**New Community Opportunities Two-Part Series: Part 2: CIL’s Involvement in Managed Care presented by Bill Henning, Merrill Friedman and Suzanne Crisp on August 30, 2012**

>> TIM: I'm Tim Fuchs with the independent council on living here in Washington, DC. And I want to welcome you all back to our webinar. Of course, this webinar just like Tuesday's is presented by the new community opportunities center, a national training and technical assistance program of ILRU, that's independent living research utilization in Houston, Texas and this webinar was organized and facilitated by the National Council on Independent Living. The support was provided by the U.S. Department of Education RSA. Today's call is being recorded so that we can archive on the ILRU website and just like Tuesday we're going to break several times during the presentation to answer your questions.

Let me quickly remind you, since you've already done this once, that you should have the PowerPoint and access to those handouts on the training page that was sent to you in the confirmation email.

Of course, that's the same confirmation and Web Page as Tuesday's call.

If you don't have that for any reason, you can email me at Tim@NCIL.ORG. That's Tim at NCIL.org and I've got that that's the PowerPoint for today, and the additional handouts that we encourage you to look at as well as the evaluation form for today. As I mentioned on Tuesday there are separate evaluations for each you will ca. So if you did it on Tuesday, thank you very much. If you did not do it Tuesday, it's not too late. Please do go back and do the one for Tuesday, and then please fill out the one for today when you're done. It's very easy to complete.

So, anyhow, I want to welcome back our presenters, Bill Henning from the Boston CIL, Merrill and Suzanne, and without any further adieu I will turn it over to Suzanne to get us started. Suzanne.

>> SUZANNE: Well, last Tuesday we had a really interactive and energetic discussion with our panelists. Basically we talked about concerns that individuals had about managed care, and then we talked about potential interventions or solutions that might ameliorate then the concerns.

By way of in formal summary I'm just going to go through a list of the concerns that we identified. The first is the loss of services or loss of eligibility transferring from a fee-for-service Medicaid agency-run program into managed care.

Also, we were concerned about losing the providers that we currently have, to a large degree managed care providers will create their own network, and we might be at risk of losing the providers that we've -- that have been providing us services for a long time.

We were concerned about the knowledge of the managed care organization, about disability issues, particularly, about the Americans with Disabilities Act and Olmstead. We also were concerned that they may lack some cultural sensitivity to -- to dealing with Persons with Disabilities.

Merrill talked about operating in a highly medical environment. Managed care entities first coming into long-term care, managed care seemed to be more comfortable with acute here in a medical environment as opposed to a social or non-medical environment.

Um -- we identified one big problem area, when a health plan does not include nursing facility services. We felt there was a -- always an incentive to transfer people, particularly with high needs, into nursing homes as opposed to keeping them in the community.

So we saw this as, certainly, a disincentive to home and community-based services.

We also were worried that a strong transition service component would be available, transitioning individuals from nursing facilities back into the community. And we were unclear about the lack of attention of behavioral health services that we were wondering if they would really be offered and be offered under the true effectiveness of recovery and peer mentorship.

Some of the solutions we came up with, we all agreed that being at the table when the program is being designed is really critical.

Having that seat at the table and a voice in the design of the programs.

Also, we -- we felt like Centers for Independent Living could offer training to managed care staff on both consumer choice and control and the Americans With Disabilities Act, Olmstead, the how to demedicalize your operation, and then available community resources. We also all agreed that continued advocacy to become the expert in the managed care process would be great for us in order to serve as advocates for the community. So with that in mind, I would like to ask Bill or Merrill if I've left anything out.

>> BILL: I think you almost said what we were going to say in today's presentation as well, very thorough.

>> MERRRILL: I think this call will be 60 minutes instead of 90 now.

>> BILL: More time for questions.

>> SUZANNE: Great, great, great, great, great. No, go ahead and talk about those things, these are just some of the concerns and interventions that we talked about on Tuesday then. I also wanted to mention that the -- we didn't get to all the questions and answers last Tuesday. ILRU has graciously put the answers to the questions by Bill and Merrill on the ILRU Web Page in the training section. You can easily link into the answers to all of the questions we didn't get to last Tuesday then.

So, with that involved -- let me ask Bill first, Bill, how are Centers for Independent Living involved in managed care, long-term care services.

>> BILL: They're involved in many, many ways. Presently in more so, I think, even potentially.

One of the ways to look at it, and to repeat some of what was said on Tuesday, and there's a lot of information turned out there and if someone's new to this, probably wouldn't hurt to repeat some of what we said or to just reaffirm it. You know, advocacy role that our center plays is critical. It's a core service for Independent Living Centers, so it shouldn't be foreign, it shouldn't be something we're afraid to do.

And it's going to be really essential, and there are so many places to speak up. But what we're really speaking up about is ensuring that these plans, which are coming, I think one of the key points you made on Tuesday, Suzanne, is that by 2014, over half the states in the country may have a managed care plan for people with disabilities. And it could only go up, because this will be a resort as states look to innervate or recoup savings, because in theory these plans may save money. It's not always clear they will but it may be there.

When you look at advocacy you want to see as soon as possible what a State is proposing. And the ways to do that are to contact your state Medicaid director and the centers for Medicaid and Medicare services, who over- -- CMS, as it's known, which oversees distribution of funding of Medicaid.

It's real critical.

Some states are pretty tight to the vest on this. They're afraid of reactions. They're just looking to thrust something out there, to in theory save money. You know, there is this search for panaceas to the increasing costs in healthcare provision, and one of the things that's clear to me is that the cost of long-term services and supports, home and community based services is now pretty widely known in the general public. For years it was almost a little dirty secret, I think, everyone focused on health reform for non-disabled populations. The costs associated with people with disabilities are now pretty well-known.

You know, I don't know the figure exactly, but 20% of the enrollees in Medicaid may be seen yours and people with disabilities might be 30%, but it's about 60 -- 80% of the cost. It's almost inverse on enrollment number versus percentage of cost.

So we've got to really be at the table, because people will look at ways to save money on the backs of people with disabilities.

So it's very much an IO imperative. Getting those plans, I know, one State has put a plan out there and advocates had to go through a freedom of information request to see the plan and to be able to comment.

Other states may be much more amenable to sitting down with advocates and designing the plan, looking at what's in the benefits package. Very critical.

Does it offer personal assistance services? Does it speak to community-based services in compliance with the Olmstead decision, so that we are having a real emphasis placed on getting people out of institutions? Does it speak to community-based meant tl health services, with a real emphasis on peer counseling as opposed to just a professional level.

That's a real important part.

Can you create forms? Can you get a state to have Forums on a plan, a real key thing. CMS is requiring this for states that are involved in the duals initiative, which is a plan in approximately -- over 20 states have submitted plans to have duals served which will be an integration of services for people on Medicare and Medicaid. CMS will require public Forums.

I know in one state, the one I live in, we had over 400 people with disabilities attend the forums. And, you know, a lot of what's vo fld in the health insurance plan is complicated. And you can find allies who know all the technical elements, the Legal Services, attorneys, the healthcare advocates, but it's really about saying: I want choice in my healthcare, I want continuity of care, I want consumer direction, hardcore independent living principles. Advocacy is just so important, getting the voice heard in whatever suits you, you know, working with legislators, working with members of Congress in your state. If you're hitting road-blocks.

In a way it's really by any means necessary, which is to say, it might be protest, it might be writing letters to the editor. It's what works for you and what gets our voices involved in these plans, because these plans are going to be dealing with how community-based services are provided across the nation.

