Webinar Transcript

**LTSS in a Managed Care Environment: Advocacy Strategies for Increasing Independence**

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*This transcript is based on closed captioning used during the webinar. Steve Clark of Home Team Captions did the captioning. The power points from the webinar can be found at* [*www.nsclc.org*](http://www.nsclc.org) *under For Advocates/Events. An audiovisual recording will also be posted there.*

**GEORGIA BURKE:** Hello, everyone. And welcome to our webinar, which is entitled long-term services and supports in a managed care environment, advocacy strategies for increasing independence. I'm Georgia Burke of the National Senior Citizens Law Center, and I'm joined by Eric Carlson of NSCLC. We're jointly presenting today with Mary Lou Breslin and Silvia Yee of the Disability Rights Education and Defense Fund.

We are, both groups, very grateful to the Center for Personal Assistance Services at the University of California at San Francisco, which is hosting this event.

In case you're unfamiliar with our organizations, we're both advocacy organizations. NSCLC's focus is low income older adults. DREDF's focus is persons with disabilities.

So, with proposals to deliver long-term supports and services through managed care in Medicaid proliferating, including managed care to deliver all Medicare and Medicaid services in one package, we thought it was important to really look specifically at long-term services and supports. Things like personal care services, home health, adult day health and think about what consumer protections are needed as these services are placed under a managed care umbrella.

We at NSCLC along with DREDF sought to combine our senior and disability perspectives and to create a toolkit for advocates, and in this toolkit we've identified 15 areas of consumer protections. We've been calling them internally -- buckets.

Drilling down to create a list of specific consumer protections in each area. The toolkit is going to be on both of our websites. And there's links at the end of the presentation.

Today we want to walk you through some of the items we've identified. Here are the 15 buckets. We'll take you through roughly about a dozen of them, with just a couple examples in each of specific protections we think need to be part of basic planning contracts. Then we'll leave a little time for questions.

Before digging into the consumer protections, Silvia Yee of DREDF will set the context for us. Can you get us started?

**SILVIA YEE:** Yes. Thanks, Georgia. Looking at the context, I'll give just a very brief look at what we mean by managed care. In very general terms, it is where a state's contracts with a care organization or organization to deliver that state's Medicaid services. The contract can be specific about which Medicaid beneficiaries are being targeted, for example children or families. It can be specific about which services, such as primary care and mental health, as an example. Or it can be specific about which areas, for example, seven counties in the state or the entire state.

The managed care organization receives a payment per member per month from the state. If the actual services needed come in above or below the calculated payment, the difference between that payment and actual services is lost or gained by the managed care organization.

There are variants on this financial arrangement, but that's a basic look. Usually, long-term services and supports, I'm probably going to say LTSS now, because it is easier, have not been part of managed care. What we've been seeing over the past few years are two very specific trends. First, states have been looking at enrolling more seniors and people with disabilities in managed care. These are populations that traditionally have not been included and are now being looked at more carefully.

Also, the states are tapping the managed care organizational role to include long-term services and supports. Traditionally, as I mentioned, LTSS has not been part of managed care.

Here I'm going to give a very brief snapshot of managed care as of May 2012, managed care of Medicaid services, and specifically LTSS.

There has been an integrated managed care-like program that existed for a while in the country. 29 states have the PACE program, and it is a relatively small program, with only 200,000 enrollees across the country.

As of May 201216 states have Medicaid managed care LTSS programs. There are 19 programs, three of the states have two programs. So this is information that was actually presented by the new federal administration for community living in a May 29 webinar on LTSS.

From that webinar it was clear that 16 states have the LTSS programs, all of the programs, in fact, do target seniors. 11 of the programs target people with disabilities. And eight of these include people with intellectual or developmental disabilities, and eight of them serve children.

Enrollment, the numbers vary widely, from a small number of 200 in I think for a managed care program in Pennsylvania to 400,000 in a program in Texas.

The number of managed care contractors also varies. Some states just contract with one. Michigan actually contracts with 18 managed care organizations. 10 states have voluntary enrollment. That means it is up to the beneficiary whether they go into the managed care program or not, and nine have mandatory enrollment, which means if you want your Medicaid services, you join the managed care program.

