Effecting Policy Change in Medicaid and Community Services

presented by Bruce Darling and Suzanne Crisp on February 13, 2013

>> OPERATOR: Good afternoon, ladies and gentlemen. Thank you for waiting. Welcome to the effecting policy change and Medicaid conference call. All lines have been placed on listen only mode. The floor will be opened for your questions and comments periodically throughout the presentation. Without further ado it is my pleasure to turn the floor over to your host, Mr. Tim Fuchs. Mr. Fuchs, the floor is yours.  
>> TIM FUCHS: All right, thank you, Amanda. Good afternoon, everybody. Thank you for being with us. I'm Tim Fuchs from the national council on independent living here in Washington, D.C. Welcome to our newest webinar and teleconference program, effecting policy change in Medicaid and community services. Presented by the new community opportunities center, national training and technical assistance parking lot of independent living research utilization, ILRU in Houston, Texas. The webinar was organized and is facilitated by those of us here at NCIL. The support for the presentation was provided by U.S. Department of Education and RSA.  
Today's call is being recorded so that we can archive it on ILRU's website, available in about 48 hours. We will break several times during the call to take your questions.  
For those of you who are on the webinar today, you can ask your questions in the public chat. You can do that by using the text box under the's mote cons on the right-hand side of your screen. Do be aware that your question won't appear until we go too will quhee break. Don't worry, we are receiving it. If you type it in and hit enter, we will get it. You'll see it displayed during the Q&A break.  
The materials for the call today, including the Power Point presentation, very important handout and the evaluation form were sent to you in the confirmation e-mail that you should have received in the last 48 hours, depending on when you signed up. If you don't have those for any reasonf you don't have that confirmation e-mail you can e-mail me at time@NCIL.org, and I'll -- Tim@NCIL.org and I'll respond to you. If you or the webinar, of course, it will display automatically. If you are just on the telephone, make sure you have the Power Point.  
The other thing I want to be point out is, we sent a handout to you all that will be, we'll be going through in relative detail. I want to make sure you noticed that and that you have that handy, too. That will be really critical to helping you follow along on slide 6. So again, that DEHPG organizational chart was also sent to you in the confirmation pale. We will go over that on slide 6. Whether you are on the telephone or webinar, you want to have that handy. You can review it after the call. We'll describe what it says. That will help you follow along if you have it.  
Do please fill out the evaluation form. It is really short and sweet and really important to us. Please fill that out after you participate today. I know a lot of you are calling in in groups, which is great. Please fill it out as an individual. We want to know what each and every one of you thinks of the presentation and how we can improve for the future.  
With those announcements I wanted to get started, starting with our presenters today. We have two great presenters and I'm happy to have them with us. Back so soon after last week's Medicaid 101 call is Suzanne Crisp, director of program design and implementation for the national resource directed for services in Boston college. We have had the pleasure of working with Suzanne many times and becoming our Medicaid expert and she knows a tremendous amount about these programs and is going to do a great job setting the stage for us today. Also with us is Bruce Darling. And Bruce needs no interest deduct, but he's cofounder and president/CEO of CDR, the center for disability rights in Rochester, New York. And if you are not familiar with Bruce's work, he is a passion 8 and very effective advocate for creating community based alternatives to institutionalization. Suzanne and Bruce, thank you so much for being with us and putting together this presentation. Suzanne will  
start us off today. Suzanne, I will flip to the next slide. Why don't we begin?  
>> SUZANNE CRISP: Great. Thank you, Tim. It's always a pleasure to be here. If y'all were in our Medicaid 10 would be last week, this will build on that experience and hopefully be a lot more fun than just dry Medicaid.  
Today we hope to provide you all with insight into the importance of providing input on both the federal level and the state level, and how you can do that. How basically easy it is for you to do that.  
Then next, briewnsd I are going to briefly go through the Medicaid torts. Forgive me if this is redundant from last week but we feel like we need to set the tone for what the various authorities are for you. We will do some back and forth there. And then we will come to the real meat of our webinar and the exciting part. Bruce is going to provide to us some of his experiences and ideas about how to provide meaningful input to our federal partners and just what that outcome can look like if done, and if done with vigor. That will be really an interesting part of the entire webinar.  
First I wanted to guide us through the importance of public input and telling the federal government just what our thoughts are. Surprisingly enough, it is required by the federal administrative procedures act and has been for a number of years. In the distant PAS past there has been an opportunity to provide input best of your recollection it hasn't been as user friendly as it is now nor as transparent. Today we are going to give you some tips on how you can provide both informally and formally feedback to the federal government.  
Those who sponsored the Federal Administrative Procedures Act and did encourage the requirement that public input be required had a lot of thoughts as to how this could improve the document. First, they thought that by giving individuals a preview of what the federal regulation was going to be, and allow individuals the opportunity to comment, that that probably would reduce the amount of potential litigation or conflict that they had after the regulation was produced. They also thought that the, that it does significantly impact the quality of the legislation. CMS and all the people there are experts in a lot of things, but not everything. When they issue regulations in a comment mode, then what they are doing is saying: Look at our work and see if A, if it's accurate; and B, does it make sense.  
That's exactly what they are asking you to do then. So are experts can come in and say this violates another law over here. Or this would not go well in our state because we have a law against this. So we need to give that more review.  
So it actually distributes the expertise. We found this helpful when we were, when CMS was creating the community first otion, first choice option regulations. We found that their original regulations had some issues that violated IRS law and employment law. So it was real helpful that we were able to comment on that and they made then the associated changes that were necessary. So all in all, public review does improve the final outcome of the product then.  
We also can see that this has played over into a couple of more recent authorities that have introduced. The community first choice option does require the development of an implementation, the creation of an implementation and development council that will guide the operations of creating that new program and managing it. So from this requirement within the federal legislation we see that CMS has taken a much more active role in requiring states to bring people to the table. Another evidence would be that there has been a new policy on sol is iting input in the development of 1115 demonstrations. CMS has taken this requirement so to heart that they have returned a couple of different 1115 demonstrations back to states, saying that there had not been a sufficient time to give public input. So the State did have to start all over again. I know of at least two instances where that has happened. CMS is quite interested in making sure that states understand the importance  
of soliciting public input then.  
Let's look at our next slide. The federal regulations provide two different ways by -- three different ways by which to solicit public comment. First of all, the Notice of Proposed Rulemaking or as people in the people call it, the NPRM. That's a hard acronym to remember. Let's keep calling it the Notice of Proposed Rulemaking. But some friends at, particularly those friends at CMS do like to use acronyms, though. We'll at least understand what they are trying to say then.  
The first step that the federal government takes in developing formal policies and procedures then is to issue a notice of rulemaking. This actually proposes the policy that is going to be under question. And it identifies the statute and does solicit then public input. Issues in the -- each Notice of Proposed Rulemaking is announced through the Federal Register. It is the first hint that you see that a regulation is coming through the pike. This is your first opportunitytor comment on it.  