I don't know, Merrill, if you want to add some points from your perspective as a provider, representative of a provider organization.

>> MERRRILL: I mean, I think that was probably one of the more comprehensive overviews (laugh) out there, but I do think a couple of things to add to that are, you know, other ways to kind of track kind of even what we would call a pipeline, what's coming down the pipe with Medicaid expansion, you know, and additional populations being enrolled and new states that are looking to it, and I think Suzanne referenced some of this the other day is the National Association of States United on aging and disability issues a Medicaid tracking. And so they show where states are and where they are in the process, and that's also another good tool to use.

The managed care organizations, I mean, you know, you guys already know this, but once there might be just a little blip on the radar, right? That a State is looking to do this, managed care organizations start showing up. You know? And they hit the ground running. And so to really build those relationships with the managed care organizations, and, you know, say, okay, if this is, you know, where the State is going, I mean, we want to be at the table now. You know?

And, you know, we want to be part of these conversations.

And I was mentioning when we were teeing up this call before everybody dialed in that I was, you know, really just supremely disheartened to hear that it was Florida that mentioned it, that parts probably irrelevant that managed organizations didn't want, you know, centers in training, you know, capacities and whatnot. But I think we're -- Bill and I are both involved in a group right now trying to change that perspective of managed care plans and their openness, if you will, to see the value of the IL community in totality.

And so we're -- we both took that very seriously and are going to be addressing it.

But I do think it's another way to get at the table and begin those conversations.

'Cause when -- when managed care, I mean, a little background, if a state starts to Buzz that there may be some managed care, either expansion or just start-up, the managed care organizations start meeting with legislators and cabinet secretaries.

And I know that's no surprise to you all, but, you know, to be part of those conversations and saying, okay. Here is how our state works now. We know there are going to be changes. And so anything that we can do, we being a managed care organization in alignment with the IL community to try our best at least to convince the state of what should be in there, because we referenced it last week on the call. You know, all of us can -- can ask a state to include, you know, certain benefits within these packages, but they're still going to do and operate that and we're learning more and more, I can think of a recent experience where the state just made decisions.

And, you know, they're not what is perceived by the centers as the best decisions.

And so we have to continue to try to influence this together.

>> BILL: Yeah, absolutely. I mean, advocates in this state are in conversation with ten potential managed care organizations who will be trying to run a program for people on Medicare and Medicaid in Massachusetts.

All things being equal, my sense is they want to do it right.

Do I think that every one of these managed care organizations will do it right? No.

Will some of them be huge national providers whose -- you know, organization product, you know, is bigger than your state's? Perhaps. You know, they may have a net income in the hundreds of billions of dollars or something, and you may say: How am I going to deal with them?

Well, you can deal with them. They will have some good people. And, you know, it doesn't even matter in one way, because if a State is bent on doing this, they may succeed in implementing one of these plans. And it's imperative to be engaged, and you may not get everything you want. And I'm not trying to be fatalistic here but I'm also saying as advocates and representatives of the community of people with disabilities, it's kind of our obligation to cut the best deal we can in a certain way.

I've had people say to me: You don't want to talk to that company. They don't have a good track-record in this other state. And I go, from the BCI L perspective I sure do 'cause the consumers don't care about what their track-record is in another state. They want good services, and we have to work with our consumers to try and cut the best deal. It may not be the best thing, but half a loaf may be better.

Again, I'm not trying to say settle for something less. Push your good benefits and if it's totally, totally horrible, maybe you try to stop it from coming in now, but I think one of the key contexts we laid out on Tuesday was: This health reform is coming. We have an election in November.

One party's candidates are proposing some very serious cuts to Medicare and Medicaid and the other party isn't talking about that, but there's a real undercurrent that they're going to be forced to make cuts to Medicare and Medicaid, too, because of the national deficit.

So, managed care may be one way to look at these issues in advocacy at all levels. And, you know, working with the managed care entity. And I said, trying to find out what's going on from CMS. They have Regional Offices around the country. I believe they're affiliated with the U.S. Department of Health and Human Services.

So there may not be one in your state, the Regional Office may be elsewhere or something like that. But find out where the Regional Office is for your region, and try and speak with the CMS rep who may be able to give you information, if you're being Stonewalled from a Medicaid director or whatever.

>> MERRRILL: Right. And the other thing is, you know, as well as in those resource buckets is the ACL, the administrator at Community living. I mean, they're actively engaged in the managed care conversation, and we have more people under the direction of assistant secretary Greenlee and Henry Claypool that are going to be keeping an eye on where this is going and how it's going and are extremely committed to ensuring that it -- that it -- I'm going to say goes right. You know, that it goes as right as it can. That, you know, the IL community is absolutely off the table and if not they're going to take issue with it.

>> BILL: Right. Claypool is heading it up and he's a person with a disability comes right out of the independent living community. He's coming to speak at the conference in two weeks. That's not by account. That's not a mistake, it's part advocacy to get the IL perspective out there. We're inviting the potential managed care companies to come to a Forum that will be, you know, an annual Forum that will be heavily populated with people with disabilities who will speak about consumer direction.

It doesn't have to be a fancy gathering or something special. Who -- it was a preestablished setting and we worked to get Henry to come. That's not going to solve everything, but it helps set the climate that has to be created around these things.

>> MERRRILL: Right. And it does. It's the climate and it's the accountability. And I think that, you know, we talked a little bit, you know, last -- on Tuesday about kind of the not so hot start of managed care, and, you know, some of the very bad decision-making that took place, and I know people, you know, kind of joke and say, it's, you know, dialing 1800 say no. And those days really are gone. And all of this increased server site and the growth and I would say even the growers of the managed care organizations and hopefully more are going to catch on, to realize the benefit of nobody knows what a day in the life of a person with a disability. And everybody is so different.

Nobody's going to know that except for you guys. And so it really is imperative that your continued advocacy is on educating managed care organizations and that's not enough.

>> BILL: Yeah, and just one last thing, it's part of it. If you can get on advisory boards or demand oversight entities such as only buds people, that have reviews of consumers and consumer plans all the better. Right now we have consumer review of the proposals submitted by the ten managed care organizations in Massachusetts. The state convened six people who are duly eligible for Medicare and Medicaid to review the proposals along with the state. That gives us some voice, it's off-record. I don't know what's going on, but it's six people who will be using the services. People with disabilities.

If they don't let you in, create your own scorecard, you know, get the plans, do a Freedom of Information Act, and grade them. You don't have to grade them on the complicated elements of how they're going to finance it. It may be above our heads, but will they support consumer-directed services? Will they support community-based services instead of nursing home placements?

Will you get something like support for DME or home modifications? They're important things out there that are definitely part of our language and should be part of plans or could be, whatever.

>> MERRRILL: Right. Well -- and because -- and part of that is, I mean, going forward, I mean, the new transparency, you know, regulations are helpful. And the fact that when managed care organizations get up and running, most states are now requiring that there is some form of a member, so an enrolle, a beneficiary advisory board as well as some stakeholder advisory board. But the thing is, I mean, it's -- that's not the time to get involved. It's great to be involved then, and please stay involved and get more involved, but to be involved earlier on that, and a year and a half and two years before that.

>> BILL: And one other and we'll keep adding in one more thing and one more thing, of course.

>> MERRRILL: (Laugh).

>> BILL: Make alliances with healthcare advocates, they're interested in this, from my experience, there are networks around the country. We work with many of them. We've received some financial support and grants from healthcare advocacy organizations.

They recognize the importance of the changes being thrust upon people with disabilities and elders via managed care.

