

GCDD Webinar: “Medicaid and Health Care Protections: How People with Disabilities Could Be Impacted and What You Can Do”

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CART Transcript

>> Good afternoon, everyone. This is Dawn Alford with the Georgia Council on Developmental Disabilities and I want to be respectful of everyone's time. I have 1:30 p.m. I want to thank you for joining us for the webinar today for our Georgia Council on Developmental Disabilities sponsored educational event entitled threats to Medicaid and healthcare protection, how people with disabilities can be impacted and what you can do.

I just want to remind everyone a few housekeeping notes.

We do have everyone muted, so if you have a question, please go ahead and type your questions into the Q&A box.

Assuming time allows, we will try to answer all your questions at the end.

This will be recorded and archived on the Georgia Council on Developmental Disabilities' website for future reference.

With that, I am so honored to be able to announce to you, through our special presenter for today, Alison Barkoff. She is a Georgia native who now works in Washington, D.C. as the director of advocacy at the Center for Public Representation. She works on policy and litigations related to community integration and inclusion of people with disabilities, including Olmstead enforcement, Medicaid policies, employment, and housing and education.

We are very lucky to have her with us today, so without further ado, I'm going to turn it over to Alison.

Alison?

>> ALISON BARKOFF: Thank you, dawn. Can everybody hear me okay?

>> Yes, we can hear you loud and clear.

>> ALISON BARKOFF: Okay. Thanks so much, Dawn, for the introduction and, of course, the piece that Dawn forgot to say about me which is the most important thing when I speak to Georgia audiences, I may be known as Alison Barkoff but in the state, I am known as Evan Nodvin's sister, he is a Georgia Council member and one of y'all's superstars and I'm glad to be speaking to Georgia advocates and it's good to do a webinar to see my parents' names to call in and I wanted to thank Janice and Joe being on too.

I want to spend some time helping people understand what is happening in Washington, D.C. and helping people understand that probably every single person who is calling in today is impacted by what's happening here.

I really want to motivate people to get involved and get engaged and I'm going to spend some time talking about this.

So, with that....

I'm mostly going to be focusing today on threats on Medicaid but I will be touching upon some of the other healthcare protections for people with intellectual and developmental disabilities.

Just to make sure everybody understands what we're talking about when we're talking about Medicaid, it's the primary health insurance program for people with disabilities, for older Americans, seniors, and low-income populations.

And there's more than 10 million people across the country who have disabilities who are on Medicaid.

And even for people who are working and may be getting private health insurance, private health insurance typically only pays for medical services and Medicaid is the only source for people with disabilities for long-term services and supports. So things like residential supports, things like employment supports, and things like respite.

It provides a whole range of services that help people with disabilities to live and

thrive in the community. And one thing that I've been really running into as I've been talking to families across the country, Medicaid isn't called Medicaid in every state.

So, in Georgia, if you are getting services through the comp waiver, the NOW waiver, source, ICWP, CCSP, GAPP, or any EPSDT services, you or your family member are getting Medicaid services. And this bill will impact you.

So, when we think about --

>> ALISON BARKOFF: When we think about Medicaid and, again, how the bill I'm going to walk through really changes Medicaid, what I want to point out is while people with disabilities make up about 21% of the Medicaid population across the country, we are about 48% of the total spending of Medicaid. And that's in part because people with disabilities need long-term services and supports over the life span.

So, when I talk about the cuts to Medicaid that are in the proposed bill, I want everybody to remember that people with disabilities are going to be hurt more than other people with disabilities because we make up a larger proportion of the spending.

So, the way Medicaid, since 1965 when it was started, it's a federal and state government program. So, the federal government pays a part of the services and the state government pays a part of the cost of services.

And the shares that the federal government pays is based on the income and poverty level in the state.

So, in Georgia, 68.5% of every Medicaid dollar is funded by the Federal Government right now. That means Georgia only pays about 1/3 of actual Medicaid cost.

So, in a moment when I start talking to you about these huge cuts to federal spending, you need to think about, in Georgia, what that means for your state.

So, why are we talking about Medicaid right now? We're talking about Medicaid

because it is tied up in the middle of the Affordable Care Act repeal.

The name of the bill that's been introduced in the House is called the American Health Care Act or AHCA and it was introduced in March, I don't want to get into what they're using but they are using something called budget reconciliation and basically that process means that it can move incredibly quickly, it only needs a majority of both the House and Senate to support the bill. There can be no veto. There are very few amendments.

This bill was just introduced on March 13th. There hasn't been a single hearing, but it's already moved out of two committees in the House and we expect it to be on the floor maybe in the next week to ten days, and potentially even on the floor of the Senate by the end of this month.

This is unlike the regular order of bills.

So, I think the only thing that you need to know is because the Republicans are choosing to use this special budget bill, we really have very few chances to stop this and everybody really needs to be thinking about the implications and really engaged right now.