You can comebt as an individual or you can comment as a group or as a national association. CMS does look at all comments. They consider all comments regardless of where they come from. So know that you can just look at the prescribed process and just follow that, and your comments will reach a desk at CMS and then be considered in the total scheme of things.  
Once that is, once the Notice of Proposed Rulemaking is completed and then CMS works to incorporate the comments in a readable fashion. They classify those according to like topic. And then they consider these comments to see if the comment has merit, if it's possible, if it is to the advantage of the proposed rule. And if they don't -- if they do take the comment, they make a note that they took the comment. If they don't take the comment, they make a note as to why they could not take the comment.  
The next thing we see coming from CMS is an interim rule with comments. It appears in the fermd registry and it is an outline of these are the comments that we received and these are the ones we accepted and these are the ones we didn't. Sometimes that document is quite a very long, complex document. It is somewhat of a hard read. At least CMS is acknowledging that A, we did receive the comments. And we considered them or accepted them and if we didn't accept them, then why they didn't.  
After this, it is at this point where there are individuals and states and groups and agencies, associations can come together and then continue to comment on even the comments.  
Then the final rule -- then the comments again are reviewed. Some are taken. Some are not. Then the final rule is announced again through the federal registry and the final rule represents the final part of that entire process then. Of course, all this takes time. It can take as long as six months. It can also take as long as a couple of years. We still have some interim federal rules with comments that programs are being operated against, but they are still not the final rule, but they are out there and implementable then. It is not an ideal situation, of course, but that does happen.  
So in our next slide we talk about federal policy guidance. There are three basic ways that once final rules become the law of the land, then if CMS wants to make a, give guidance or clarification or an interpretation of that final rule, then they do so under three different approaches. One is the State Medicaid director letter. The other is a letter to state officials. And the last one is an information bulletin.  
A State Medicaid director letter, of course, CMS does apply an acronym to that and call it an SMD letter. These are policy clarifications that go out from CMS directly to state Medicaid directors. And there are probably three or four state Medicaid director letters issued every month on various topics. You can access the CMS website to see what state Medicaid letters have been recently announced. I looked on the website before this call and there are quite a few state Medicaid directors letters that have been submitted since the first of the year. Most of those are on the Affordable Care Act.  
A letter to state officials is just that; it does not have the formality of a State Medicaid director letter. It still is a policy clarification or interpretation.  
Then there are information bulletins that come out periodically. Again since the first of the year there have been many particularly tied to the Affordable Care Act. These communicate with states and stakeholders regarding operational issues that are related to Medicaid and specific rules and regulations.  
This is a new communication format. It was first developed in 2009 and it is yet another way that the State can both informally and formally communicate with the state and with stakeholders then.  
So let's now look at the, on the next slide, let's look at the State process. The State process also requires public input. The laws vary according to states. The process varies according to states. But typically I have just made here kind of a roadmap of what it looks like in each state, some of the commonalities in each state.  
Advocates, participants in the community come together and say, you know, we either need an interpretation or a new regulation or a change to an existing regulation. And states, state officials in an ideal world react positively to that and say okay, let's see what we've got here. So the stakeholder group meetings are convened generally, or town meetings are convened in order to get broad input from the community about a particular issue. Then after this is completed, then the State then looks to see what changes might be in compliance or out of compliance with federal rules and regulations. And then they draft a proposed rule and send it for public comment. Again, all of this is unique to your own special state. So you'll need to familiarize yourself with that particular process.  
And then after the public comment period, changes are made and then there is a legislative review and approval process. So just know that there is a process in your state. It may vary from division to division, but there should be a public process in your state then.  
Next we want to draw your attention to the handout that Tim talked about. The handout is an organizational chart. I initially tried to send out an organizational chart of CMS. You can imagine how huge it was. Basically it was Medicare on one side and Medicaid on the other side. It was just awfully busy. But what I did was I took a particular organizational chart that I felt like was most meaningful to us and I want to go through that then. If we could, if you can follow along with me there are many different groups within Medicaid in Baltimore. All in one building. The one most meaningful to us is the Disabled and Elderly Health Programs Group or DEHPG as they call it. Here is where all of the things that we're interested in take place. Things are created and policy is developed and reviews are done on existing documents and existing programs. When we say that a compliance issue with CMS, we are generally talking about the Disabled and Elderly Health Programs Group.  
Of course, it's composed of -- if you look at the first page on the handout, it just is a large box and then five divisions down below. And this is basically the setup then. If you turn to the second part of that hand out, the second page of the hand out you'll see that there are specific things things under each of these divisions and I would like to quickly go through those. Of course, the director's office has oversight of the Affordable Care Act and all of the waivers, state plan, and demonstrations within the Medicaid system.  
The division of benefits and coverage -- here, we won't go through it in gross detail today, but I just want you to know that this is the resource. If you need to talk to someone at CMS about something specific, this will give you guidance as to who does what then.  
We know the division of benefits and coverage basically manages all of the State plan services and the 1915 (judge.) which is the cash and counseling short, and the.  
(k.) the community first choice option. That's important to know how to reach. Next is division of long-term services and supports. This is where the 1915.  
(c.) where the home and community based services are located. The division of community systems transformation is basically special projects. They have the balancing re-budget act and the Money Follows The Person, Ticket to Work. They have all the special grants awarded. And demonstrations then. And they did quite a bit of analysis of how well grants achieve the goal that they were trying to reach then.  
The division of pharmacy, we typically have nothing to do with. So we will by pass that. The division of integrated health systems is a new division within DEHPG. This is where managed care programs and organizations function. It also is where dual eligibles have become quite a highlighted event. It has health homes and then also is in charge of the mental health parity then.  
With that, as I say, keep this as a research. When you need to talk to someone at CMS, you'll know what office to try to get to then.  
And here our next slide shows that we are taking an opportunity for questions then. So I'll stop.  
Operate operate the floor is now.  
>> OPERATOR: The floor is now open for questions. If you have a question, press the number won on your tefl keypad. If your question has been answered, press 7 again to -- please pick up your hand set to provide favorable sound quality. Please hold.  
>> TIM FUCHS: I'll just remind people if you are on the webinar you can ask questions in the public chat. So you can enter them in the effects box under the's pet mote cons there. -- the Emiticons there and even if you don't see it, it will display when we take the question.  
  