So, you know, don't call me up to ask where the money is. I'm not sure I can -- I know any other place than what we've been able to tap into, but there may be local resources for it. But the bottom line is legal service entities, P and As, senior citizen advocacy groups, all are very involved in this.

We don't have to be isolated, and in fact, that's where we can get a lot of the technical expertise on things that we haven't always considered, like outcome measures for health insurance plan, um -- you know, functional assessments, data collection, things of that nature that are critical to how a plan is providing quality services for people with disabilities.

>> MERRRILL: You brought up a really good point, Bill, not shocking, but (laugh) that there are healthcare advocacy organizations within states that some kind of managed care organizations are more inclined to go to first 'cause it's familiar territory and I have found that often times there's not a connection between some of the healthcare other vocation organizations and the disability advocacy and service organizations.

And if you can start to make those connections, then you're going to get looped in as well earlier on first -- and because there are significant general healthcare -- um, policies, and -- that have to be included, and so people go there first when they look at healthcare and it makes sense.

>> BILL: Yeah.

>> MERRRILL: And I think, you know, that's a great point, that greater healthcare community is driving a lot of this much earlier on than the disability community is getting involved of the so if you can start linginging there, I just think that's great. And we can even help you, you know, connect to some of those not on this call but offline in some of the states that we know are some go-to organizations.

>> BILL: Absolutely. I mean, and two really strong groups around managed care issues just to throw out there that are -- outside of the disability world, a little bit are community catalyst, based in Boston which has a national presence.

>> MERRRILL: Correct.

>> BILL: In almost half of the states, and the national senior citizens law center out of California with an office in Washington, who have done some amazing analytical work on all the duals initiatives that states are putting out there. We've worked closely with both -- both -- most recently this morning. So.

>> MERRRILL: Right.

>> BILL: The disability advocates in Massachusetts who have been very active are hardly isolated on this stuff. We couldn't survive just on our own because some of -- you know, you're looking at multi-billion dollar remakes of the Health Care System. But we would lead this stuff. We lead this stuff and the people who are leading it are consumers saying I want consumer directed personal assistance services. I don't want to see my mental health services severed and be taken over by a provider I've never dealt with who doesn't understand me. That's what the core of this is.

And advocates get that message and serve in a supportive role, not in a leadership role, necessarily.

>> MERRRILL: Yeah. And you know, I think one thing, I'll just throw out there, and -- and this is -- it's not a frequent experience, but it has happened, and it's happened just even in the last couple of months, where we've reached out to centers, you know, to -- to get face-to-face time and learn about what's going on, and people will refuse -- the centers will refuse to meet with us. And I understand the anxiety around managed care, but refusing to meet with the managed care organizations and have that conversation at this point is not going to get the services to your folks coming in the door. And to you for your own center's sustainability.

>> BILL: Right. That's exactly what I was saying, because this stuff's coming, I keep saying it in a pretty not so sophisticated way. This stuff is coming (laugh) stuff. Managed care.

>> MERRRILL: Yeah.

>> BILL: Health reform. Health cuts, and the private entities, the private managed care organizations, good or bad, are going to be more and more in our lives, I think. I mean, I could be wrong, but, you know, as Suzanne said on the last call, up to 26 states by 2014 are projected to have managed care for people with disabilities in some form. And that's a huge chunk of the national population. Some of the smaller states are out of the game. So we're looking at 60, 80% of the country, and there may be more. You know, that's the latest prognostication.

>> MERRRILL: And meeting with the managed care organization doesn't mean that you're agreeing, you know, to do anything. It just means that you're agreeing to meet, and you're engaged in the dialogue, because your advocates are people with disabilities it's ensuring their long-term services and possibly your own are going to be covered in these things and allow it this step (laugh) in terms of these things and the stuff. I mean, it is here for a lot of people. It's very real for a lot of people. And saying no to that -- just the conversation is not putting the centers in the state's mind, right, in leadership positions on this, and that's what would be really cool to have happen. It's clear the centers are leaders in ensuring people's rights with their disability healthcare.

>> BILL: Then it's an informed no. The blanket saying no probably won't be that well received in the climate of change in the healthcare world whether it's proactive health reform or reactive health reform in the basis of we're going to cut the budget 20% and trim services.

Being engaged gives you a valid platform regardless of your ultimate position.

Pro or against managed care, but just to say, no, and I'm not engaging can be very disastrous in the current climate because there is such incentive to policymakers to try something new, and some room and it's going to be different in each state, innovative to destructive.

>> MERRRILL: Uh-huh.

>> BILL: And maybe little bits of both everywhere.

>> SUZANNE: So we've talked about advocacy in talking about the CIL involvement in managed care we've talked about advocacy and certainly inclusion involvement engagement in planning and developing and making sure that the NCO is our ally and serving on advisory boards and creating ombudsmen position. Is there anything else such as training for managed care staff or the provision of services that a CIL might look forward to in engaging with the managed care organizations in their states?

>> BILL: I can speak to training and Merrill can talk about specific services, we're putting together a package to offer to the managed care organizations. Doesn't mean they'll take all of these but I know there's some receptive have the because we're get the state to say they have to ramp up pretty aggressively on cultural competency around disability issues so here are some of the ways we hope to do that.

You know, training on disability culture, history of independent living, creating a welcoming environment for people with disabilities control, and life-lines for people with disabilities, accommodation strategies, over view of the ADA, working with interpreters, special topics in subpopulations which could be linguistic minorities, people who are deaf and hard-of-hearing, et cetera.

Those are some very basics we would envision using some of the well-known, you know, videoing out there, such as the life's worth living video put out last year by PBS on the history of the independent living movement.

The older one: When Billy broke his head with Billy Golfu is -- that appeared on PBS. These are some pretty important ways to start to change a culture that doesn't really grasp, I think, what it takes to provide services to people with disabilities, and it's long-term services and support/home and community based services are merged into managed care in lots of places, it's real critical that they understand how opinional those services are to the independence picture, the integration, the wellness, positive health out comes and then, of course, there are some individual services and Merrill, I know you're working with some CILs across the country to set up contracts.

>> MERRRILL: Yes. And one of the other videos, and I've actually had our executive leadership watch it known as the ten Commandments videos which is really kind of old school People First. Um -- and, you know, and I'm sure that they've seen that. So I think there's a lot, you know, building off of Bill's list that he just ran through.

>> BILL: Oh, yeah, it's hardly. (Laughter.)

>> BILL: Inclusive. That's for sure.

>> MERRRILL: Of ways.

>> BILL: And I haven't heard the video. Hadn't heard of the one you just said. That's already on our list in ten seconds.

>> MERRRILL: Right. (Laugh). Um -- you know, of making sure they're -- you know, we're having that. And I actually in terms of kind of People First and disability literacy over all have brought folks from the centers in to do the training with me, you know, for our folks, and so I mean there are definitely ways to get in on the overall perspective of, parents of, you know, children, whether young or adult with disabilities.

People with disabilities raising children, and how should those types of resources be incorporated. What the dignity of risk is. How do you define community living, I mean, our conversation is in the disability community is growing bigger and bigger every day as these health reform issues grow. And so the role of just that MCO education where Bill was just listing off, you know, really great opportunities, that list is going to continue to grow.

>> BILL: Uh-huh.

>> MERRILL: And then from that I think what you're asking us to do is to kind of spin into even some of t that services can provide, and so, you know, that list can also be sort of standard, if you will, and also very re88tive. So standard to me at least would be personal assistance services. Community reintegration nursing facility transition, liberation, I mean, whatever we (multiple speakers)

>> BILL: Yeah.