So, I do want to just touch on and I'm going to focus almost all of my presentation on the Medicaid pieces, but I do want to remind people that there are some very significant provisions in the Affordable Care Act that impact people with disabilities and many of these are on the chopping block in the AHCA.

The first thing is the Affordable Care Act expanding Medicaid, and we don't think about that with people with disabilities, we know that 1/3 of the population are people with disabilities.

It's primarily people who may have mental health or substance abuse disorders who fell through the cracks of traditional Medicaid eligibility, but there's also a large number of people who are waiting for Social Security things to get in with the GAPP period and that includes people with developmental disabilities.

It eliminates some of the essential health benefits that are required for the Medicaid expansion and exchange plans and those included services that are called habilitative services. There was another option for community services called Community First Choice which provides an alternative for people who would like to remain in the community and need help with activities of daily living as an alternative to nursing home care.

And many states have taken up this option and used it in their IDEA system, especially in Oregon.

The most important thing this bill does and why we're talking about Medicaid is it takes away most of the revenue uses of the Affordable Care Act and many of the taxes and mandates.

What does that mean? Budget reconciliation requires that to go through this process, it has to reduce the federal deficit. So that means not only does it have to be a cost-neutral bill, but it actually has to save money over a ten-year period.

So, what is Congress using as the "pay for" for this Affordable Care Act replacement? They are using Medicaid cuts.

So the Affordable Care Act restructures and significantly cuts spending on the Medicaid program on what is called per capita caps and I will explain to you what those are now.

So, these caps are truly a threat to Medicaid as we have known it for the last 55 years.

As I mentioned, the current structure, the bargain of Medicaid between states and the Federal Government is that for all actual spending on Medicaid-covered services, there is a split.

And you can see a picture, I have a graph that shows federal share in one color, state share, which is a smaller piece of the graph in another color.

So, again, on average, the Federal Government pays about 63%, 63¢ out of every

\$1 that a state spends.

And in Georgia, the rate is 68.5%.

And there are some services and some populations that get a higher match.

I'll just mention one that I know Georgia is using called Money Follows the Person, where the Federal Government pays 100% of the cost for the first year someone moves from an institution to the community.

And Georgia has very successfully been using that to transition people from nursing homes and from the state hospital.

So, again, the 68.5% match doesn't even include these enhanced matches under the current structure.

So, before the actual bill came out, we had heard a lot of talk from the Trump Administration and from Tom Price, who is now the head of Health and Human Services, and from leadership in the House, Paul Ryan, and some of their plans, that they would like to block grant Medicaid.

So, I want to talk about what that is really briefly, because I think people have now heard per capita caps and think we've dodged the block grant bullet.

But what I want to make clear is per capita caps are basically blocked grants by a different name.

So what a block grant is, is instead of splitting the cost of actual services, what it means is that the Federal Government would give a chunk of money to the state and the state would do with it as it pleases.

So, the most important thing about the block grant, and it's the same thing in the per capita caps, is the goal of this is to massively reduce federal spending.

So, how they set the formula for giving money to the states is set at a rate that is intended purposefully to grow a lot more slowly than the actual cost of Medicaid.

So, that means you get an initial funding and maybe in year one it covers most of your costs or just a little bit short, but over time, the difference between state

spending and the share it's getting from the government grows.

So, in ten years, that cost is going to be many times over, a huge budget shortfall that the state has.

This is a massive cost shift to the states.

In addition, there are Medicaid protections and eligibility and services that very, very likely will be cut as a result.

So that's what a block grant is. And I think we did a really good job explaining to people how bad block grants are.

So now this current bill does something called per capita caps. And, again, I just want to emphasize in many, many ways this is exactly the same.

So what the Federal Government is going to do is set a set amount per person enrolled in Medicaid, based on at least in this bill, the 2016 spending level.

So, if, for example, there's an aging population and more people need more services, this funding doesn't take that into account.

If, for example, the state would like to raise provider rates, as I know the state of Georgia is trying to do to make sure that people with more complex behavioral or medical needs can be served, they can't do that under this formula, they're stuck in a same rate.

If you're in a state, like Georgia, that has 9,000 people sitting on a wait list, you're not going to be able to have funding to help address that.

So, the only difference between a block grant and a per capita cap is if more people enter into the Medicaid program, say there's an economic downturn, the pot of money will grow, but, again, it does not take into account aging populations, changing healthcare needs, new technology.

So, just like block grants, it is a huge shift of costs to states. It's going to create a budget shortfall and huge pressure, which is going to lead to service cuts, lower provider rates, wait lists, and enrollment cuts.

And I have a picture showing that on my slide.

So, I just want to, again, I have a chart here talking about comparing the current structure of Medicaid to block grants and per capita caps.