(CART correction: Press 7 if you have a question and press 7 again to release your question.)  
>> TIM FUCHS: If you are on the CART screen today, I am in that chat and I will voice questions from there also.  
Any questions in the cue?  
>> OPERATOR: There are no questions at this time.  
>> TIM FUCHS: We wanted to take this early break for Q&A questions but it looks like we're doing just fine.  
Suzanne is going to continue with our overview here. Suzanne, I'll turn it back over to you.  
>> SUZANNE CRISP: Thanks, Tim. We are going to briefly go through several slides now, giving you the, at least the resources to identify the federal authorities. This first slide lists all the federal that's right r authorities that list Home & Community Based Services and I will go through these very briefly because I wanted to have the majority of time for Bruce and his fabulous story that is we are going to hear.  
Basically, quickly. We are going to talk about state plan services, Home & Community Based Services C waivers, I waivers, J, community first choice options, 1115 demonstrations, and then the two managed care authorities then.  
Let's look quickly at state plan services. I bet you all are familiar with what state plan services can be. They can be mandatory or optional. Some of the State plan services that we all know and love and come into contact with probably daily personal care, home health care, rehabilitative services, targeted case management and self directed are personal care or attendant care.  
On the next slide we see to be eligible for medical assistance under the State plan, you do have to achieve eligibility in one of the several categories. States also have to develop a needs-based criteria that will establish who is eligible for the service or not. It is needs-based and not an entitlement. You do have to have the medical need in order to receive the service. You must reside in the community. You must have income that may not exceed 150 percent of federal poverty level and the Affordable Care Act has offered to us the option to cover people in the State plan up to 300 percent of SSI if they are eligible for a waiver. I'm going to ask Bruce to talk about 1915C.  
>> BRUCE DARLING: We are on slide 11 now. 1915C are the Home & Community Based Services waivers that we are familiar with, they provide an alternative to institutional placement. They are currently the way that states are providing noninstitution placement for people with significant exclusion. They allow self decks but the states may limit locations or specific groups these waivers serve people in a home or a home-like setting, but be cautioned that states may define what home-like is in a variety of ways. We are currently Duking that out in the regulatory process at the federal level.  
Income. They may use a higher income ceiling like 300 percent of the federal benefit rate and spousal impoverished rules. These must be cost neutral so that the cost of serving people in the community is no more than the cost in the institutional setting, but they can do that in a couple of different ways. They can do what is individual budgets where you look at the individual's costs not exceeding the cost of the individual being in the institution, or they can do it aggregately, based on the total cost of the entire group. I knew, as an aside, I knew about those two, I didn't know they could use a mixed approach. That is basically where they are telling you one thing and reporting something different to the federal government. It is important to find out what they are actually doing because like as a case here in New York, for our long-term home health care program we were a rare wear that I individuals were capped at 75 percent of the cost of institutional placement, but  
unaware that the states were report to go the feds on an aggregate and they did that to dovetail where there were limited costs involved. There were seniors capped at 75 percent, people with HIV who could have basically unlimited costs and then that loud us to leverage some issues with the state health department to move that, basically by suggested that, perhaps they should go forth and get HIV in order to qualify to stay at home. It is fortunate to look at what the budgeting is in the background for that. Suzanne, I'll turn it back to you.  
>> SUZANNE CRISP: I'm going to cover I and J quickly. 1915I is important. This is the first time that we see that a person can get Home & Community Based Services and not necessarily meet the level of care requirements for admittance to an institution then. That means that less sick people can also be given Home & Community Based Services services without a 1915C waiver.  
This, a 1915I can be targeted to any special group. We have been seeing a lot of targeting for individuals with behavioral health issues and some self direction, some targeting to self direction. I think because states have to operate these, must operate these statewide and may not cap the total number, there's been some hesitancy by states to move into 1915 (i.)  
And then I'll quickly cover J. 1915.  
(j.) is also titled the cash and counseling authority. Due to the success of cash and counseling, a participant-directed program in the early 2000s, CMS encouraged the federal Congress to pass an authority by which they could duplicate cash and counseling. This is the authority by which Congress gives states that opportunity then. So it allows states to provide participant or consumer direction, personal assistance services as a State plan services. It may include permissible goods and services. Also includes a cash ab lowness if the State so desires. And you can pay prospectively to participants as opposed to having the service be rendered and then payment can be made. It provides budget and employer authority. So individuals have the right to hire their own staff and service the employer of record or at least the co-employer. And budget authority, which means they are given a certain resources by which they can purchase permissible goods and services. And take a more  
flexible approach to meeting their needs. States may target and limit the number of people on this waiver then.  
I'm going to ask Bruce now to talk about the community first choice option.  
>> BRUCE DARLING: On slide 15 and community first choice option is 1915.  
(k.). It is a new option added under the Affordable Care Act. It allows states to provide person centered Home & Community Based Services services and supports. For those who may not be aware of it, we have advocated for years for addressing the institutional bias in Medicaid in giving people an alternative to institutional placement across the board. This, the community choice act both established a system for doing that and created a mandate. We were not able to get the mandate in the Affordable Care Act but were able to establish a system, CFC. Participants may meet the institutional care for an IMD, an institution for mental disease. I didn't name them. States, there is a carrot attached to this. States receive an extra 6 percent are in federal funding for implementing this. That 6 percent turns out to be some significant dollars and a very enticing carrot for states. So as we are working on this, know that they get extra money. That money doesn't expire. It  
continues as long as they selected the option.  
The next slide, slide 16, CFC option provides assistance with accomplishing the activities of daily living which is essentially the hands on personal assistance needs the person may have. Instrumental activities of daily living which include things like banking, participation in the community transportation, recreation, decision making, those types of things. Assistance with health related functions or tasks. And those would be things including feeding tubes, ventilator care, those types of tasks which people think of as mostly nursing tasks.  
Assistance is provided through hands on support, safety monitoring and queuing. Basically think -- cueing. Think about the things that a person needs to stay out of an institution. We covered all of them. Services and supports must be consumer-controlled. There may be a number of models that states can use. Agency provider model, self directed model with budget where an individual has a lot of the consumer controls that sews ab just talked about in.  
(j.) or there may be other sption options in terms of rachers and such. It comes down to an agency model or something with a budget.  
What is critical with 1915.  
(k.) and CFCs, like all of these it's implementation, how the State chooses to implement these options and exercise the authority.  
I'll turn it back over to Suzanne to talk about 1915B and C.  
>> SUZANNE CRISP: Thank you. Many states really enjoyed 1915.  
(c.) and the Home & Community Based Services that were offered under those waivers. They also wanted to have some control over the provision of those services. In other words, they wanted to possibly hire a managed care organization to come in or several managed care organizations to come in and actually run the program. But they wanted it to operate like a 1915)c.)  
What someone smart did a while back, I believe it was in Michigan. I think Michigan had the first -- I know they had the largest BC combo, but they created a 1915 (c.) and applied the authority of the 1915)b.) over the.  
(c.) and that allowed them to say you have all of these waiver services but they have to be managed by a managed care organization then. So you don't have freedom of choice of providers then.  
So for years the BC combo has been the way to operate a managed care organization environment. Lately we have been seeing, though, the use of the section 1115 authority and Bruce is going to talk about that next.  
>> BRUCE DARLING: Moving to slide 18 and we are looking at 1115 demonstration projects. These are used when states want to demonstrate whether a new service or intervention would lead to a change in Medicaid policy. The secretary may waive compliance with any requirement related to Medicaid. So there is a lot of flex. The states have huge amounts of flexibility when they develop 1115 waivers. They may use this authority to manage their entire Medicaid program.  
It is important to understand that they are sometimes referred to as 1115 waivers, demonstration projects, but states implement a variety of things. It is amazing the range that states cab do.  
What is important to know is that with great flexibility comes a lot of potential ones full things can happen and not so wonderful thing. So we found in New York that one of the proposals that the previous governor put forward as an 1115 waiver was basically to's little 98 entirely the personal care option in New York. While advocates were calling for a waiver, the governor's office responded with: We'll give you a waiver. It's an 1115. We had to explain the difference between a 1915C and 1115. Our community was good about rallying around that but it is important to know that there are significant differences. Make sure you nail it down, especially with 1115s the devil is in the details. Know them!  
Moving on to slide 19. There are dual eligible demonstrations. It is important to know that out there we are looking to figure out ways of integrating Medicaid and Medicare. There are 15 states that have demonstration programs. They are listed. California, Colorado, could be net cut, Massachusetts, Michigan, Minnesota, New York, North Carolina, Oklahoma, Oregon, South Carolina, Tennessee, Vermont, Washington and Wisconsin.  
These are programs that are or demonstrations supposed to mix together acute care, behavioral and long-term care and services into a could be sol dated care program. I attached a link, I did a short link so that folks could find out more information about these programs. If you are in one of those 15 states it is really important to check this out and see what's going on.  
Moving on to slide 20: Where do we start? First, find out what is going on in your state. Sews ab talked about the fact that CMS has a -- Suzanne talked about the fact that CMS has a website where you can look things up. You can look at the demonstration programs to see what is going on in your state.  
At the bottom is a long link provided by the government. So that is, they might have shortened that, but I realize this will get to be a project. So go to this link and look up your state. You might be surprised what is going on in your state and what waivers there are. I know that the first time I did, I was. So there are a number of waivers that we in the community were not aware of. As advocates this is a great place to start to learn what's going on.  
Moving on to slide twub, we are now going to open it up to questions.  
>> OPERATOR: As a reminder, if you have a question press the number 7 on your telephone keypad.  
  