10 programs also offer self-direction and we'll be going into -- my colleague Mary Lou Breslin will go more into that later.

We're going back really to what Georgia said about the proposals to integrate Medicare and Medicaid services. That's been a move that's been prompted by the Center for Medicare and Medicaid Services incentivizing states that are looking at integrating they're services.

26 states have drafted proposals for integrating Medicaid and Medicare managed care in their state, and 11 of these have actually given official proposals to CMS, Center for Medicare and Medicaid Services, on the integrate.

Look at the managed care contracts in terms of concerns, I think one of the most fundamental areas of concern is just the fact that managed care does not have a lot of experience with LTSS.

In fact, this information is a little older, but as of 2009 LTSS under managed care programs represented only about 5% of the total Medicaid LTSS spending. So we're not talking about managed care programs that have been working with LTSS for a long time, or working with populations that need LTSS. Traditionally, Medicaid managed care has been about families and children, and young adults, who don't necessarily have chronic conditions or various disabilities or functional impairments.

So a steep learning curve lies ahead for managed care organizations that want to jump into providing LTSS. Even if managed care organizations figure out the basics of LTSS and fairly quickly, it isn't just a matter of head knowledge. How about they demonstrate actual competency in LTSS delivery?

In addition, LTSS is not just about the fact of a service. Individuals of all ages, with chronic conditions and various functional impairments, have really worked to infuse the ideals of independent living and consumer control into home and community-based services. Home and community-based services is one aspect of LTSS. A part of LTSS that is delivered to consumers who wish to live as independently as possible in the community. Which is actually most consumers.

This is something that, again, managed care does not have experience with, and there is the risk, the fear that how do these principles of independent living and consumer control accord with the way managed care works or managed care organizations themselves traditionally both manage and gatekeep the health services.

A fourth concern is whether managed care involvement in LTSS service delivery will help with the goals of rebalancing. This is a long-sought after goal of people in the disability community and the senior community, and it involves redressing the bias towards institutional care, by turning administrative and financial attention in our public health programs toward developing home and community-based alternatives.

On the screen is a slide about defining community. How will managed care define the kinds of home that constitute community for home and community-based services? Will long-term supportive services that are delivered in a home that has a congregate mandatory schedule for meals and sleeping constitute a community-based services for the purposes of rebalancing?

In our next slide, we're looking at some of the specific risks that are raised in a managed care context. One of the first risks is continuity of care. It is very, very important for many people with disabilities to maintain the provider relations they've had for, often, decades, and those relations are necessarily threatened in a managed care context and are limited to a provider network that one managed care organization has.

There is also the fear that home and community-based services and personal assistance services will require medical justification. Managed care organizations are medical experts, and they go according to medical needs. Is there a medical need to be able to go to dinner with your family and use attendant services? Perhaps, perhaps not. There's a fear of that.

There's also a fear that managed care organizations will deny service or underserve in the goal to save money and to be extremely efficient with resources.

Another specific risk is that managed care organizations will reduce provider rates. There is the additional concern of the risk that states will reduce Medicaid LTSS funding once LTSS is managed by managed care organizations.

Finally, quality has been a longstanding concern with managed care organizations, relating partly, again, to experience, and perhaps partly again to the desire of many experienced providers to avoid managed care practices.

The last slide I have is looking at managed care context in terms of potential opportunities. We have three big ones here. One of the first is that it's open to -- if managed care is done right, it could provide a huge improvement. It will help to coordinate acute and long-term care, chronic care. It will help to coordinate physical and behavioral and mental health services. Again, if it is done right. So, the potential is there.

The second opportunity is rebalancing. As I mentioned before, it is an opportunity to shift the focus from institutional care to home and community-based services, allowing people to age in place and to remain or return to the community.

Finally, one big potential opportunity is reducing nursing home placements. Managed care organizations realize that the provision of home and community-based services can be a very cost effective alternative to nursing home placement.

So I will turn the mike over now to my colleague Eric, who will cover -- who will begin to cover the specific 15 topics in the LTSS tools.