So, it says on my chart if your state wants to add more enrollees, will you get more federal money under the current structure, yes, under a block grant, no, and under a per capita cap, yes.

That is one way per capita cap is bad.

But there are ways, say your state doesn't cover community-based outings or some new type of community-based service or they would like to start a new waiver, under the current structure, any of that spending would be matched 68¢ for every -- for the 30 something cents that the state pays. Under a block grant or per capita cap, you would not get any new federal money for any new services.

If the state decides they are going to cover a new prescription, under the current structure they would get matching federal funding, block grant & per capita cap, no.

Again, if you would like to increase provider reimbursement under the current structure, that is split under block grant and per capita cap, that would not be.

So, I want to talk about how a per capita cap is designed, and Georgia is particularly harmed by the way this is designed.

So, as I mentioned, there is a base year spending level that is set and it's based in this bill on 2016 spending.

I was literally in the office of a senator from Georgia today and they know that Georgia, in 2016, was 48th in spending on Medicaid.

So, what does that mean? That means that you're going to be based on a really low spending level and stuck in that for a very long time. Forever.

So, the base level is set. And then there is a growth index that's used every year.

And I have a chart with a picture of that in showing an arrow just going up just a little bit each year over time.

So, the growth index is what is really, really important, and that is what is leading to the very purposeful design of huge decreases in federal spending over time.

So, the AHCA, like its prior proposals, uses a growth index that's not based on actual historical Medicaid spending, but on the Consumer Price Index, which increases much more slowly than Medicaid spending.

So, as I mentioned, because it is lower than actual Medicaid spending, the federal funding gap grows each year and that means that state budget shortfalls, and their Medicaid programs will increase each year.

So, it's really going from bad to worse.

I have a chart here that shows both the reality of what the cost in the Medicaid program will likely be based on historic spending and the per capita cap growth, and you can see in the picture, it's an angle that shows the difference between reality in the per capita cap gets larger over time (and).

So just on Monday night, we all wondered what does this bill actually mean? And so there's something called the Congressional Budget Office that looks at the bill, that looks at the estimates and the number of people covered, it looks at the estimates in cost savings for each of the different provisions, so I think there are two pieces that I would really like to emphasize.

Number one, that 24 million people will lose healthcare coverage under this proposal.

And 14 million of those will be from Medicaid. Largely the Medicaid expansion, but it may very well be other people from Medicaid who, if a state tightens up its eligibility for traditional Medicaid, that could impact people with intellectual and developmental disabilities.

The second piece I think was 2½ times worse than actually we had predicted was the amount in cuts in federal Medicaid spending.

So, the Congressional Budget Office, and I have a picture of a graph showing what

the cuts to federal Medicaid spending will be over time.

And over the next ten years, and that's what this bill looks at, there will be an 880 billion, that's a B, billion dollar cut to Medicaid. That is over a 25% cut to Medicaid from where we are today.

From where we are today, with half a million people sitting on wait lists, where we are today with many, many providers not being reimbursed in a way that they can serve people with complex needs, and we are cutting 880 billion from this.

So, if you compare on my chart, I have a graph that shows this. In the first year, it's only a \$3 billion cut, and so maybe states can deal with that.

If you look at five years out, in 2022, it's \$111 billion cut, and by 2026, it's \$155 billion that year.

I just want everybody to have that sink in. We are talking about billions of dollars.

And, to be clear, the entire bill's cost savings is only \$327 billion. So, again, we are -- what is being proposed in the AHCA is to dramatically cut Medicaid in order to pay for access to healthcare for middle and upper-class people through a replacement of the Affordable Care Act.

So, what is the impact of a budget shortfall going to be? Again, I can't say it strongly enough. I'm here in D.C. with people who have been through this before and every single person says this is the most real potential to cut the safety net for people with disabilities.

And as these budget shortfalls grow, we are likely going to see cuts to services.

So, for example, for those of you who are on waivers, we may start seeing the states offer skinnier waivers and say well, we're not going to offer as much, as many hours of employment supports or residential supports or respite, for example.

Because the pot of money in the state's Medicaid budget is going to be shrinking, they're going to have to address what are called mandatory services first. Those are the traditional Medicaid healthcare services and they are the institution services.

Every single home and community-based service is an optional service. So all of the waivers I talked about, those are options for the state.

The Congressional Budget Office itself said it is very likely that states may completely eliminate optional services.

In addition, wait lists will grow. We know Georgia already has 9,000 people on wait lists. And with less money, there will be less opportunities to put new waivers out. Again, decreasing provider rates.

I want to, again, emphasize that Georgia spends less per capita on Medicaid than almost every other state. And Georgia is going to be tied in at that 2016 spending level.

I know that that is something that the Georgia delegation in D.C. understands and I would assume that your state Legislature and Governor understands or needs to be educated, how the per capita caps are going to particularly hurt a state like Georgia. Now, we keep hearing that these funding caps will do so much to give states flexibility and they're trying to sell these huge cuts.