>> TIM FUCHS: Okay. While we wait for people to get in the queue, of course, you can ask questions on the public chat on the webinar or in the chat on the CART screen.  
  
>> SUZANNE CRISP: Tim, I don't have a question but I did want to -- I should have added this at the end of the resource, but the national association of states united for aging and disabilities, NASUAD has created a system on their website whereby you can tap on to this tracker and go to your state. It will show you everything that the State is planning on doing or in the process of doing, too. So.  
>> TIM FUCHS: Oh, good.  
>> SUZANNE CRISP: So the CMS website will have what has been completed, but this will show what is pending. And I look at that all the time and am very, very surprised so what all that is about.  
So I will give you that website and maybe we can send it out after this.  
>> TIM FUCHS: Sure, yeah. That's for any of you who are interested that's www.NASUAD.org. We'll get you a specific Web link.  
>> SUZANNE CRISP: Or you can go on their national site and over to the left-hand corner it will say "state tracking tool."  
>> TIM FUCHS: Okay, thanks. I just post that had in the webinar chat. It looks like we have questions rolling in, too.  
I'm going to start with these and we'll go over to the phone. From the folks at SCRS in California they are asking: Who is overseeing the State of California dual program? Are they required to have community input? Suzanne, do you know that?  
>> SUZANNE CRISP: It would be the State Medicaid agency within California and I don't believe that the demonstration states are required to have input, but let me check on that. I can easily do that.  
>> TIM FUCHS: Okay, great. The second question comes from.  
>> BRUCE DARLING: Tim, if I can add in? I would encourage you to go to the link that I've provided that short link on slide 19 thaflt can take you to the thul application. You should be able to read what the State has provided and get the actual names of folks who are working on this from there. I believe that should be in there.  
States have engaged in a public participation process on these demonstrations. Although the level of involvement that each state has done may vary. There's a lot of anxiety about this, particularly in California. So I encourage you to go to the website. Look this up and start there.  
>> SUZANNE CRISP: Thank you.  
>> TIM FUCHS: Great. Thanks, Bruce.  
Second question comes from Melissa prier. She asks: Earlier you mentioned there are some types of groups limited under 1915 (c.)  
Can you share what groups those are who are limited under 1915.  
(c.) Bruce?  
>> BRUCE DARLING: With a 1915C waiver you can target a particular group of peel within your state. So, for example, here in New York we have a waiver that serves people with developmental disabilities. It just serves that group of people who are at that institutional level of care under that waiver. We have also, you can see waivers for people with brain injury. They may have a traumatic brain injury waiver or one that targets older individuals or people with disabilities.  
So these waivers allow you to target a particular group of people when you are providing services and specialize the services around that particular group. Suzanne, is there something to add maybe?  
>> SUZANNE CRISP: No, I don't think so. Some other examples of smaller waivers would be AIDS and autism and just, they sometimes refer to these as butte teak waivers because they are very small and specialized and -- boutique waivers because they are small and specialized.  
I see the trebd as not being waivers, but one large waiver that would have a service for specific individuals with AIDS or autism or behavioral health or brain injury.  
  