**ERIC CARLSON:** Thanks very much, Silvia. I appreciate it.

Let's start with looking at the benefit packages offered under managed LTSS. Silvia mentioned one of the potential promises of a managed care setting is the opportunity to do better rebalancing, to balance in favor of community-based services as opposed to institutional services. This is going to come up most likely multiple times during the presentation today. We mentioned a couple reasons why the system might aid rebalancing. The first is that the managed care organizations are responsible for costs, and then they have a financial incentive to choose less expensive home or community-based services over facility- based care.

Secondly, with managed care you hope that the management is done with the beneficiary's best interests prominent so that the management will not be about limiting services, but instead ideally about coordinating services to be provided most efficiently and beneficially to the beneficiary. We'll address that topic in more detail once we address specifically the assessments and care planning issues.

The first issue related to benefit packages is an issue you get when talking about managed care or not. You want an entitlement to home and community-based services, and you don't want those services limited by arbitrary limitations, such as wait lists or geographical limitations. We're still living in 2012, and state Medicaid budgets are a strong driving force in states making decisions regarding managed LTSS. So it's important from an advocacy perspective — not the exclusive focus obviously, because there are issues beyond costs — but we as advocates want to be able to say, with justification, that home and community-based services can be cheaper and more efficient, and we have listed here a recent publication by Steve Kaye of the University of California at San Francisco that addresses this issue and demonstrates that, indeed, HCBS can be efficient financially for states, particularly as the programs mature.

That being said, that's not necessarily the philosophy that's driving a lot of proposals out there, and we as advocates need to be very careful to make sure that the programs as drafted really do lift those artificial limitations. Sometimes you will see very aspirational language floating around the proposals, but when you actually look at them more carefully, there's less there than meets the eye.

One example is the current Michigan dual eligible proposal. I was reviewing this last week, taking notes, and I ran into the first provision cited here that said that the cap on the current waiver is lifted. I made a note, I said what a good thing this was, but went on to the proposal to find much more equivocal language, such as the language quoted here on the screen. There's a potential for addressing the significant wait, depending on how the waiver and the demonstration relate.

I really encourage people, when reviewing the proposals, the dual-eligible proposals or straight Medicaid proposals, to push this, not just assume things are going to be OK, because unless it's explicit they may likely not be OK.

I just mention all of the dual-eligible proposals are on a website maintained by the National Senior Citizens Law Center at [dualsdemoadvocacy.org](http://www.dualsdemoadvocacy.org/).

Speaking of Medicaid-specific proposals, Florida is proposing to move their Medicaid LTSS into managed care, but the enrollment cap under the proposal would stay the same throughout the five years of the waiver. This demonstrates perhaps that there needs to be change if Florida intends to take their rhetoric about expanding HCB seriously.

At a minimum, the services have to be adequate and match at least the services that they are stepping in for — the pre-existing legally required Medicaid benefit packages and Medicare benefit packages, in the case of a duals program.

Ideally, you want additional services added to the benefit package. A couple of examples from Virginia are shown, where the dual eligible proposal adds some services specifically focused on doing better care planning and allowing people to move into appropriate settings and not to be unnecessarily institutionalized.

Some additional services in the Virginia plan, going beyond some of the bread-and-butter Medicaid services, provide for assistive technology, environmental modifications. This is assistance which obviously assists folks in staying in their own homes, rather than being in institutions.

Also, from an advocacy perspective, it would be very useful for people to reference the community first choice option benefit package. These are regulations released earlier this year implementing a proposal enacted in the Affordable Care Act. You will see a wide variety of services authorized in the regulations, specifically benefits that focus on transition costs and also, though not listed here in this slide, there is some authorization for home modification, as long as the home modification supports a goal that is set forth in the individual service plans.

Provider choice is a very important issue. Flagged here is a provision in the Oregon duals program that requires the managed care organizations to do some professional comprehensive work at the development, and also annually thereafter.

It's something that I think other states may well want to emulate; otherwise a lot of proposals dealing with adequacy of networks may just have some fairly low floors, saying at a minimum that an individual has to have a choice of at least two plans or two providers. I think we want to shoot higher than that, so that the choice is really meaningful to the folks needing LTSS.