But, again, what I want to emphasize is there already is a lot of flexibility in Medicaid, so there is a range of optional services that states can have.

There is lots of different ways you can target waivers, there are enhanced options like the Community First Choice, there's managed care authorities, there's a 1115 demonstration.

So it's really important for us to emphasize we don't need to cut \$880 billion from this program in order to give states flexibility.

And in fact some of the most innovative programs actually require front-end investments and that's not going to be able to be done with caps.

So, I hope I really have conveyed to people have serious the potential impacts are on all people with disabilities.

And it's up to all of us to educate our representatives and to tell our stories about

what Medicaid means to people with disabilities.

So, I want to talk about all the ways people can get involved.

So, what can you do?

The first thing you can do is it is incredibly important that you educate your representatives in Congress about the importance of Medicaid for people with disabilities, and your concerns about the impact of cuts to federal Medicaid spending through per capita caps.

I have met with a whole lot of legislators over the last several weeks and people don't generally understand what Medicaid means for people with disabilities. They think of it as a traditional healthcare program where you get access to medical services and prescriptions.

They do not understand that for people with disabilities, people like my brother, it means Evan can be a tax-paying citizen because he gets support through Medicaid, it means that my brother can live independently. For many families, it means the parents are able to go to work because they're able to get in-home supports.

And the people don't understand the cost effectiveness of Medicaid.

For someone like my brother in Georgia, the waivers are in the range of, you know, he gets around \$38,000 of Medicaid supports. Again, that is only 1/3 of it paid by the state.

And to be in an institutional setting is over 120,000.

So we need to get people out there to understand how important Medicaid is, what the cuts mean, and how cost effective it is.

Every single, you know, person that I've met with in D.C. has certainly talked about one of the main players here is not only Congress, but state governors, because it is your governor that's going to have to deal with these budgeted shortfalls.

So, it's very important to educate your governor and your State Legislature about how per capita caps would hurt your state's budget and shift costs to your state.

We have a lot of information. The national association of councils of developmental disabilities, my organization, and about a hundred other national disability organizations are part of a consortium called the consortium of citizens with disabilities.

We have been creating fact sheets and alerts for the disability community. We're working together with other groups like The Arc of the United States and we have great resources for anyone who's willing to tell their story, you do not need to be an expert on the Affordable Care Act or on this new legislation.

What every person on the phone is an expert at is talking about why Medicaid is so important to their lives or the lives of their family member.

And that's where families and people with disabilities are most important. Certainly people can go and talk policy, but what I have found to be most effective is people sharing their stories.

So, talking about what was your or your family member's life like before you were receiving Medicaid services? What was it like being on a wait list? You know, if you or your family member are on Medicaid, including a waiver, what are some of the most important services to you and what difference has that made in yours or your family member's lives?

You know, are you able to work? Are you able to access healthcare or therapies that you wouldn't be able to access otherwise?

So, telling your story is so important.

People need to be working and getting out the state level grassroots is critical. This doesn't only impact people with intellectual and developmental disabilities, it affects all people with disabilities.

And not only disabilities, but also seniors.

So, across disabilities and aging advocates should really work closely together.

You can connect with other national advocates.

I am a co-chair of the consortium of citizens with disabilities in helping lead this work here, and we have a whole grassroots committee that I'm part of where we are trying to get out people in key states.

Georgia is a key state, because Senator Isakson is on the Senate finance committee and the Senate health committee and both of those are critical to passing this.

And, again, I think that Senator Isaacson and others in the Georgia delegation understand that the per capita caps would particularly hurt a state like Georgia.

So, connect with efforts. Get people out. Calling -- meeting in person is best, if you can do that; if you're in D.C., if you can meet in their local office, there will be recess coming up in April.

Picking up the phone and calling is important. Sending a letter. Engaging the media is really helpful too.

If people can write an op-ed and place that in a paper in Georgia, talking about what Medicaid means to your life, that really, really is important.

Again, I don't think we're getting out there enough the face of Medicaid.

For people who are tech savvy, using social media, the #saveMedicaid, we have a whole week of social media action happening this week, people can follow me or others on Facebook and we have a different theme each day. We have something called a thunder clap that's happening tomorrow to have everybody be engaged in social media at the same time.

So, hopefully some of that information is out there. But, again, engaging and talking about why Medicaid is important and what cuts would mean to people with disabilities.

Finally, I will end with I have a slide talking about resources that can keep you informed and help you advocate.

As I mentioned, the Consortium for Citizens with Disabilities has an entire web page.

If you go to our front page, www.c-c-d.org, there is a -- something you can click on

that says protecting Medicaid and the Affordable Care Act and all of our alerts and our fact sheets are there. People should feel free to use them in any way that would be helpful.