>> MERRILL: You know, options counseling. I mean, that's a great, great, great superb role in helping, you know, NCOs to really work to ensure under both like nursing facility diversion so people that, you know, don't end up with the option of nursing home, right, and also, nursing facility transition community reintegration liberation connecting housing resources, you know, at the NCOs, not every State has MFP, but where states do have money follows the person we can often work directly with the center's MFP coordinator but if there's no money follows the person, you know, what role can the centers take in really helping to find housing and locate housing?

You know, so those are -- and how to connect with home mods organizations 'cause I know sometimes at least two states the connection for that really isn't a very good connection that the State's picked so sometimes they have to be creative.

There are homemaker services, but, you know, centers can provide.

There are accessible transportation, if you already have transportation or have looked into providing accessible transportation, you can contract with the NCOs for that. Care-giver training. And again, that -- some of these are going to be very state-specific. We ran into a state just recently where the centers didn't meet the state's requirement for care-giver training but I think those things need to be changed. I don't think there's anybody better for people with disabilities to be giving care-giver training than the Centers for Independent Living, go ahead.

>> BILL: No, go ahead.

>> MERRILL: No. You go.

>> BILL: No, I mean, it's -- inculcating the managed care organization with independent -- independent living philosophy. Sometimes, you know, as we've looked at what we can provide, it really took some analysis, because it's so second nature, we didn't even realize how much it can be transferred to another body and how Alien it is in some sense to the whole medical community.

Of course, people who live it know it, but when you really think about what we talk about in the hallways of our Independent Living Center there's so much assumed between us, and then you start talking to a different population, and it's a foreign language, of course. So it's.

>> MERRILL: Right.

>> BILL: Trying to transfer a lot of those concepts which aid and abet wellness as we know in so many ways. And, you know, a little bit of the carrot, I don't want to overemphasize it is if you can make somebody more independent, you may make them healthier and if you make them healthier it's attractive to a managed care because they've got a fixed rate, usually, to provide services.

And if it's something that's cheaper, and again, I don't always want to just say, sell everything, if it's cheaper, because if it costs more, we don't want to see it forsaken either, you know.

>> MERRILL: Uh-huh.

>> BILL: Sometimes it's even more expensive to live in the community than a facility if someone needs round-the-clock services and we still want that person in the community.

>> MERRILL: Right.

>> BILL: But you can start to have some carrot approach to this stuff -- this stuff, there's the word again, but I mean, talk about housing search.

You know, one of the biggest predictors of instability which is a predictor of poor health does not having a stable housing situation. If someone's living in a homeless shelter or stuck in a rehab facilities or a nursing home.

So there would be some real attraction for that housing component. Even if it's not directly funded the NCO may be able to be convinced that this is attractive in some ways, and you know, and we would do that for consumers anyway at certain levels. You may be able to get some contractual arrangement that -- you know, fee-for-service even within this managed care setting to provide that.

>> MERRILL: And there are a lot of services that you guys instinctively provide that are very, you know, very attractive to a managed care organization. And even orientation mobility. Reading classes, you know, for people who are losing their vision as they age, you know, and how to utilize technology. So anything, you know, when people -- like we -- a lot of times, I saw early on, at least from our perspective that orientation mobility was really for people with visual disabilities, but the reality is, you know, people with -- you know, who newly encounter a physical disability or spinal cord injury later in life really need, you know, new ways to navigate their home.

So for you all to be doing that and having it reimbursed by the NCO makes perfectly good sense. So health and wellness and Bill is really you know touching on that in some of these more preventive services that you all can provide, and we've looked at doing things around partnering on nutrition, you know, finding physical fitness for people with disabilities in the community. Partnering on supportive employment and job coaching. Um –

>> BILL: Yeah, I would really emphasize trying to, you know, in advocacy or services if you're able to get something around vocational assessments and employment placement. I mean, it may be a stretch, but the -- you know, in the independence picture, employment can be very vital, whether it's full-time or part-time employment.

If you can get that looked at in an assessment, advocate for that. Hallelujah, you know you may not get what your local VR agency does, but people look at this that you need this community based service that may be part of the managed care in order to go to work. It's important that that start to register so that if somebody is going to be prescribed 30 hours a week of personal assistance service, but they really want to go to work they may need 40 hours now so they can get up earlier in the day or something like that. It's important wherein they're making that argue.

You know, you're not going to score on every point. No one is going to have the perfect system. We were asked what's the perfect system. Well, we aspire to that, we may not get there. But, you know, there's a niche for everybody to push their key component.

>> MERRILL: Exactly. And west brook services, west brook is incorporated in almost every managed care benefit package. And some organizations like a mere a group actually have an enhanced west (inaudible) benefit. And so the center is to be engaged in providing respite and being reimbursed for that as well it's a great capacity builder for you guys, and there's what we've talked around and about on it, we mentioned it the other day, too, but I just think provider training is critical. We find it way too often for kids, you know, born with disabilities, and, I mean, providers and traditional physicians just don't -- haven't gotten past some of the paternalism that's been experienced.

And for centers really to be engaged in educating providers on capabilities, on community resources, on individual capabilities of people in that, you know, everybody when their services and supports really should have this opportunity and not just an opportunity to live in the community but an opportunity to be fully included.

>> BILL: Yes.

>> MERRILL: And to have all of -- you know, um -- the available social, education, work, healthcare, housing, transportation. And a lot of providers just have not dealt with it. And as these provider networks really have to grow, and that is a standard, you know, under the oversight of the states, is to have a very diverse, strong term that's used is robust provider network. To do that we feed providers who actually understand.

>> BILL: Right. I mean, one of the things that's really emerging as a key need is understanding about the autism spectrum.

Great increase in the number of people with autism, of course.

Medical community doesn't know how to respond to it. Looks at it as a total medical issue of the doesn't know where to go with it. We can help educate. We can reach out to autism networks. Very important component of the discussion, I think.

>> MERRILL: Yeah. I mean, the autistic self-advocacy network is on the ground in many of these states and would be more than happy to, you know, participate in that training.

>> BILL: Absolutely.

>> MERRILL: I think as well people with psychiatric disabilities, you know, folks are still trying to figure out relationship with people with long-term psychiatric illnesses be in the community. Well, heck, yes, if that's what their choice is, you know, but there's still a lot of stigma. There's still a lot of unsure are the how to do that. And so I think it takes everybody at the table for educating on the tape abilities and normalcy of what disability is.

>> BILL: Did we want to work in questions at some point? (Laughter.)

>> TIM: I was just looking at the clock and we're half way through, it's 3:45 Eastern so let's break and take some questions and then we'll proceed after about ten minutes here. So...

Wes, would you mind giving the instructions for people on the phone.

>> MALE VOICE: If you have a question or comment please press.

>> TIM: I'll start off with people in the queue on the phone. Let's see. First of all, Matt asks if there is an easy way to determine which states already have a managed care plan, and if so, can the plans be reviewed? Any tips for Matt?

Suz this is Suzanne. You know, the true ven report that we made reference to on Tuesday, most of the report actually is a summary of all of the states that are currently operating with Medicaid and managed care.

So I think that would be a really good place to start. That gives a lot of detail about who's -- what organizations are involved in managed care, what programs within the state Medicaid structure are affected by managed care.

And I think that would be just a really, really great place to start. That's not going to give an indication of those that are currently thinking about managed care, but I would start there.

>> TIM: Okay. Thank, Suzanne. So for Matt and anyone else that's interested, after the all, if you open the PowerPoint from Tuesday, it was one of the first slides, has an actual link to that report. And that's where you can find that.