Another provision, which certainly needs emphasis, is a provision that would require managed care organizations to provide necessary assistance to providers who may not enter the application process with adequate administrative capacity.

Think about a lot of the personal care by providers that we deal with. These are not big businesses. They're not international corporations. They're individuals, they're small community providers, and we don't want to move to managed care to eliminate the ability of those people to participate. We want to be able to retain the small provider participation and not have them swallowed up in a managed care setting.

Requirements such as this would be extremely important to make sure that the initiation of managed care doesn't drive out or dissuade the smaller providers that really provide the individualized care that folks can benefit from.

And then let's talk briefly about care transitions. It’s an extremely important time. A lot of studies have identified that unnecessary institutionalization oftentimes is tied to poor transitions. People are in hospitals and nursing facilities. When they leave, they go to the wrong setting.

Some of these factors we've already discussed. I want to also mention more targeted programs that, for example, identify the nursing facility setting as an opportunity for change -- diversion programs that keep people out of nursing facilities to begin with, or programs such as money follows the person, authorized in the deficit reduction act, reauthorized in the Affordable Care Act, that concentrate on moving people already institutionalized into community based settings.

Then a couple of additional points: the program should be set up to make the financial incentives work. The nursing facility expenses should not be carved out of the managed care organization's services so that the care organization is at risk. When it chooses to have a person move into a nursing facility, that decision should have consequences to the managed care organization.

Mentioned here, you will see the citation to the Hendrickson and Mildred report, which has a lot of very good examples regarding many of these financial incentives, and those that are already used by states and could profitably be used by states in the future.

I mention the one in Arizona, where savings derived from greater HCBS usage are split between managed care organization and the state. There should be provisions as well to protect states or to give managed care organizations the incentive to, in some cases, use home and community based services even though they may be more expensive than nursing facility services in that situation.

Also, folks should not forget existing options. Under Medicaid, retainer payments which allow the personal care providers to be, quote unquote, retained, while the beneficiary may be temporarily institutionalized. Medicaid income allocations that allow people to retain their residences, even while temporarily institutionalized.

Then also if assisted living is an HCBS benefit there should be protections so those rooms don't become unavailable when a person is temporarily institutionalized. With that, let me turn the microphone over to Mary Lou.

**MARY LOU BRESLIN**: Hi, everyone. Thanks very much, Eric. I'm going to be talking briefly about three components of the toolkit that have been mentioned previously. The three components will be assessments, person centered planning and self-direction.

Let me start with assessments. As managed LTSS rolls out the states will have to require managed care organizations to use uniform assessment tools and processes. These offer really, I think, an important opportunity to establish protections and safeguards. The overall assessment really plays a vital role in assuring people with disabilities and seniors receive necessary and appropriate, both clinical care and supports.

Ideally, the assessment tool can be used both for determining eligibility for and planning of services. It can encompass multiple domains, including social, functional, medical, behavioral, wellness and prevention. It's a starting point, and a really important starting point for creating an individualized care plan.

The assessment must include, for example, services and supports currently available to the individual, as well as those that are not currently available but that are needed. It should also include information related to the person's ability to remain in or move to a house, apartment, or other community based setting -- as well as recording their interest in doing so. A variety of processes must be in place. Let me mention a couple here. I refer you back to the toolkit for many more examples.

The process must include, for example, a conflict of interest standard for people conducting the assessments. Specifically, the person developing an assessment should not be a service provider, for example. Or related by blood or marriage to the person receiving services, or a person financially responsible for the individual, or someone who is empowered to make financial or health-related decisions for the person.

In another example, states must require that MCO's formal assessments when there is a significant change in the person's condition, or in their circumstances and also at the individual's request, or at least once every 12 months.

OK. Let's move on to this principle of person-centered care planning. The concept of person-centered, as I'm sure is familiar to most of you here, one of the meetings, not the only, but one of the meetings emanates from the disability rights principle of nothing about us without us. The concept of person centered also can be found throughout the Affordable Care Act, which mandates the delivery of person centered LTSS.