The Arc of the United States has put together a life-line toolkit.

The National Health Law Program has a lot of great materials.

The Center on Budget and Policy Priorities has been looking at the financial impact of each of the proposals, and there is, if you'd like to join a Protect Our Care Coalition that is focused on saving Medicaid.

So, I'm going to stop there for a minute and open it up to questions.

>> KATE: Hello, folks, this is Kate Brady, the deputy director here on the Georgia Council on Developmental Disabilities and you'll see there on your screen there is a Q&A window. We would love to get your questions through that platform and I'm going to read them out so that everyone can hear the question and can hear Alison's response.

And Alison, this is just wonderful and such critical information, so thank you very much for being with us!

The first question that we have is how will UCP group home residents be impacted?

>> ALISON BARKOFF: So, I want to emphasize that anyone who is on Medicaid is really at risk here. So, as I mentioned, there's a couple different ways that, you know, I'm assuming people who are in UCP group homes are on Medicaid waivers. So, as I mentioned, I think it's very possible that as the budget shortfalls start happening in the state of Georgia, they might be limiting the amount of hours that someone might get in their waiver.

They may change, the people who now qualify, for example, for a full comprehensive waiver and comp waiver and getting supports, they may push more people into your day support waivers and saying do you really need to live outside of your home?

Can you be supported in your family? That costs us less money.

As I mentioned, already many group homes have very low reimbursement rates and I know from other work I'm doing in Georgia, it's really led to problems with providers being able to support people with more complex medical or behavioral needs, and so I'm very concerned about these cuts, not only disproportionately hurting people with disabilities, but, frankly, hurting people with the most significant disabilities.

And then I think if you're looking at new people coming in to waiver services, I think it's very likely that that 9,000 person wait list, it will explode if these Medicaid cuts go through.

>> Hey, Kate?

>> KATE: Thank you. Yes?

>> This is Mark Johnson. Can I ask a question?

>> KATE: Yes, go ahead, Mark.

>> Okay. Well, first of all, I want to thank GCDD for organizing this call. And Alison, I want to thank you for taking the time out of your busy schedule because I know you're on a lot of different calls.

>> ALISON BARKOFF: I am!

>> Doing this for a lot of people around the country.

I also want to just take the opportunity to thank a couple of the ADAPT groups here in Georgia and access to Columbus and disability link for signing your sign-on letter, so we did have some presence in some folks here in Georgia sign on that letter.

You referenced -- so I have two questions. One is you referenced that you were in a senator's office; am I to assume that was Senator Isaacson's office? And were you meeting with Jordan? Or can you give us a little more information about just who that senator was?

Are they hearing from us? That's what I want to know.

>> ALISON BARKOFF: So I'm happy to connect offline on all the details.

>> Please.

>> ALISON BARKOFF: But yes, on behalf of the consortium of citizens with disabilities, we are meeting with all of the key offices. And as I mentioned NACDD is part of it, actually Mark Nickel was there with me at this particular meeting.

So, we're trying to meet with all of the people that are in key committees and Senator Isaacson is a meeting we had because he is a Republican on the finance and health committee.

I think it's really important that we come in there and I particularly went to this meeting as a most of my life Georgia citizen and a sibling of a Georgia citizen.

I think they care so much more when they hear from you.

So, I would really encourage -- I first want to say to Mark, he has been awesome at getting people out. He is a maven on social media and I'm embarrassed to say I don't know how to tweet, but I got on this week, and thank you to Mark, because he's part of several great grassroots doing this.

And making sure, when you're asking, are they, like, people like Senator Isaacson are hearing from us, it's good that they hear from CDD and it's better if they get hundreds of calls from you guys.

I'm really pleased, I think there's going to be a delegation of a lot of people from Georgia at the Disability Policy seminar coming to D.C. next week and there are some Hill visits planned.

I cannot underestimate how important it is for people who are residents of that state to directly contact their representatives.

They'll listen to us, but they'll really listen to you.

So, Mark, thanks for bringing that up.

>> Yes.

>> ALISON BARKOFF: And it's really important. I know they're hearing from you,

but there was -- and I was surprised today in the meeting that per capita caps are on Senator Isaacson's mind and I think that probably when people are looking at the math and, as I mentioned, the CBO (sp) score just came out on Monday night and it was 2½ times worse in terms of Medicaid cuts, I think a lot of southern states are scratching their head and saying we really don't -- we didn't get a very good deal in this.

>> Just a follow-up question, some of you know that -- I know the council and some other folks attended the task force meeting that our lieutenant governor set up, the one response to our crisis in general and, two, respond to any changes that may come from D.C.

I can just tell people right now, the lieutenant governor and our governor need to hear from you.

>> ALISON BARKOFF: Yeah.

>> They really, really need to hear from you, especially our lieutenant governor, who is, in essence, facilitating that task.