>> TIM FUCHS: Okay. Thanks, Suzanne. We have, let's see, another question that has come in. I do want to go over to the phones to take any questions that have come in there. Amanda?  
>> OPERATOR: We have two questions waiting. The first is from Lawrence with one other on the line in South Carolina rehab services. Go ahead, Lawrence.  
>> OPERATOR: Lawrence, your line is unmuted.  
>> I'm with NCRS. We already asked our question. Thank you.  
>> OPERATOR: Okay. We'll take the next one. From Amber small with two others on the line with Access Living. Go ahead, Amber.  
>> Yes, this is Tom Wilson actually speaking. Are you concerned that the new structure in the disability and elderly health programs that disability issues and concerns will play second fiddle to the more numerous seniors that get long-term care services?  
>> SUZANNE CRISP: No, not really. The way they are arranged within DEHPG is more by Medicaid authority. Then that authority, if it covers persons with disabilities, fine. If it covers aging, fine. If it covers children, fine. I do see a problem in that there is a lack of expertise in one particular category. I think what they try to do, though, within the small division is they have people who are well versed in persons with disabilities issues and well versed within aging issues.  
I used to work there and when I was there it seemed like the bulk of the attention went to the developmentally disabled or intellectually disabled waivers. It seemed like a lot of attention went to that.  
And I didn't see that aging was at all the focus then.  
>> Thank you.  
>> SUZANNE CRISP: Uh-huh.  
>> TIM FUCHS: Okay. That's all the questions on the webinar. Amber -- excuse me, Amanda, has anyone else gotten in the queue on the phone?  
>> OPERATOR: There are no further questions at this time. As a reminder, if you have a question, press the number 7 on your telephone keypad.  
  
(Pause.)  
>> TIM FUCHS: Okay. All right, thanks. Let's get back to the presentation and I will click over to slide 22. And Bruce is going to continue.  
>> BRUCE DARLING: So the question that folks might have is what is CMS telling the states? Suzanne talked about resources that go out to the states. My advice to advocates is read it for yourself. Go to the website. I've actually included a link on this slide that takes you to the guidance page. Look up what is important to you. A search tip would be to search for Olmstead, see what state Medicaid director letters have come out regarding Olmstead. This is a great resource are in materials of knowing what CMS is telling your state, is telling the states in general. Sometimes they even include information about best practices within these letters that are things that you can identify as things you might be looking to do in your state.  
Now, moving on to slide 23, when you are looking at that organizational chart or thinking about the federal government, I know what you're thinking: You start with: You can't fight city haul so changing CMS must be impossible. Well, I want to be clear that's wrong. We can in fact change CMS. So moving on to slide 24, I'm going to give you some examples.  
The first example is changing the MDS or minimum data set. I'm talking from the adapt perspective on this. The MDS track the number of people in nursing facilities that expressed an interest are in returning to the community. But it simply tracked it, nothing was done with that information.  
I can attest, a DAPT changed that. When an individual expresses an interest in returning to the community they are supposed to be referred for assistance. As advocates you might need to see it. Moving on to slide 25, here is a link, yet another link that shows a CMS brochure that was creating for nursing facilities residents about returning to the community. It explains why they are being asked by the facility staff about whether they want to return and about the possibility of returning to the community.  
Here is a brochure. Then moving on to slide 26, again implementation is always critical at the state level. So is the MDS change working in your state? If you are not sure, first if you are not sure what the process is in your state ask your state point of contact.  
If you are not sure who that is, we've provided yet another convenient and extraordinarily long link that can give you the name of the person in your state who is responsible for dealing with this. So this is a good placetor start. We know that it is an uneven process. Not only within states but among nursing facilities. I can attest that it is working where advocates are involved. What we have found in New York is, we actually now are getting referrals from the nursing facilities through this process. It's a great step forward for us.  
Moving on to slide 27, I'll give you a second example of how we changed CMS. Public comment. We talked a lot about leaf 15 waivers and Suzanne talked about the public comment process and that those demonstration programs have been sent back to the states because they didn't provide adequate public comment.  
But states had been making massive changes in their Medicaid programs without advocates even knowing about it. There were no public requirements for public, or no requirements for public comment for 1115 demonstration programs. That's another thing ADAPT has changed. A final rule effective April twoafl established a point of new 1115 demonstrations as well as extensions of demonstrations. This is extraordinarily powerful. It opened the door for our involvement. It is a tool that we can use now. I will move -- we are going to move on but skip the next two slides, 28 and 29. My apologies for that. I can help orchestrate the take over of a federal building, but I can't seem, I'm stimied by the use of Power Point. I inserted two doubles.  
Slide 30, how can I make comments? Again, you may want some proof as to you can actually make comments on 1115 waivers. CMS has a Web page for that. Seriously. So here is yet another really long link you can use. This is a link to the public comment period or the public comments on 1115 waivers. Please go there, see what is currently active in your state and respond.  
Moving on to slide 31. I've talked a lot about how ADAPT made changes with CMS. And you're probably thinking as a local Center for Independent Living I don't have 500 people available to storm the HHS building in Washington. Can I make a difference? Yes, even without 500 activists you can make a difference in these things. Use the opportunities for public comment and let the State know that you are going to be using this opportunities for public comment so they are aware that you are now a player within this process.  
Moving to slide 32. We want to bring this national work home. I'll give you some examples. So nationally we fought to get resource centers to include Center for Independent Living. We talked about putting the A in the ADRC. This is an uphill battle around the country, especially here in New York. What we have done, though, is to push the issue we actually scutelled the State's application for ADRC funding by complaining about the fact that it didn't include the CILs. This is not strictly CMS, but the State also submitted an 1115 waiver or demonstration program application that included funding for the ADRCs. We again raised concerns very vocally and let the State know that we were weighing in with CMS urging them not to approve the 1115 waiver as the State had submitted it because it did not include the Center for Independent Livings and the disability community in its model for ADRC work.  
The State is very invested in getting those 1115 demonstrations and waivers and applications approved. So any of this kind of controversy is something that is a great pressure point for you to use. I can tell you now that the impact of this is that New York just applied for the balancing incentive payment program. In it they described for the ADRC model that it would use a no wrong door system and incorporate the Center for Independent Livings and specifically mentioned that twice in the application. We can indeed make a difference.  
So moving on to slide 33. I have identified five basic things advocates can do in terms of moving forward with this advocating. First, as I've said, let's participate in the public comment process. So see what CMS is, what your state is going to CMS for. Participate at the state level where there is a public comment process. Comment within CMS. Make sure that the State knows the stuff that you are going to say to CMS. If they are looking at doing something moving forward, let them know what your concerns are and what they need to put in there so you will be quiet. Maybe not, but essentially list your demands.  
Two, question state policy changes that promote institutionalization or undercut self direction. So at the state level when the State says they are going to do something, question them on that. Question them. If they say -- they may explain why that is. Ask CMS, get technical assistance from CMS. Go to CMS and ask them questions about the state policy. Get feedback from them. Ask the State how it is proactively supporting people in returning to the community from institutions. That's something, it is not just that states are forcing folks in. We want to see how the State is proactively helping people return to the community. Put these questions on the table. Let them know what your concerns are before they move forward with developing these applications so that they can incorporate your ideas.  
Learn what other states are doing and ask why those best practices aren't being done in your state. Use the State Medicaid directors letters. Actually, don't just use those letters. Talk to advocates. One of the best things for the advocacy that we have done in New York is talking to folks from other parts of the country and bringing that information back to New York.  
Now, this is sort of a regional thing, but I personally love being able to say in our state capitol here in Albany that by the way, did you know this is what they do in Texas? Or states as liberal as Texas are actually diagnose these things which support people living in the community, or throw up Arkansas. Makes New Yorkers crazy! They just don't like being told other people are doing it better. It's a thing we have here.  
But it is very effective as a tool. Learn what other folks are doing. Use that to set the bar for your state.  
Demand that managed care and have consumer protections and use contract language and rates that promote community living. One of the biggest threats and opportunities for us now is the implementation of managed care in our states. Whatever the federal authority they are using to do that, this is the direction that things are going. So whether it's a dual demo, a B slrk C combo or 1115 demonstration, whatever the State is doing, this is a very big deal right now. States, CMS and states should be aware that they can structure these managed care opportunities in a way that promotes community living. You'll have my contact information with this. We have some stuff we've done in New York that is easily transferable to other states. This is one of the things we need to make sure is on the table. Demand it of your state up front F they submit an application to the feds and it doesn't include that comment and complain.  
Moving on to slide 34. So ask questions of CMS. So one of the things that -- okay, just waiting for ...  
>> TIM FUCHS: Sorry, it's taking my computer a second to catch up with you, Bruce.  
>> BRUCE DARLING: I just wanted to take my time and let it catch up.  
(Chuckles.)  
>> BRUCE DARLING: So, sorry about that, folks.  
Tim, I'm having an issue here. Is that me or everyone?  
>> TIM FUCHS: It should be up now. My computer took a minute to load the slide, but it should be displaying. Can you see it?  
>> SUZANNE CRISP: It looks like it's working.  
>> BRUCE DARLING: All right. I'm having an issue on my end.  
>> TIM FUCHS: Let's hold on then. That probably means others can't see it as well. Let me go ... back to the previous slide and try to reload it.  
  