Person-centered planning recognizes that the person receiving services is a primary expert in his or her own goals and needs. However, really realistically, for this to be more than an empty promise it has to be accompanied by really substantial and substantive standards.

A person-centered approach is not limited only to health status, but also should encompass values of independence, control, autonomy, and the person who is receiving LTSS must have control over who is included in the planning process.

That individual defines the desired outcomes, along with the preferred methods for achieving them. Most importantly, I think, specific delivery of LTSS has to be customizable according to the needs and preferences of the individual.

OK, let's talk a little bit about the idea of a written person-centered plan. A written person-centered services and support plan also should be developed, and it should reflect the elements contained in the assessment. Although there must be a number of elements to the plan.

Here's just a few examples. The person-centered plan supports the individual's ability to direct self- -- self-direct services. The plan must also document and integrate the amount of and scope of services and supports to assist the individual to achieve goals. Mechanism has to be in place to minimize conflict of interest. And states and MCO's should develop appropriate standards and guide them to ensure quality outcomes, but also should give informed consumers the opportunity to opt out of general requirements where this is an appropriate.

For example, an individual who is skilled in instructing his or her personal assistants, provider should be allowed to waive prior training or certification requirements for care providers. For those of you who use -- those of you who use personal care services can relate to this the important of this suggested provision.

Let's talk a little bit about the role of both the states and of CMS. In order for the plans to be meaningful and consistent, CMS and states should develop very specific requirements. Let me offer a couple of examples. All the elements of needed medical, clinical, community living supports must be fully integrated, and an integrated team with both clinical and LTSS expertise must have responsibility for developing and implementing the plan.

The plan must be comprehensible to the person involved and also to the representative. Managed care organizations must also have procedures in place to monitor and follow up implementation of individuals and person centered plans.

OK, let's say a little bit now about the obligation of CMS states and the MCO's. CMS and states, as well as the managed care organizations, this is a really important element I think in terms of the actual rollout and success of these programs. They have to ensure that the time it takes to do adequate person centered planning is considered in setting reimbursement rate, and they have to consider the quality of person centered planning when evaluating MCO performances.

I suspect this is going to take some significant refinement to turn into a meaningful performance standard. They also have to implement person-centered – to incorporate person centered principles into their policies, mission statements and operational documents.

Finally, staff and leadership must receive training in the principles of person-centered planning. This really needs to be incorporated from the top down and throughout all of these structures.

All right, let's talk a little about self-direction. Again, this a concept really familiar to I think virtually everyone who is participating today. As many of you know, it is rooted in deep principles of autonomy and independence, and self-direction allows individuals to directly control a range of services and supports. This is with the help of representatives if desired.

These are based on preferences and needs, and with the goal of maximizing independence and the ability to live in the most integrated community setting appropriate. Managed long-term services and supports must preserve and enhance the idea of self-direction.

Although self-direction is an optional delivery mechanism for most Medicaid funded programs, those that propose to integrate LTSS into Medicaid -- Medicare and Medicaid managed care must be required to further enhance self-directed options. As a practical matter, making participant direction real may include ensuring that they have authority over personal service workers and budget authority over HCB service delivery or both. For those of you who live in states where this is already in place, you can certainly appreciate how important it is to tend this as the rollouts take place.

Another important aspect of self-direction is an individual's -- that individuals must have the right to take risks and the responsibility to develop or help develop a backup plan for assumed risks and for emergencies.

That's a very quick overview of assessments, person-centered care planning and self-direction. I urge everybody to take a look at the toolkit online for a significantly more detail. Now I'd like to turn this over to Silvia to talk a little about civil rights protections.

**SILVIA YEE:** Thanks, Mary Lou. I'll leave this up for a moment, because I'm going to take a couple minutes to talk about civil rights as a component of the toolkit.

There are various federal civil rights statutes that apply to healthcare services, and the Affordable Care Act, which has been part of many dual projects, specifically references a number of civil rights statutes in relation to the flow of federal healthcare money to the states and out to providers.