Okay. Good. So, let's see. We had a request for training topics but then Bill and Merrill, I think you covered that really well. So if anybody wants more advice, we can follow up afterwards, but that question came in before you all went through a number of other examples.

So I also have a question here from skill in Kansas, and they are asking if copies of the package that you all described would be available for download. Is there a way to get that online?

>> MERRILL: What package are you referring to?

>> TIM: I'm not sure.

>> MERRILL: Okay. Okay.

>> TIM: Copies of the package just described. It's the folks at skill want to clarify that. We'll find out if that's available online.

>> BILL: It may be that we listed all these services which is a composite and a potential (laugh).

>> TIM: Uh-huh. Uh-huh.

>> MERRILL: Got you.

>> BILL: I don't think you're going to find any single plan or any single state embracing everything we just spewed. But I think we're stating it so that people can seize on what may work for them in their comfort zone and where there is a real need.

>> TIM: Good. Well, let's go over to the phone, and see if any questions have come in, and then if I get a follow up from skill I'll let you all know.

>> MALE VOICE: There are two questions Billy Rich. The floor is yours.

>> FEMALE VOICE: Hello. Can you hear me? Hello.

>> MERRILL: Yes.

>> TIM: We sure can.

>> FEMALE VOICE: Yeah, Suzanne, I'm calling from disability partners in western North Carolina and you were talking about the respite. And since we have already experienced the managed care with two LMEs that I used to work with under the Case Management and now I'm with the CIL, respite has been removed and how they've covered this is they're stating that the provider now covers respite in the residential home. ICF MR homes or individuals in level.

>> SUZANNE: Oh, dear, no, no, no. No, no, no, no, no, I think that you into he had to contact the Medicaid office and tell them what the Independent Living Center is saying, we don't want to nushlize these people as a -- as a respite opportunity. That -- I mean that might be appropriate in some situations, but there definitely should be a choice of in-home respite or certainly not the only respite is in a -- in an institution. I'd contact Medicaid about that.

>> FEMALE VOICE: What has happened is that the provider is now responsible for providing the respite. For example, if you live in an AFL and it's run by you know A, B and Z company. They have to provide the respite where they used to contract it out that they'd have -- it was preremoved from residential care is what has happened under this managed care with the innovations that if you live in a residential setting and you receive services such as cap, that respite's been removed from the -- as far as a service. That the provider is now charged with taking care of it.

>> SUZANNE: Uh-huh.

>> FEMALE VOICE: That they provide the respite.

>> SUZANNE: In the facility.

>> FEMALE VOICE: The facility, which is a home, the AFL.

>> SUZANNE: Okay.

>> FEMALE VOICE: And so that what has happened is that they either won't utilize the respite services or they're going to provide respite in their home which does not allow the person taking care of the individual time like respite would be they would either go off and spend time with somebody. They rarely spent respite time at home.

>> SUZANNE: I don't think they understand respite. Respite is relief for the care-giver.

>> FEMALE VOICE: Exactly.

>> SUZANNE: Yeah.

>> FEMALE VOICE: That's the problem, that's why it doesn't add up. The relief for the care-giver can't happen. It doesn't happen -- it's basically been removed. It is no loner a service.

>> SUZANNE: Oh, dear.

>> FEMALE VOICE: In western North Carolina under western Highlands and smoky mountains if you live in an AFL and you have an individual that needs special needs you don't receive respite.

The provider will give it to them and they are stating that that has to happen in the home. Which means that the care-giver can't stay in their own home and have a break or they can oh on vacation but the individual who is coming to give respite will be providing it in their home while they're away, it's really -- this is happening, that's already started as of January 1st.

>> SUZANNE: Oh, dear, dear, have you talked to the Medicaid agency about this –

>> FEMALE VOICE: There's been lawsuits but nothing's been really happening and the appeals process is another thing that's a problem.

>> SUZANNE: Oh, dear.

>> FEMALE VOICE: There's not been any. I'm just surprised nobody has -- this hasn't happened to anybody that we are one of the first, it sounds like North Carolina was one of the -- as far as being managed care.

> SUZANNE: Uh-huh.

>> FEMALE VOICE: That it's really they've kind of operated it or started it.

>> SUZANNE: Has anybody else on the phone experienced respite services being provided in this manner? Or Merrill, maybe you could help us out here, too.

>> MERRILL: No. I mean respite is not about people living in AL Fs or anything, my comment was going to be I would encourage your states to also to really start to look at respite going beyond just being relief for care-givers and families. I mean it's really for, you know, the person themselves who might actually want to get away from their family and get away from their care-givers that respite should take on a -- you know, it's a benefit for them, as well.

>> SUZANNE: Uh-huh. Good point.

>> BILL: Some of the question -- I just wanted to respond to some of the questions that pop up online about the package of, you know, we were just asking a question, the package on trainings. We will be able to put together after this call some of the trainings we suggested for people, training topics, things like that, and some of the other healthcare advocacy groups that are out there that people might be able to tap into. I'm not going to recite every potential training opportunity we said that's out there.

>> MERRILL: And some of the healthcare advocacy groups are very specific to the state. They're not national. And the ones you know, that are being tapped by the states are those that are at the state level. So each state's going to have their own.

>> BILL: In the disability world look at nickel and adapt right off the start.

>> TIM: Good. Okay. So we'll get those posted thanks, Bill. Let's go back towest and see if we can take that second question from the phone.

>> MALE VOICE: Megan the floor is yours.

>> FEMALE VOICE: Hi, this is Megan in St. Louis, Missouri and my question is about -- well, let me just ask it, we talked a lot about trainings that CILs can provide to medical providers you know, talked about these packages and everything, I guess I'm curious as to what accountability thes are there for the providers to take advantage for those trainings, what are those insurance companies doing to make sure that those providers are actually taking advantage of the training that CILs are willing to provide.

>> MERRILL: Take the question, we referenced some of this on Tuesday, but within the contract that MCOs assigned with the states it lists out accountability standards and oversight measures for the NCO and then for the MCO with the providers and so every state dictates, basically, what the obligations are to be, and then managed care has a A meet those and then hopefully exceed them to some extent. So they could be around, you know, a certain number of trainings, you know, for providers, and how often they would be and the providers have to be there to meet their credentialing obligations, and they could be from cultural competency to ADA accessibility to -- I mean, any aspect of it. But it is spelled out within the contracts, and the measures that you have to meet and the state audits you.

>> BILL: It reemphasizes this somewhat critical but seemingly technical element of being there, if you can, as contracts are written, what are the standards, what are the outcome measures, because absent our voices in this discussion, they will probably resort to whatever's easiest. You know, it may be so much as a paste and clip on Medicare standards, if it's a duals program and Medicare is primarily focusing on primary care, not the home and community-based services, and then there is no standards to hold people to. And the same would be for training. So, that is the place to do it. Use whatever priority you can to -- to hold them to it.

>> MERRILL: Right. And so like you know one of them that we do and that we've talked, which is why we, you know, bring the centers into it is that we want to en shoo you are that our providers are getting training on working with people with disabilities and are interactive with people with disabilities in helping to really make a dent and move the needle on healthcare disparities, and you know, their cultural component of people with disabilities that may live in frontier land and rural lands and in urban areas. So I mean, it is somewhat -- unless it's very prescriptive by the State contract, it could be held up to the discretion of the MCO and that's where, again, that advocacy comes in at the table to ensure that the MCOs aren't just you know training providers on how to submit a claim. Right? Because that's pretty standard. They should be doing that, but training needs to go beyond.