>> BRUCE DARLING: Well, what I say on this slide better be worth it.  
>> SUZANNE CRISP: Bruce, I had a question. Sometimes, have you ever seen this work? If you can find a champion within a State agency and take that champion to lunch every so often and just maintain good contact with them, has that been an effective strategy by which to make inroads into Medicaid agencies?  
>> BRUCE DARLING: That is an excellent suggestion. It really is. For those of us who don't have any money, you don't necessarily have to take them to lunch. A lot of times there are a lot of folks within the system who are interested to do very cool things and move the system in the right direction, but they are stuck in the bureaucracy as well. A good inside-outside game is great where they are pushing on stuff inside, they provide you with information about what is going on. Sometimes having secret sources hotel you is a very effective tool for you. So that's a great resource.  
>> SUZANNE CRISP: Okay.  
>> BRUCE DARLING: We've done that both with the, some of our waiver work where we had a very strong champion within the administration in our health department and in the legislature. Look at the champions wherever you find them but there are people who want to do good things.  
>> SUZANNE CRISP: I learned that actually from Richard Petty. So thanks.  
>> BRUCE DARLING: Honestly, I think one of the things that is interesting, in New York as we move forward with the community first choice option, a couple of cool staff people were assigned to work on it. We had been talking about, they see how historic what they are doing can be. They are excited to be doing something new and different. So you really do want to build those relationships.  
So ask questions of CMS. So sometimes, though, your state is going to tell you CMS told us we had to do it this way. I don't know. When someone tells me that, generally I guess the idea is you are supposed to stop and just accept it. Well, CMS said so.  
No. Don't. Ask CMS. And then close the loop with your state. One of the -- I'll give you a very concrete example of this. When New York decided to move forward with the community first choice option, it said that it had some questions and wanted to get guidance from CMS. As advocates we were very interested in what CMS was going to say. So we said to the State: Oh, can we sit in on your call where CMS is giving you guidance? The state of New York said: Oh, no. CMS won't let that happen. So immediate we contacted CMS. We asked: Can we sit in on the call? CMS's answer was it's fine with us if it's okay with the State.  
Then we looped back to the state and said -- of course, got this in writing in e-mail and forwarded on and said CMS says it's okay. Can we do this? Now the State is locked into a position where they said CMS is the problem. They can't turn and and say oh, no, we're just being a jerk. So they opened up the floor and we were able to do a conference call that involved CMS, the State, and the Center for Independent Living and ADAPT activists working on CFC.  
It's particularly important if the State is saying that CMS has to do something in a particular way. Find out if that is indeed the case. Sometimes CMS is going to hold things over your state's head. I know in fact New York has a whole lot of things that we would like some money for and it has some bad history with doing some things not so correctly. So CMS is holding back approval on some things, needing to get other issues cleaned up. There is a give and take in the negotiation. CMS may be telling the sates that they need to behave in a particular way. But close the loop. Find out what the facts are.  
Moving on to slide 35, it is important that you know you don't need to do this alone.  
So I think it can be intimidated. I don't think. I know it can be intill dating when you work in all of this. Years ago I swore I would never learn the difference between Medicaid and Medicare because it scared me. That didn't work. But I broke that promise, but what I found was that there are lots of people who know a lot of information about the system and they are happy to coach you and provide you with support. I encourage you to find and work with experienced Medicaid wonks in your state, the people who love to talk about Medicaid eligibility and services. They are out there. Engage with them and ask questions. They like to share the information that they have. Start or join, if you don't already have one, my Medicaid matters coalition. I provided two links and they are shorter. One to the my Medicaid matters coalition in Texas and the ADAPT Web page that has things on Medicaid matters, the rally that we had.  
Working together, what is important is to build a coalition of folks working on these issues and who support each other. Know that we don't have to agree on every issue when we are working together. Here in New York we have a Medicaid matters coalition. We are advocates. ADAPT folks, Center for Independent Livings, we are on that coalition as are the nursing facilities. We clearly don't agree on some issues but we all agree that Medicaid is important. In fact, based on -- it is a formal coalition. We have recommendations to the State that it can save money by moving towards Home & Community Based Services. I encourage folks to get involved with ADATPT. We have training coming up. It's a great place around the country where you can build your advocacy training. Learn from other CIL and ADAPT advocates. We are willing to help. You can reach out to me. I provided my e-mail.  
Moving on to slide 36.  
I want to give you a homework assignment. As if you don't have enough work to do. But if your state has not sleeked the community first choice option ask that your state do a formal analysis to determine whether it should. And then okay, I went to high school, a Jesuit high school and it was never enough for me to put down the answer. I had show my work, how I got there. Insist that the states show their work. You are not looking for a yes or no. You want to see a financial calculation. Does it make sense? Does the 6 percent increased federal funding work for this state? Now, what you'll see on this slide is eight states have already selected or are in the process of selecting the community first choice option. Some of them are the usual suspects, liberal California, New York, with big programs. So there's a lot of money there that the State can pull in. Other states like Arkansas, Louisiana, where you don't necessarily expect that they would have sleeked CFC.  
It is important to know that, that list is helpful because when you look at your state there might be a State there that your state is similar to politically. Maybe there's a State there that your state -- I know that New York would be horrified if I pointed out Louisiana did something better than they did. Look at that list. See how you can use it. Ask your state toe evaluate the community first choice option. Going into these kinds of meetings you might feel you need additional information. Here are three links on this slide with those three links you are an automatic expert about CFC. Basically this is very new. You have the opportunity to, you can print these out. Use them. It's freely given. There is no copyright. This is a tool for advocates. Please feel free to use those.  
And that's my ask for you. I'm happy to provide additional help if folks have questions about this, but we really need to get every state to do the evaluation. Asking them to look at this is a way to get them potentially more Medicaid money from the feds.  
So you are doing them a favor by asking them to look at it.  
With that we move to slide 37 and open it up for additional questions.  
>> TIM FUCHS: Thanks, Bruce.  
>> OPERATOR: The floor is again open for questions. If you have a question, press the number 7 on your telephone keypad.  
  