These statutes prohibit discrimination on the basis of age, disability, gender, linguistic, cultural and racial background. The ADA in Section 504 of the -- I'm sorry, Section 504 of the Rehabilitation Act, requires entities involved in the provision of healthcare services to provide reasonable accommodations where necessary to ensure people with disabilities receive an equally effective service. This includes physical accommodations as well as reasonable policy and procedural modifications.

Now, it may seem that LTSS is a specific subset and LTSS providers are a specific subset of providers. I'm going to take a moment to talk about all providers, because I think that the acceptability of providers, all provider primary care specialists, mental health, etc., that their accessibility is key to the health of seniors and people with disabilities who want to remain in the community.

One can always, at any point, need a new provider, and if managed care organizations have networks of accessible providers, that is very important for the health and well-being of everyone who is a Medicaid beneficiary and on managed care programs.

In terms of civil rights, going to the next slide, what is really interesting about managed care is the opportunity it provides to have an intermediate layer between the states and actual providers. What I mean is there is an actual entity now in between, that can help provide technical assistance, can help look into the actual accessibility of providers' offices.

Literature has shown that if providers are left to themselves to figure out how accessible they are, they tend to overestimate their accessibility. A managed care organization could provide a third person external mechanism to review the accessibility of providers' offices. That is one of the first things on this slide, that provider networks can and should be reviewed for their physical and programmatic accessibility.

The physical accessibility concerns the state of the office: Are the doors wide enough? Are the bathrooms accessible? Etc. Are there stairs? Is there an elevator if in a building with stairs in it.

Programmatic accessibility refers to all of the policies and procedures and practices that can be reasonably modfied, and includes does the provider office have accessible exam tables and weight scales, for people who can't just hop onto a table or get onto a scale and stay there.

Does the provider know about the possibility of extending appointment times or making an appointment window? Are there sign language interpreters available to people who are deaf? Do beneficiaries who are blind or visually impaired have access to alternative print format, such as Braille or large font print?

These are all very important parts of delivering an equally effective healthcare service.

Beneficiaries also need access to this information about just how accessible provider offices are so that they can make informed choices about which providers to choose. Maybe there's a provider that is farther away, but actually has the accessible tables that you need.

Also, do managed care organizations have -- managed care organizations can help develop language access plans for limited English proficient individuals, and can help their provider network provide linguistic translation as needed.

These are all also among the top three goals, civil rights goals, for any managed care organization that is involved in Medicaid managed care and wanting to deliver LTSS. So, that is a brief overview of the civil rights opportunities that can be raised by a move to managed care. I'm going to turn the mic over now to Georgia for the remaining tools.

**GEORGIA BURKE:** Thanks, Silvia. I'm going to do the wrap-up of four more items. First is care continuity. As Silvia mentioned in the opening, no matter how well a system is designed, one of the big challenges is making sure that when people join the new system that they don't experience disruptions in their care. Protections need to be in place to make sure that existing services and supports function well until there's a smooth handover.

We believe that a transition period of up to 12 months is a reasonable requirement to place on plans. During that period, the plan would have to pay an existing provider of a new member, if the provider hasn't joined the plan network, at the rate the provider had previously been paid, or at the in-network rate, whichever is greater.

I think it's really important this be clearly extended to all providers, including LTSS providers, and not just limited to physicians. In California, we recently had a move of Medicaid-only seniors and persons with disabilities into Medicaid managed care, and CMS told the state it was OK not to have transition protections around durable medical equipment, assuming that didn't really matter that much. But for people who had wheelchairs, where they had a long relationship with a DME provider who did a lot of adjustments to the wheelchair, it turned out to be a problem.

It's important these transition protections are available to the whole range of providers.

Another really critical LTSS continuity protection concerns Medicaid-funded assisted living or nursing homes. These are homes to the people who live there. They've lived there, as Eric mentioned, many, many years. Nobody should be forced to leave his home just because he's in managed care.

So if there's a Medicaid certified nursing facility or assisted living facility an individual is living in under Medicaid, and if that facility doesn't join the plan's network, either because the plan doesn't want the facility or the facility doesn't want to join, for all members, the plan still should be required to offer a single-case contract for the particular members who already live there, at full Medicaid rates or network rates if they're higher, so that the individual has the option of remaining in his home for as long as that member wants. Not just for some limited transition period, but for as long as the member wishes to stay.