So, just a heads up, folks. It's very important, as Alison said, to get our own congressional members, but don't underestimate what our -- in fact, our governor just got a letter from HHS and CMS and Tom Price and the new folks there, so please pay some attention to the lieutenant governor.

>> KATE: Thank you both.

We've gotten some really good kind of connected policy questions here on the feed about how this interacts with the Katie Beckett waiver and if there are any conflicts with EPSD and Olmstead.

>> ALISON BARKOFF: So, a couple things. I mean, we're all trying to figure out what this means. And, you know, what we're hearing here, at least in the press conferences that the Trump Administration has been having, as they're saying we're going to do this in three pieces, we'll push through the budget reconciliation, the

changes that we can, we'll make a bunch of regulatory changes and then we're going to do some other healthcare law later that changes things that we can't change through budget reconciliation.

And not to get too weedy about the process, but you're only allowed to put in budget reconciliation things that directly reduce federal deficits. So you couldn't rework the entire Medicaid program and lots of different things.

It's very hard to think about, because all this does is hugely changes the funding to Medicaid.

And we're trying to think about, well, what does that mean?

So when you ask about things like EPSDT, which is a mandatory service, I would say, you know, that falls into the bucket of things that the state is going to have to put its money towards first. I mean, EPSDT, state plan services, and nursing homes.

And that's why I'm saying when there's a shortfall, what I'm most concerned about is probably the thing that almost everyone on this phone cares a whole lot about, which is home and community-based services for adults.

Those are the things, any optional services are the ones that are on the chopping block.

In terms of Olmstead, you know, what does that mean? I mean, that's a little bit harder to talk about. You know, certainly that is the Americans with Disabilities Act and people have a civil right to live in the community.

On the other hand, the ADA does look at cost as part of it. There's a fundamental alteration defense and we've been so successful in Olmstead enforcement because we've been able to use Medicaid and have been able historically to say you can provide services to people in the community at a fraction of the cost in providing them services in institutional settings.

On the other hand, if the Medicaid program completely implodes and there are these huge cuts, I think it will make it more challenging for us to really implement

Olmstead.

On the other hand, I think it's one of the most important tools that we have.

You know, it's not something that the administration can take away. The ADA and Olmstead can be enforced by private organizations, like the Georgia Advocacy Office, like my organization, and so I do think it's an important tool that we have out there. But having access to community-based services and funding for it has been key to fulfilling the promise of Olmstead.

>> KATE: Indeed. Thank you.

For those of you that have asked about the PowerPoint, you'll see there that there's a link posted by our wonderful associate, Hanna Rosenfeld, and you'll be able to download this excellent document from that link and from the GCDD website. We've got a question here around the emphasis we've seen in the news about tier two and three of the process, and wondering if they passed the first portion. Is there any chance of a change significant enough to reinstate the federal share of Medicaid?

>> ALISON BARKOFF: So, this is where kind of the order of priority works.

So, if there's going to be a change to the Medicaid statute, it has to be done by Congress.

And if Congress passes a statute that says we are now doing per capita caps, the only way to change that per capita cap is by another statute.

And let me just say, if you've been watching any news channel, getting anything through Congress right now is, other than through this very unique budget reconciliation where you only have to get 50 people is really a challenge.

So, I think, you know, this is my own opinion, tier two and three are very theoretical.

You know, we did see Mark refer to there was a letter yesterday that came out that went to governors, that basically what the administration is saying is to the extent

we have any flexibility, any waivers, we're going to do everything we can to unroll the Affordable Care Act, to give states more flexibility around Medicaid within the limits of the law.

If they do things that are outside the law, they are -- they will be, I can say, talking to [chuckles] the different healthcare organizations in D.C., if they do things that are not allowed by current Medicaid law, they will be sued for violating federal law.

So what they can do by regulation is limited by law.

So, I'm very concerned if the per capita caps are part of the law, the only way to undo the per capita caps is by passing another law that undoes them.

They can't undo them through regulatory action.

This tier three is doing another piece of legislation through regular order, but right now there's -- I have a very hard time seeing that there's anything that enough Republicans and Democrats could agree on to get a piece of legislation through.

That's why the Republicans are doing this through budget reconciliation.

You know, they only have a couple-person majority in the Senate and they don't have enough of a majority in the Senate to prevent a filibuster, as you know.

So I am not relying on tier two and three.

So, we need to really, if what I'm telling people today concerns you, if \$880 billion in cuts to the life line for people with disabilities living in the community concerns you, don't wait for tier two and three.

The time to raise our communities' concerns is now.

>> KATE: To your point about timing, Alison, we have some questions here about timing. And when you expect will really start seeing the effects of this bill, if it passes?

>> ALISON BARKOFF: So, one thing that this current bill has most of these per capita caps and rollback of the Medicaid expansion happening in 2020.