>> TIM: Okay.

>> SUZANNE: And now, I have a question, are the contracts that are negotiated between the state Medicaid agency and the MCO, is that a public document?

>> MERRILL: Um -- oh, God, each State is different, what they post.

>> SUZANNE: Oh.

>> MERRILL: As public. Right? So there are always going to be parts of contracts that are not going to be public.

>> SUZANNE: Uh-huh.

>> MERRILL: And then there are other parts that are actually posted even online that you can get to, and some of these, you know, measures and training. So if your state sites should have them, your state government websites and some -- I don't know that you'd even have to FOYA them, you may, but that varies, too, I know that's such Anne knowing answer after a while that it all varies, but it does.

>> SUZANNE: Uh-huh. Okay, thank you.

>> MERRILL: So.

>> BILL: And just because.

>> MERRILL: The communication you have with the state, like if we send the state a letter, even that gets posted online. (Laughter.)

>> SUZANNE: I love the transparencies.

>> TIM: Just quickly, Bill, before we go back to the presentation you've mentioned working with healthcare advocacy groups and we've got a question from someone looking for some examples of who that might be. Do you -- do you have some examples of healthcare advocacy groups that you've had success with?

>> BILL: Well, I mean in a national level I had referenced earlier, community catalyst and national senior citizens law center.

DREDF has been very big on some of the issues around healthcare delivery disability rights and education fund.

Of course, NICL, ADAPT. As various disability groups active on healthcare advocacy and community organizing. There are -- you know, you might do a Google search: Healthcare advocacy groups in my state. Healthcare for all in my state.

We've worked very closely with healthcare for all in Massachusetts, who were well-known for some of the Massachusetts health reform initiatives.

And they've been very close partners with us, and have opened up avenues and you know, legislative arenas where we had connections and we didn't.

It's really knowing who's in your backyard, who is in your backyard, whether it's a national group supporting a local group or just a locally-funded group.

>> MERRILL: Right. And so like the autistic self-advocacy network, the National Council on Disability, we've already mentioned, NI C element, adapt, all of the large disability groups really are engaged in the healthcare conversation right now. But then there are, you know, policy groups that already state, like Nebraska Apple seed or a children's alliance in Washington state or a health institute. I mean, there really aren't are, but, you know, Bill is right, a lot of it is just having a Google who they might be. And if you're State is already starting to talk, they're going to be listed on your state website as to who's already communicating with the state on healthcare issues.

>> TIM: Okay.

>> BILL: And check your protection and advocacy agencies as well.

>> MERRILL: Yeah.

>> TIM: Thanks, Suzanne, let's get back to the presentation, we've got half an hour left.

>> SUZANNE: Okay, okay, good. I think I'm going to combine Slide 4 and 5. They ask virtually the same question, it's just different components.

So what is the service administrative and financial capacity that CIL should have in order to operate a managed care environment?

>> BILL: Gosh -- um -- you know, one of the things -- that is a challenge. Capacity is a real challenge, I think, for a lot of programs the there may be some very big Independent Living Centers, I believe we may know some of them across the country. That said, a lot of centers are smaller, have smaller budgets.

And that's where getting a contract there requires, I think, some business sense. You should be paid if you're providing consistently a service to a managed care entity. You know, it does raise some questions. We're funded through RSA to provide core independent living services. You may be fortunate and get a state supplement to that. You may not.

So in theory you're supposed to provide some of these services already. So is it double-billing? Well, it's a very unique service specific to the managed care organization, it may not be anything ethically wrong with that. You have a right to do fee-for-service. You have a right to sell your expertise. And that's a lot of what we're talking about with these services, and it's a way to finance it and build your program.

Administratively, you know, one of the concerns is going to be if you're working with an entity, if you're providing services, say, even service coordination, if you're doing that, then, you know, your data system has to have some compatibility or transferability with the MCOs and that, you know, you can ask the MCO for assistance with that.

Um -- you know, it is a real issue, but it's also opportunity. I think, you think, one of the things that challenges Independent Living Centers is that there's finite money. There's finite government money. We're in an environment where government money is likely to be shrinking if not already minimized in your own state and locality. So you have to look at this as a business venture as well. And it's an opportunity. It's a new shape of how community services are going to be provided. It is getting in on the game. You know, some decades ago independent living advocates in many places took the step into the game by saying: We will provide personal assistance services. Some programs will say, no, we should advocate. We shouldn't provide the services and I respect that. I've been on -- in a center that's on either side of that equation.

But we are talking about remaking a system that is intensely involved in the lives of people with disabilities, the Health Care System, and most especially, the home and community-based service systems as funded by Medicaid. And if -- you know, it's repetitive, but, you know, if we're not at that table, if we're not engaged, advocating, agitating, organizing, then the system isn't going to look the way we want it. I do not think it's a sin to be part of this.

My organization is a founding member from a local -- of a local managed care organization, and our partner is healthcare for all, the health advocacy group in Boston, and this is a program that specializes in services to people with disabilities and Sr.'s through a managed care, consumer directed model. Not just person-centered but consumer-directed and there is a difference there. And the goal was to shape the system. Not just talk about it, but to have a live, living model that can be built upon.

And, you know, there are some programs elsewhere in the country out of New York, Rick Serpen's group in Manhattan has heavy involvement. Out in Wisconsin with Tim cook. There are some models out there and they're worth replicating, they're worth jump anding in. Challenges some of our separation of church and advocacy but the game's pretty serious these days. (Pause.)

>> SUZANNE: Great. Merrill, do you have anything to add as far as capacity for the CILs either administrative, financial or service capacity?

>> MERRILL: I -- you know, I hate to say this, I think Bill kind of ran a pretty comprehensive list, you know, from there, but it really is, you know, even with the conversations that I've had with many of the centers, and it's hard sometimes 'cause you start to predict and then an RFP kind of comes out or the integrity of the contracts have changed, you know, from a state perspective. You know, and so you can't always predict. I think predictability is very difficult. But to really look at the services that are incorporated into managed care over all and to MLTSS, managed long-term services and support, and say: Where -- where do I fit in here?

So I understand that my -- you know, center advocacy hat, but here are some services that I really think our organization has -- um, the strength, you know, to do and the bandwidth to do and I'd like to start to build that up. You know, and kind of get ahead of the game so if there are licensing requirements and Certification requirements, you're taking care of those things along the way. Because once those RFPs hit the street, it's chaos. I mean, and people have felt that.

And, you know, it's like oh my God, we have to get this LOI, this letter of intent. But, you know, we can't really say we can do that, because we're not ready yet. So, it is trying to predict the trend of what your state might be looking for, in getting some of those Certifications out of the way, getting some of those people, those conversations with other community resources that you may want to partner with.

Let's say just to even get started before you fully bring it in-house and really start to build that up, because there are requirements that -- that are in it. Sometimes it's billing systems, you know, if your computers aren't really up to par, you know, you may want to start looking at how am I going to get better computer systems so that I can, you know, submit claims, right?

'Cause that's kind of part of the history with managed care is if you don't submit a claimed claim you won't get paid. Well, nobody wants to deal with that. You know, you want to be able to, you know, get your claims in, and you want to get paid timely from the managed care organization. So even just some of those kind of technical pieces.

>> BILL: But I do think this precedence within our industry so-to-speak, you think, lots of centers provide personal assistance services at varying degrees whether it's skills, training or actually coordination, referral for attendance, even some higher attendance in an agency model. You know, many centers are Medicaid vendors.