(Pause.)  
>> TIM FUCHS: There are no questions on the webinar. Go ahead when we get someone on the phone.  
  
>> OPERATOR: There are no questions at this time. Again as a reminder if you have a question press the number 7 on your telephone keypad.  
  
>> SUZANNE CRISP: Bruce, this is Suzanne. I have a question. Give us an idea of what New York is doing under CICO. Are they taking their state plan services and couching them under the K? Browse Bruce yes. Suzanne, this shows a lot of what is exciting about the community first choice option. Here in New York we use the State plan Medicaid, personal care services to provide a strong network of services with an assist tabsing with activities of daily living. We have added on to that a consumer directed program still through the personal care option that picks up health related tasks as well. But in New York we have not provided assistance generally with instrumental activities of daily living.  
So what the State is doing is they are folding the personal care services into K. So we are going to maintain the personal care program for people who are not at the institutional level, but people who are at the institutional level will now be receiving services from the, under the community first choice option. It is going to expand what attendants in that program can do. They are able to provide assist tabs with instrumental activities of daily living. If you look that up online, the instrumental activities of daily living is much broader. People think of it nerms of medical tasks or very disability-specific things, but care of others is included as an instrumental activity of daily living. We've put forward the concept that the State needs to look at issues are in terms of pet care and childcare for parents with disabilities in terms of how this is put together. I think there's unique things around the services that are going to be available in New York and how this  
gets structured. Traditional attendant services through a home care service is going to be folded in. The States will give more control over who provides those services in their home so that traditional home care is in a more consumer-directed model. We are going to see an expansion of services to people with psychiatric or mental health disabilities with CFC, as well as the's little nation of waiting lists for people with disabilities. When I talk about the staff being excited, they understand there is an historic change happening in New York and we are very excited about having that happen saw sue fascinating.  
>> SUZANNE CRISP: Fascinating.  
>> BRUCE DARLING: It is. For us in New York, a lot of A development APT folks have been fighting for the community choice act A before that Micasa, with various spellings. When we started the process, we were on a quest for the Holy Grail. Now it's in front of us and now you have to figure out how to implement it. Exciting and terrified. If you are not a little bit terrified in the process, hey, you're missing something.  
So that's where I think the network of advocates is really important and we should be working together.  
>> SUZANNE CRISP: Good, thank you.  
>> TIM FUCHS: Thanks, Bruce.  
We have a question that came in on the webinar from gashing Smith. Bruce, I'll ask you to start since you were talking about the community first choice option. Jake asks if you can expand a bit and discuss the relationship between those people that are dual eligible and the community first choice option. How might they relate?  
>> BRUCE DARLING: Well, that is a question we have been raising with the State. So you have to understand that the CFC -- for New York, oh, God, we are not -- let me start with, New York is not the model you want to look at when figuring out how to integrate and implement a managed care model. The issues we are racing is the CFC option becomes a State plan option that all of these managed care models need to provide access to or it is essentially the services are available through those various models.  
This becomes complicated in a State that has multiple models for managed care. In New York we have a separate model for managed care that we are preparing for penal with mental health disabilities. We have two different models, Medicaid managed care and managed long-term care for different groups and then a federal demonstration.  
What we have pointed out to the State is all of these models need to implement the community first choice option. Basically what that says is that we need to look at streamlining and coordinating all of that and bringing the system into a less siloed model. So it is rather complicated. We don't have a final answer on that. Basically the CFC option becomes a service that an individual sis eligible for through that you managed care benefit.  
Suzanne, does that cover it?  
>> SUZANNE CRISP: I think so. I would just like to say this. I'm working with Arkansas now and their community first choice option. They are not a managed care State, nor do they want to be by design. But it still has a place for dual eligibility coordination. So what we are trying to do is use the community first choice option and the counselor case manager type person there to use that individual as a more assertive and in-tune service and support coordinator between both programs then. So it's more of an informal thing. And we think that we are going to have some good outcomes from that. So if you look at dual eligible coordination as coordinating services and supports not necessarily under managed care it also is a very effective tool.  
  