And, again, I'm just sharing what is, you know, all throughout the media, so this is

not even just insider knowledge, but there are a whole group of people who think this is way too slow of a rollback and are pushing for 2018, so next year for these dramatic things to happen.

There's a whole set of, you know, again, it's really about getting the votes on the Republican side. There's a whole set of Republican governors who have come from expansion states who think this is way too fast, we need to slow it down.

So, again, if you look at the chart that I had a couple things back -- let me go back to it

This is what is based on the current bill right now, which if you look at 2020 is when the major cuts to Medicaid spending start happening, because that's when the block grant and the enhanced federal match for Medicaid expansion happens.

So it's a really, really steep increase between 2020 and 2026.

But there will be harm starting, you know, pretty quickly.

\$18 million loss in 2018 is nothing to laugh at.

And, again, there are some people who want to push up this timeline and if they do, probably the \$880 billion cut will go up, as well as the amount in the earlier years.

>> KATE: Thank you.

Another question: Since Georgia spends so little money on Medicaid and it is a high poverty state, does this possibly mean reopening institutions?

>> ALISON BARKOFF: You know, I'm -- as someone who has spent my entire professional career fighting for community-based services and making sure every person in an institution has an opportunity to be in the community, I'm very concerned about that, because we have a Medicaid that was written in 1965 that has what we call an institutional bias.

People have an entitlement to institutional services. All of the home and community-based services are optional, and if we're in a place where the wait list goes from 9,000 to 20,000 to 30,000 people, there are families who are sitting on

that wait list hanging on by their fingernails that may have no choice.

We know that's certainly true in the aging community where people would like to age in place and if they don't have those supports, they may need to go into nursing homes.

So, yes, I'm very concerned that given that this cuts funding hugely but doesn't change what's mandatory and what's optional very well could lead to more people in institutional settings.

>> KATE: Is it your estimation that governors in states facing big cuts are working together to make changes in the bill?

>> ALISON BARKOFF: So, what I do know that's public is right before the bill came out, the Republican Governors Association had a meeting, they met with Republican leadership, the Trump Administration -- again, this is all publicly available -- they had a set of principles they had agreed upon that got leaked out to the media. And what I can say is it was a lot more moderate than what was -- than what is in the bill.

And so certainly what they proposed did not end up in the bill.

Again, this is all in the media. We know there are a group of governors, particularly Republican governors in states that did the expansion, so they have a whole lot to lose, that have been meeting with HHS Secretary Price, Republican leadership in Congress, and the Trump Administration.

But, you know, because this budget reconciliation process, there's really not room to make changes.

I know what we're being told is they'd like to pass something out of the House. The plan is in regular order, a bill would go to the Senate and go through committees and have hearings.

None of those things are going to happen, it's going to go straight to the floor of the Senate for a vote up and down.

So, I think people are very concerned that the opportunities to make changes to this bill are limited.

But I think that the point Mark made, governors are a really important audience.

And we keep hearing that from people on the Hill, for sure.

>> KATE: So just because our time is getting low, we have some good questions calling us to kind of recap how grassroots advocates can best track the developments and know when to act, so maybe we could just revisit those resources.

Like the APSI -- the association for people --

>> ALISON BARKOFF: For people supporting employment first, yep.

>> KATE: -- they have some resources available and here's the slide from Alison's PowerPoint that you can use to connect with daily updates.

Anything else for you to add, Alison?

>> ALISON BARKOFF: Yeah, sure. So, yeah, APSI is part of CCD, their executive director, Alison Wool is very active and been on many Hill visits and active with me and talking about how important employment is.

Of course, many Republicans are very focused on jobs and we want to make sure that they understand that people with disabilities get supports through Medicaid to become tax-paying citizens, so I think it's a really important point, whoever brought that up.

We are working on doing alerts. So, again, you know, The Arc of the United States is a great resource. If you go to their web page, you can sign up for their alerts.

I am sending around all of CCD's alerts and we have that great page.

And, again, we use those.

If there are people who are interested in kind of taking a leadership role on a state-level in getting out the grassroots, I can coordinate, and you can feel free to send me an e-mail.

We have a list of people that we are sending things, alerts out to, so people get that.

The goal is not just for you, yourself, to get out, but for people to take a leadership role in getting out the grassroots in their states.

And I know we have the names of several people that I see on this phone call.

Social media, it's been kind of new for me. I learn it mostly from my 10 and 12-year-old, so I'm a little out of my element.

But for people who have some tolerance to join Facebook, there's a lot of activity happening there.

And, again, you can follow all of these different organizations. CDD has a web page, Arc has a web page, you can follow me. I do a lot of postings about information and alerts.

There are a lot of opportunities.

Mark is a great person to connect with in Georgia, he is part of another grassroots group that I am part of called disability for power and community integration that's been really, really active.