It's daunting, you know, and on the call on Tuesday somebody referenced what about if we're providing services, will that compromise our advocacy and I think the response to that is you have to do what you do best at your center. It can be an either/or although it doesn't necessarily have to be an either/or situation.

But look at those centers already with Medicaid contracts which gives you a leg up on trying to work with a managed care entity or the state. Maybe it's just providing trainings, where it's a flat fee. We will provide a training on independent living philosophy and the history of disability rights or something like that. You know, 500 bucks, a thousand bucks, it gets you into the game. And that's where we need to be.

>> MERRILL: Right. How does your state view that? Is that going to be a covered expense? You know, a covered service. But, yes. Get into the game. As Bill said.

>> SUZANNE: Great. Thanks, thanks. I'd like to ask a question now. Let's put ourselves in a CIL situation.

Why should I become involved? Why should I even consider going through all of this, building my capacity, in order to be a player at the table? Why should I do that?

>> MERRILL: You know, I'll kick this one off and then I know Bill is going to just run, run, run with it. So, you know, I would say when centers kind of do that gut check and say: How do I have my advocacy hat and not marginalize that by providing services, you know, this is where when you say: Why should I be involved? It is your advocacy hat that's going to drive the why. Right?

Because people with disabilities who are accessing services need you to be at the game and the core principles that -- of a center. And an advocate. And so, then it just comes to talent. Why you should be in the game is because centers have the talent. Centers have the resources, centers have the know-how and centers can provide well beyond, I mean, were he don't want to leave it to people to start providing home services, for personal services for people with disabilities.

>> BILL: You need to get care.

>> MERRILL: Right.

>> BILL: Fine line of care which can be important for some folks, yes, but it can be patronizing, it can be demeaning as opposed to personal assistance services. We will surrender -- surrender the agenda if we're not engaged.

>> MERRILL: Right. And so if somebody comes in, exactly, to provide care for you, and do that, they're not going to say: All right. What can we do to help you? Okay, you're already up and showered today. This is great. So, you know, where do you want to work? What do we need to do for your employment skills, where do you want to go banking, where do you want to go over here, how do you want to get your modified car? We need people from the centers to be driving them.

>> BILL: Yeah, you know, and, you know, the whole, I think, basis of what Merrill and I are saying, and really for all of this, it talks about managed care, but I can't say enough. Almost everything we're talking about is pertinent to the whole health reform scenario.

I mean, there may be touching u you're not going to be able to get yourselves a contract with some entity that's cutting services, but being at the table that we've said 500 times today alone, is going to, perhaps, mitigate some of the cuts. Maybe, you know, allow for innovation instead of devastation.

That's what this really, I think, is focusing on. And just this inextricable link between what is healthcare and Medicaid services and home and community-based services, and independent living, for so many of the people we serve.

People with disabilities aren't necessarily poor, but a lot of the people coming into the centers are poor, are on -- therefore, are on Medicaid, and that's where -- um, a lot of reform is going to happen. I said earlier, you know, the little dirty secret that was in many of our communities for a long time, that LTSS home and community based services are expensive, is not a secret anymore.

It really is not. It's addressed in, you know, the affordable care act. It's addressed and will be addressed in, you know, reform proposals put out by -- on the other side of things by Mitt Romney and Mr. Ryan. And I'm not saying which is better or which isn't. But both will change the systems that our consumers are very involved with iflt and we're not going to be able to change the face of healthcare. You know, which I think we all want to be involved in, and we talked about it some on Tuesday again, you know, kind of this demedicalizing the healthcare model.

But for the future of long-term services and supports, if we're not changing that perception that Bill has just mentioned there about healthcare and ensuring that it incorporates employment and housing and transportation and almost it applies -- and so many other pieces, and you know if somebody's going off to college and they use a wheelchair, and they're part of, you know, managed care, and somebody says -- and the person says, you know, I want lights on my wheelchair. You know, and managed care comes in and says well, I don't see that as medical necessity.

Why do you need lights, at least your wheelchair goes forward you delve into the depths of an insurance plan, it has many components, all of them of high importance, but on a baseline level, it's just talking about -- you know, to repeat myself, it's consumer control, consumer direction independent living. You can start out at the most fundamental level. People will ask you questions and you find out how much you really know.

People do interact with these systems way too much. It's not always positive, and that's why speaking truth to the -- you know, speaking power to this truth and truth to that power, real important in this context.

>> SUZANNE: Great. I had a question for Merrill. Merrill, are your -- managed care organizations, are they sensitive to supportive employment? Are we seeing that come forward as a viable service?

>> MERRILL: Um, I don't want to swear to you that every managed care organization really understands supportive employment and its value.

>> SUZANNE: Uh-huh.

>> MERRILL: Nor would I say that every managed care organization sees how important competitive employment for people with disabilities is.

I will say that because of this wave of engagement in the stakeholder community that supportive employment is being included into some of these new 1115 global waivers.

>> SUZANNE: Uh-huh.

>> MERRILL: And population enrollment is changing, and so managed care organizations if they're not already, have to see the value of it and how important it is. And so I can't commit to you that they're all there now. No. In fact, I'd say probably not.

>> BILL: No. I think we have.

>> MERRILL: (Multiple speakers) trend.

>> BILL: We have a long ways to go, but I know Merrill's referenced the autistic self is there advocacy network, they're trying hard to include VR evaluations and medical assessments and that's so appropriate, because you don't, you know, we don't want a medical (inaudible) around an assessment but you want it understood that the support services that we're talking about in managed care, the LTSS is critical to they live. It's about mirroring that, so that people can choose where they live and then choose the services that they're going to get. And they may want those services to be delivered, you know, at the park, and at the playground and at their place of employment. You know, and everything else.

So it's really kind of changing some of these very structured, formally, you know, paternalistic bucket of services and making the person as they drive and select and choose and pick where they are, what they're doing and what services that they're getting that that all goes with them.

>> SUZANNE: Right. I think we're ready, Tim, to go to questions now.

>> TIM: All right. Okay. Let's do that. Let's start off on the phone this tile. Can you help us with that.

>> MALE VOICE: Certainly again the floor is open for your questions if you have a question again I remind you please press seven or Q on your key pads. (Pause.) First question comes from (inaudible). The floor is yours.

>> FEMALE VOICE: Hi. I'm from Los Angeles, the CIL down here. I have heard during the course of the presentation this morning, and I just would like to ask a little bit more about that, of the new transparencies regulations. What's that about and how does that affect the transition from fee-for-service IHSS, which is personal care down here in California to -- to the HMO model of IHSS, which we're all very nervous about, because we've had IHSS since Ned Roberts. It's not a perfect system but we've been tweaking it. And it's very -- well, it's good for those of us who are self-directing.

And so the specter of having to transition to the HMO with all the horror stories we're hearing, it's really making us very nervous. So if you can please give us some light on that.

>> TIM: Do you have information on that, Merrill? I do not.

>> MERRILL: I am not familiar with California.

>> SUZANNE: I'm wondering if we're talking about the new transparencies rules under the 1115 demonstrations.

>> TIM: Yeah.

>> SUZANNE: I know that CMS came out with a state Medicaid letter, director's letter probably two months ago that specified that any -- any -- any changes that the state anticipates in their service delivery system has to be vetted completely and fully with advocates as well as stake-holders within their group. And it does have to be a fairly formal process. And they're so serious about it that Kansas and New Mexico submitted 11 fifteen's without doing a good job of that community inclusion cpon nep. And CMS rejected their applications that's what I know about that.

>> BILL: That sounds right to me.