>> BRUCE DARLING: I think, Jake, the idea that you are loorking at how these pieces can coordinate together and how they mix and match, you can dovetail these different authorities together. One of the things that we've identified, it is not an issue here in New York, is that CFC is based on community Medicaid eligibility and there may be a gap related to folks with higher incomes who would be eligible for Medicaid in the institution. You can potentially use a 1915.  
(c.) waiver to create an eligibility bridge. With a limited service package to connect folks up and address that problem. It's important to know that these things can be mixed and matched in ways to create new things. It's a fun puzzle. Glad to hear you're looking at it that way.  
>> SUZANNE CRISP: One of the fun things we did in Minnesota, because when the CFC final regulation came out, it was limited to those who would meet institutional level of care. That kind of blew a lot of their planning out of the water. What we did was we created a 1915.  
(k.) community first option for those who met long-term care criteria and then for those who did not, we developed a companion program that looks exactly like CFCO. But it is not tied to institutionalization and the process and the management of those two programs is exactly identical.  
>> TIM FUCHS: Good, thanks. Let's go to the phone and see if anybody is in the queue there.  
  
>> OPERATOR: There are no questions at this time. Again as a reminder if you do have a question press the number 7 on your telephone keypad.  
  
>> TIM FUCHS: Okay, thanks.  
While we are waiting Jeff hen der sob asks Bruce: If we can go back to slide 26 which I'll click, you had mentioned about how you found someone at the state level that led to referrals. So Jeff is wondering if you can share a bit more about how that process worked to get referrals from the State.  
  
>> BRUCE DARLING: Okay. So the State is required to have a plan for when an individual indicates on the MDS that they are interested in living in the community for what is going to happen with referrals. So if you go to the link there is a point of contact person who can tell you what your state process is. If you are not aware of that.  
Now, here in New York the question came up: How are we going to -- where are the referrals going to go? How is this going to be handled? It was a rather unique approach here to advocacy. Basically what happened was we had a policy analyst who worked for us at the center for disability rights who got a job actually by the state because of the work we have done on a lot of deinstitutionalization. She was actually hired by the state to run the MFP program at least in part or to manage it. She was involved in the State. When the question came up at a meeting, how are we going to handle these referrals, she basically said a simple solution is to send it to these program sites operating outreach into the nursing facilities under MFP.  
It was a former staff person of our center who said these contractors should do it. The contractors happen to be Center for Independent Livings. For us it was one conversation that a well placed person within the administration was able to just have. And it was moved through.  
What is neat is to see how a policy conversation that happens at CMS in Washington, D.C. translates into a policy change that then rolls out and comes down to the state level, and that results in people who are are in nursing facilities being referred to our center to get out.  
It can become a very, very powerful tool. If you are having concerns about what is happening in your state with these referrals in this process, look to those point of contacts. Reach out to other states and find out who is doing a good job with it. I can't say that things are perfect in New York. We have nursing facilities that are not willing to do, to follow the rules. We have a lot of pushing that we have to do. But we are moving that along.  
  
>> TIM FUCHS: Great, thanks.  
>> BRUCE DARLING: Your first point, though, is to that link. Sorry, Tim.  
>> TIM FUCHS: No, no problem. Thank you very much.  
Amanda, anybody come in on the phone?  
>> OPERATOR: There are no questions at this time.  
  
>> TIM FUCHS: Okay. Well, we are about at 90 minutes anyhow. If you have a question, there is still time. I'm going to begin to wrap up here. If you have a question, don't be shy. You can get in the queue or posted in the public chat. We have about five minutes left.  
I'll go ahead to the next slide. And here on slide 38 is the evaluation form. If you are on the webinar, this is a live link. You can actually click this and it will take you straight to the evaluation form. If you are on the phone you can access this link by either typing it into your browser -- I realize it is long. Easiest way is to go to the confirmation e-mail and click on it there. If you've participated in our webinars before you know I'm telling the truth. These don't take long to complete, but we take them very, very seriously. Let us know what you think about today's call.  
Also again if you are participating in a group, that's great. We love that. Do fill it out as an individual. We want to know what each one of you think.  
Also Bruce and Suzanne have been very generous in providing their contact information. So here that is on slide 39. I want to include myself in there. If you all have any questions, whether it be in a few hours or months, don't be shy about reaching out to us. In addition to organizing these trainings we are always eager to help with ongoing technical assistance issues, especially with this webinar as you go through and visit all the links in the coming hours and days. You may have additional issues crop up and we are here to help with that. Bruce and Suzanne's contact information is here. I'm at Tim@NCIL.org. The confirmation came from me so respond to that and let us know if any additional questions come up.  
Following that is just our project information.  
So let me check in would be more time before we break. Looks like we have exhausted the webinar questions. Amanda, is anybody in the queue on the phone?  
>> OPERATOR: There are no calls at this time. Last call. If you have a question, press the number 7 on your telephone keypad.  
(Pause.)  
(There is no response.)  
>> TIM FUCHS: Good. I want to thank you all for being with us here today. I hope you found the presentation as informative as I did. Bruce and Suzanne, I can't say enough an exrent job. Thanks once again. I really appreciate it. Great call. Jackie Evans asked if I can give the e-mail out one more time. Of course. Tim@NCIL.org. TIM@NCIL.org.  
Anyhow, everybody, thank you so much. Thank you Suzanne and Bruce. Have a wonderful afternoon. Thank you.  
>> SUZANNE CRISP: Thank you.  
>> OPERATOR: Thank you. This does conclude today's teleconference. We thank you for your participation and you may disconnect your line at this time.  
(The meeting concluded at 3:28 p.m. CST.)  
(CART provider signing off.)

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