As Eric mentioned, it's also important that barriers for small providers, such as billing system requirements or maybe training requirements that a managed care plan has for providers who do a certain whatever it is, that there be some flexibility there when somebody has an existing provider that they trust and that is a trusted community provider.

Moving on. Also important, of course, is an easy-to-navigate appeals system, so that individuals have a mechanism to enforce all of the consumer protections we've been talking about today.

There's lots of important elements in an appeals system, but let's look at a couple. Certainly central is aid paid pending. By that I mean if a plan proposes to discontinue or reduce a service that an individual is receiving, and if the individual appeals, then the service will continue until a final resolution of the appeal.

This is a Medicaid right, but with some exceptions it doesn't appear in Medicare, and with the merging of Medicare and Medicaid in managed care under many of these duals demonstration projects it's really important that those Medicare limitations don't migrate over to the Medicaid side.

Another issue to be watchful for is a loophole that, under current federal regulations about Medicaid, allows, but doesn't require, that states have an exemption from aid paid pending when a current authorization period has expired.

So for example, if an individual has an authorization for certain number of hours for personal care services, and that's a six-month authorization and then the authorization is renewed but may be at a lower number of hours, the fact that the plan has, for its own reasons, set up certain periods, then had renewal periods, shouldn't be something that prevents an individual from continuing to get the existing level of service while going through an appeals process.

For someone who's got a permanent disability or older adult with increasing frailty, the need for LTSS rarely expires.

It's also important that the definition of necessity in appeals include nonmedical goals, such as independence and community integration. Appeals data needs to be collected and public, including reversal rates, so that both the state and all stakeholders can see whether a plan is routinely improperly denying care.

Another very important protection is an independent ombudsman. Wisconsin is a state that uses an ombudsman program effectively, and we think it's something that should be part of any state move to managed care that includes LTSS.

In Wisconsin, Disability Rights Wisconsin has the contract. It helps beneficiaries through the appeals process. Although the appeals can be about any service., most appeals, in fact, at least in Wisconsin's experience, involve LTSS. What we hear from the Wisconsin ombudsman is that because it has access to the plans and access to the state, and expertise, it can often resolve issues at the plan level before having to move to a higher level of appeal.

It really works better for everybody involved. Having an ombudsman also is a mechanism for spotting systemic issues, getting them resolved quickly. But to be effective an ombudsman has to be independent, has to be trusted in the community, has to be knowledgeable, especially knowledgeable about LTSS, and has to be properly funded.

LTSS consumers and their advocates also need to have ongoing and meaningful roles, both at the state and the plan level. I think here what I'd like to emphasize is that there really is a need for multiple avenues. At both the state and the plan level there's a definite need for focused committees, you can call them advisory committees, whatever, where consumers and their advocates have a really formal mechanism for reviewing and contributing to policies and procedures. This would be something ongoing with people who are really committed to taking the time to be involved.

But there also needs to be other avenues, and there needs to be broader community involvement. One example is New York state, where in its duals demonstration proposal, it is proposing that plans, in addition to advisory committees, also be required to have two member meetings a year, open meetings where the plan provides transportation for individuals who can't otherwise get to the meetings, and the plan has to provide a written summary of what transpired at the meeting, and those summaries have to be available to members and also to the public.

I'd also stress here that stakeholders can't really contribute meaningfully if they're participating in the dark. They need access to performance data, to appeals data, to other information about the plan's practices and policies and proposed changes so that their input can really be thoughtful and meaningful.

Finally, state oversight and monitoring. There's really two aspects to state oversight. One is longer term evaluation, and the other is real-time oversight to spot problems and issues that can't wait.

This slide is about the short-term, but long-term evaluation really is critical, and I just wanted to alert all of you to the fact that DREDF is taking the lead on another paper that we are both looking at that will specifically address quality measures in both demonstration projects and Medicaid managed care for long-term supports and services generally. We're hoping to have that ready in the next few weeks. So stay tuned on that account.