>> MERRILL: That is correct, there are a list of those and there are in terms of public comment periods now, I know there part of those waivers, you know, were sent back, due to not reaching out to IHS, the Native American health systems, Indian health systems.

And so it has to be as comprehensive, it has to include face-to-face, it has to include public written comments, but, yeah, there -- it's -- stakeholder -- and a lot of that is pushing again from leadership in DC. So I think, you know, we continue to say, you know, engage with CMS. Engage with the ACL, you know, the community administration on community living.

These folks are driving a lot of these accountability changes. And, you know, they are doing their own advocacy to ensure that there is transparencies as models are developed, as a justments are made and as changes are made that these are very public, public issues, and I think that's important.

>> BILL: Yeah, and if folks aren't terrified then it's taken publicly through the media, take it right to the door steps of the Medicaid agency or the providers themselves. You know, I -- California is huge. I understand it's got the County delivery of PAS services, it's pretty complicated, but we also know there is a budget deficit that's bigger than some state budgets in their total, and there's a horrible shakedown going on, so I think it's using every advantage that can be grasped to ensure that the integrity of services remains to the highest degree possible. (Pause.)

>> TIM: Okay.

>> BILL: And really use, I think the transparencies regs as Suzanne stated, become a very legitimate option, because some states will say: Here's the plan, and it's -- you know, give me your feedback two weeks from now. That's not sufficient.

>> SUZANNE: Uh-huh.

>> MERRILL: Yeah. Good point.

>> SUZANNE: Yeah.

>> TIM: Let's go to the next question.

>> MALE VOICE: Reminder for a question or comment please press seven on your keypad. (Pause.) At this time there are no more further questions on the telephone.

>> TIM: Okay. Thanks. Let's switch back to the webinar here, and we have one from our first Q&A session that we didn't have time for. You know, we focused so much on systems advocacy here and impending managed care plans, we got a question from one of our participants asking how to advocate with the consumer if a consumer has problems with the provider. Do you all have any specific tips for individual advocacy when a consumer receives a denial or has another problem, isn't happy with their service? Bill, do you want to start?

>> BILL: Sure. It would be not unlike if they have a complaint with a housing authority, with the transportation agency, about discrimination. You know, you have some options, you can go straight to the source and try to resolve it, have the consumer make the call, support them in that. They may say: Would you make the call for me? And, you know, you figure it out on which level of empowerment is necessary, what kind of support.

It's likely that any healthcare plan, managed care plan, is going to have a grievance procedure. You could go that route.

An appeals process is always there if you're fortunate enough to have an ombudsman available that's one option as well. You know, I think you have to assess the situation, the severity of it.

I know that in healthcare situations, a lot of times it's very personal. It's very personal what goes on. It's my body. It's very intimate situation sometimes. So, you know, it's easy for me to say it's the same as a complaint against the transit authority. It may not be, obviously. It may be about a physician who you then may depend on for some lifesaving service down the road. It's quite conceivable.

In Joe's case if you want to talk it through and think of creative ways to make your concern known, we've talked about accessibility of facilities, and that's a real challenge. And people, from my experience, have been reluctant to raise those issues sometimes, because, you know, do you really want to upset the person, the physician, if she's going to be providing a vital service for the next three months for you?

You know, so you have to analyze it. I think it's something an Independent Living Center can assist with. It's dialogue really in many cases with the consumer where they're comfortable -- comfortable. You can enlist healthcare advocacy agencies, P and As as well.

>> MERRILL: Ditto, ditto, ditto. Yes. That really is it and the managed care organizations do have grievance and appeal procedures and they have to be reported to the state, and the state actually monitors the grief advances that come in.

The ombudsman, that's a great route to go if you can't resolve it. We started to utilize member advocates which is somebody who's not really -- doesn't develop service and care plans, doesn't work, they do member advocacy so they really spend the time, you know, addressing how to resolve grievances and so they get resolved to the member's choice and what their goals are and what their personal and what they need and want and if not finding that com premyself still makes the member feel that they're getting the optimal service that they've requested and so I just think that.

You know P and As are now more involved in healthcare than ever before, both from the national disability rights network to your local, you know, state PMAs to their world is growing again, you know, with what's going on, so there are a lot of people who can be, you know, engaged in that to ensure that -- that you get the level of understanding, service and outcome.

>> TIM: Excellent. Thanks, we're coming up on the half an hour, we've got a few minutes left. Why don't we go back and see if any questions have come in on the phone.

>> MALE VOICE: We're, as a reminder for a question or comment please press seven or Q on your keypad. (Pause.)

>> MALE VOICE: At this time there are no questions.

>> TIM: Okay, well, that's the end of our questions on the web as well of the. From our presenters, any final words of wisdom before we break.

>> MERRILL: I would just like to say, I think this has been a great opportunity, and I think the movement, you know, from the centers has to be engaged in this conversation and to help bring it to a whole other level, is that much appreciated by me, which is an understatement, and by a mere a group for sure, but I think it's going to change your commitment to stay on top of policy issues and service issues and advocacy issues and not order event is paramount to success for people with disabilities and I think that's really what the ultimate goal is. And you know we want to do that, you know, via supporting you all through the long-term services and supports that we can help with.

So I just hope that you keep the questions coming, and you keep advocacy coming, and, you know, we can have side-bars and we'll continue the dialogue and we'll get more involved people involved and at the table because that's the only way that this is going to really be survivable and sustainable both from a -- an individual standpoint, from a state budget standpoint, and, you know, for the growth of the centers capacity so thank you.

>> BILL: And I'll use your word of (laugh) of the moment, ditto, ditto, and ditto. Drive in there, wedge in there, say what we have to, don't worry if you're articulate or not, the IL message is vital to changes in the Health Care System. I can't say that enough. Just can't say it enough. It's the future of home and community-based services, Olmstead, all these good things that we've at sustained. They are at risk if we surrender control and new direction to people.

>> MERRILL: Anybody.

>> BILL: At the table.

>> BILL: Yeah.

>> TIM: Great. Okay, well, a good close to a great presentation. So I want to thank Suzanne, Merrill, and Bill for being with us this week. It's been great. I want to remind all of you that the archive of today's presentation will be posted by tomorrow on our ILRUs's Web Page.

Go to ILRU and on-demand trainings, in addition by tomorrow we'll have the responses up to the questions that we didn't finish on Tuesday. So do go and look at that. And don't forget, too, the question about the true ven report and a summary of where we are with managed care in the country is available in the PowerPoint from Tuesday, you can access all of those materials. And since we have an extra minute why don't I put in a plug for the influencing policy training that we have coming up in Baltimore as part of the CIL net program.

We've talked a lot about systems advocacy today, and the influencing policy training is going to be really instrumental, and talking about those issues of community organizing, and policy work, so please take a look. Registration is open until tomorrow. That's going to be in Baltimore. September 10th, 11th and 12th. Thanks for indulging me. I want to thank all of you for being with us today. This does conclude the call. Thanks so much. And if you have a question that you think of whether it be in two hours or 2 weeks, you can send that to me at Tim at NCI L.ORG and if I can't answer it myself I'll share it with our presenters, thanks very much, everybody, have a wonderful afternoon. Bye-bye.

>> BILL: Bye-bye.

>> SUZANNE: By.

>> MALE VOICE: That does conclude today's teleconference, we appreciate your participation. You may now disconnect your line at this time. (Hanging up.) (End of call.) (3:31 PM CT.) \*\*\*\*\*\*\*\* This text is being provided in a rough draft format. Communication Access Realtime Translation (CART) is provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings. \*\*\*\*\*\*\*\*