And just in any way you feel comfortable being involved, I just can't emphasize enough.

You know, I've been doing this work for a long time and one doesn't want to pull the fire alarm when there's not a real reason. It's a pull the fire alarm moment.

It's really, really important for all of us to think about how far we've moved over the last ten or fifteen years and really supporting people to have real lives in the community, to live independently, to work.

And this really, really could take us backwards.

So, I just encourage every person, again, you don't have to be an expert on this law.

What you are an expert on is what people with disabilities can do and how Medicaid helps them do that.

We have got to get the face of the disability community out there. The success of Medicaid, and maybe we have a chance of stopping this or at least making it less

bad.

>> KATE: Agreed. Thank you, Alison.

We have a great many folks who have shared with us the specific situations of their loved ones who have, a cost waiver here in Georgia and of course receive significant supports through those waivers, asking if we anticipate cuts and if we anticipate those, and we have seen authorized increased rates to our comprehensive waiver, which is one of our IDD waivers and folks have asked if we should anticipate that those changes would be undone.

>> ALISON BARKOFF: So, what I want to point out, because I have brought up, actually, the fact that you just got increased rates in your comp waiver approved in 2017.

One thing, my understanding is I met with Senator Isaacson's office, well, where were we in 2016? What are some of the new things that we have actually tried to improve our spending in Medicaid in 2017?

Again, I mean, there's this -- we're in this strange place where life is operating as normal in your Medicaid program until this bill passes.

So, when you're asking about this new comp renewal with enhanced rates, yeah, the state is going to be putting those in place, and rolling those out until this changes.

Again, to emphasize, the block grant, the per capita cap funding wouldn't start until 2020, so in some ways, it almost may be worse.

You know, people might be getting -- you might be ramping people up on Medicaid and improving services over the next two or three years, and think about in 2020, if you have these enhanced rates and more people on waivers, yet you're going back to your 2016 numbers, it's really, really challenging to think about.

But I want to encourage people, keep advocating around your Medicaid system now.

I mean, we're not -- this webinar isn't focused on this, but, you know, your state is in the middle of implementing the HCBS rules, and until those notices are notified,

the rule is the rule, the Medicaid system is still as it is, so people need to be on this dual track of fighting against this complete restructure of Medicaid, while at the same time doing everything that you can to improve your Medicaid system.

>> KATE: Thank you. I think maybe our last question, is through budget reconciliation, they can push this bill through faster, is there anything that citizens can do to slow this down and given an opportunity to meet with our legislators on the April break?

>> ALISON BARKOFF: Yeah, so, let me end with a glass half full.

>> KATE: [Chuckles].

>> ALISON BARKOFF: We, you, will are making a difference. So what we heard in December is this bill's going to come out, it's going to go through the House and Senate in a week and it's going to be on the governor's -- or President Trump's desk to sign in the first week of January.

Clearly that didn't happen.

They spent a fair amount of time saying the bill is coming out, the bill is coming out tomorrow and I think people started raising concerns about the ideas out there and it caused more time.

Initially the House has said we are getting this bill through everything in one week, going through the Senate, we are going to have this signed by the end of February. And actually in the budget reconciliation, it set an end of February deadline.

Clearly that's come and gone.

When this bill came out, I guess it's only been ten days, maybe the ten longest days of my life, but when this bill came out ten days ago, people thought it would already be within the House.

And if you follow -- I post lots of things, and so do others, that even in the House, you know, in the last three days, I think not 100% sure they have all the votes in the House. Over the last ten days, on the Senate again, because it's people are

reaching out and engaging.

You know, in order for this bill to not be able to pass, we need at least three senators to oppose the bill and there's probably four or five who have voiced public concerns.

So, the thing we can do to slow this down, the thing we can do to stop this is raise concerns, be very public about it, make sure the media hears these stories, because I don't think people, even people who voted to, you know, to have representatives repeal the Affordable Care Act thought this would be done on the backs of people with disabilities and seniors and low-income children.

And the more we can talk about what this means and how unfair it is, I think the more we can potentially have success.

>> KATE: Well, thank you, Alison, and thank you to everyone here who shared information. And you're already working with --

[Background noise].

>> KATE: -- with your local legislators and that you're already doing this work to help our leadership understand the impact of these changes.

And assure you all that if you've had questions that you feel we've not answered, we'll put out an e-mail up here in the chat window and I'll offer mine right now for those of you that missed my name, it's Kate, K-A-T-E dot Brady B-R-A-D-Y at GCDD.ga.gov and I'll put it in the chat window and you can follow-up with any questions at all.

And we so appreciate your time, Alison.

>> KATE: All right, we thank you folks for taking this time and all the hard work you do in working with Medicaid.

>> ALISON BARKOFF: Thanks for having me, everybody. And keep up the good work. Thanks.

>> KATE: Thank you.