use authorization language that went out around the use of rapid antigens at the end of November.   
  
The reason we use tests is so that people are not infecting others, so there's not spread and so that people can quickly access treatment. The rapid antigens at this point, what we know as they are not picking up until days 5 to 7. The only treatment option is Paxil of it. For people to get it, first of all we know it's most effective within the first 72 hours of symptoms, but it has to be taken within the first five days.   
  
We have heard across the board that for people that need to stop medication for 12, 24, 36 hours they don't have enough time. They are not able to get called back in time to get called back at all. Generally there told with their not eligible for treatment which is not true.   
  
Medicaid and Medicare only cover rapid antigen tests. What I'm curious about is are there other states that are getting access to molecular home-based test such as (unknown term) because those are the tests that are picking up asymptomatic, those of the tests picking up on day one of symptoms. With (unknown term) they rolled out a free telehealth and overnight paxlovid delivery option. I'm curious if others have access that because we know that rapid antigens are working and giving people a lost-- false sense of security. They're losing out on their ability to treat and then infecting others, particularly in congregate care settings.   
  
JESSICA PODESVA:   
Thank you, Kate. If folks want to go ahead and stick their feedback to that in the chat or raise your hand we would love to hear from you.   
  
I also want to circle back to that question. For those of you who said no, that their states have not reached out to them, I'm really curious have you reached out to your states on this and what has been their response. If any. Or if you got no response would really like to know that as well. And what state you are from.   
  
And if you haven't what have been the barriers that have been preventing you from reaching out to your states?   
  
Anyone? Once again if you want to raise your hand you can click the reaction but not the bottom or here-- hit \*9 if you are joining us by phone.   
  
Lisa.   
  
SPEAKER:   
Hi. I'm not 100% sure if our CILs, I'm not hundred percent sure if our CILs have tried reaching out so far so don't really want to speak for them so far. But I think a big barrier for the state of Alaska has been that our programs have been in crisis because throughout the summer and maybe from the spring on they've just been so behind, and you know months and months behind and regular programs just to reach out to them I don't think, like we haven't even thought of it because they cannot even, they were not able to serve the people in a regular state of programming, you know.   
  
People were getting food stamps. Suddenly people were getting thousands of dollars in food stamps because maybe they caught up with one person. That's how far behind they were. So, I love hearing, I think it was Jane when she was talking about how she reached out to them and they talked with her and gave her all of that information. It gives me a great idea to take to the CILs and talk to them about how to talk to our public assistance and just give them ideas and talking points to take to them and start communication.   
  
I really appreciate this. Thank you so much.   
  
JESSICA PODESVA:   
Thank you, Lisa. You said you were from Alaska?   
  
SPEAKER:   
Yes.   
  
JESSICA PODESVA:   
Thank you. Alright, we have about five minutes left. Two we have any other hands raised? At this point I want to give the opportunity to either Erica or Vicky if you want to say a few words or if you have any questions that you have that maybe we have not hit yet. From ACL.   
  
SPEAKER:   
I'm Vicky, Deputy administrator for policy and evaluation at ACL. Thank you so much for inviting us to participate.   
  
I took a lot of notes. I think that access to testing is one area that we can help folks with and I'm going to leave that to Erica to explain. We've done one blog on what CILs and other entities funded by ACL can do in their states.   
  
I hear a lot of you taking those steps. I really appreciate the last speaker from Alaska seeing CILs are overwhelmed with their day-to-day work. So this is just something else to add to that.   
  
We know there are two separate issues. Medicaid eligibility and then you can retain your eligibility. One of the Medicaid coverage issues you will face likely you have your aid.   
  
There is a new document that (indiscernible) and states put out. ACL will be doing another blog on what happens to the defendant's case. That's really useful as well.   
  
I've got a number of notes on the issues. I'm going to put my email in the chat so if you have questions for me feel free to reach out as well. Thanks.   
  
JESSICA PODESVA:   
Thank you so much. Erica, I don't want to put you on the spot but I see you put some good information in the chat around test kits. Would you mind talking about that year as well?   
  
SPEAKER:   
Sure. I want to thank you for coming today and hosting a session because I know it's a lot of heavy. It's helpful for us at ACL to hear about the barriers you are facing on the ground because we are working with those folks so we can tell them what we are hearing and hopefully start moving some of those barriers for you all. That's the hope at least.   
  
I wanted to mention because I know a lot of you brought up there's a lack of access to test kits, the funding is drying up. We've been putting it in our monthly newsletters and there's so much in there I know it's hard to find. I put in there where you can go to get free test kits. I know Kate you are asking if it's a molecular or antigen. I'm not sure.   
  
(Unknown Name) would know. He's our contact that works on this project. We partnered up with the administration for strategic preparedness and response. They are going to be doing, they continue to do COVID-19 test distributions. You just have to sign up and you can order as many as you want. You can get five, 500.   
  
But the hope is that if everyone signs up, if there's another emergency down the road we will already have the framework in place to distribute other types of supplies. So, we are asking all of you to sign up. I was asking to put a link but we don't have a link yet. Poor Ed. We will rush in with our email to get the link.   
  
We are going to take back all of your comments and see how we can help. Ed's email, I put it above in the chat. edward.ahearn@acl.hhs.gov.   
  
JESSICA PODESVA:   
Thank you. On behalf of NCIL I want to thank all of you for attending today. Your feedback is incredibly helpful in forming NCIL's next step and advocacy around this issue. I want to thank you all for taking time out of your day to give us all this feedback. Thank you. We've been compiling some resources and we will be sending out additional resources in the next few weeks to hopefully also help. We will try to follow-up and answer as many of the questions raised as we can.   
  
Alright. Without further ado thank you so much for coming. We appreciate all of you. Enjoy the rest of your afternoon.   
  
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