On the shorter term, one of the really basic requirements is there needs to be really clear responsibilities within the state for oversight. As I'm sure you're aware, LTSS programs have grown up under the supervision of many different state agencies, some overseeing mental health, some overseeing nursing homes. Sometimes, in California, for example, we've got a different agency that oversees personal care services than oversees the rest of home health. And then there's departments of managed care and state insurance commissioners. So, there has to be real clarity in who's doing what in terms of making sure this works.

The answer on how best to use the existing strengths within the state agencies and how to integrate oversight might vary greatly state by state. But it's really important that who oversees what gets nailed down, that it is clear and apparent to all.

There's also some very practical measures that can be taken. For example, the state can commit to undertake secret shopper surveys to find out if network providers really are available to new users. Again, it's important these surveys cover LTSS services, not just primary care providers or specialists.

Another really interesting protection is one used in Tennessee, where plans are required to track whether personal care workers really arrive on time and if not to get replacements out quickly. All of the information, if an individual calls in and says the care worker isn't there, goes on to a dashboard that is a computer report that is available in real-time, both to the plan and also to the state. When there are problems, very quickly there are sanctions, including monetary penalties for the plan. So this kind of really specific getting down to the nitty-gritty monitoring is really critically important.

So that's the end of our very cursory discussion of the many buckets. We do urge you very much to look at the toolkit we've developed. Our website at which it's available right away is dualsdemoadvocacy.org/resources/LTSS. It will be up on the DREDF and NSCLC site. NSCLC has a duals demonstration website that has all of the different proposals states have put up for duals demos as well as a lot of other information for advocates.

Finally, here is our contact information. We have a couple of minutes for questions. Eric was looking through the questions people have sent in. Could you maybe pick one or two, Eric?

**Q & A**

**ERIC CARLSON**: Sure. I can do that. Here's a question submitted by a couple of people. The question is: How does dementia relate to the care planning process? Any thoughts on this? I think specifically Silvia and Mary Lou, you had addressed it. How can that be dealt with in the care planning process, if the beneficiary has significant dementia?

**Mary Lou Breslin:** Hi, this is Mary Lou. I think that the care planning process must take into account all of the factors we talked about in the earlier slides, the individual needs of the person, family circumstances, the healthcare needs, all of the factors that relate to competent and appropriate, both medical services and long-term services and supports, and whether a person has dementia or cognitive disabilities from other disabilities or from other conditions, or has multiple conditions, including physical and mental limitations, the evaluation and assessment process and the care planning process should be the same, and the outcomes should be person-centered and should focus on the specific needs of the individual.

So there really should not be a distinction in terms of the planning process, but there certainly will be a distinction in terms of what the most appropriate level of supports and services are that the individual needs, and that in the case of the person with dementia if the person needs a representative, a family member or close friend or another person, to participate in or make significant decisions, that would also be considered a person-centered approach, and would be part of the process as well. Thanks.

**Eric Carlson:** OK. Thank you very much. A second question, the question is: Might the move to managed care result in reduction of personal care hours? I'll take a quick stab at that. The answer is yes, and that's one of the dangers of a managed care system. If you're in a state that already has some useful and very beneficial standards that are set, with regards to authorization of hours or that deal with budgeting, it's important to retain those as a floor in the move to managed care.

Georgia, if you're ready, here is a question that asks how many dual eligible projects do you think CMS will approve? Maybe you can give a quick flavor of CMS' attitudes towards these various dual proposals.

**GEORGIA BURKE**: Well, that is a hard one. The proposals have poured in, and I think CMS is anxious to approve as many as it can. What we're seeing, though, is several of the states where at first CMS had been pushing the states to get started in January of 2013, but we're seeing several states pushing back their timetable, because they're finding that putting all of this together really involves a lot of complexity, and there just really isn't enough time to do it right.

So we're seeing more states proposing to start either in the middle of 2013 or in 2014. So I think CMS will want to, over time, approve most of the applications that have come in, but I think it's more a question of how they'll roll out, rather than denying any state outright. That's at least my sense of where it's going right now.

While I have the mic, I do also want to let everybody know that the PowerPoints will be available. They'll be on our website at NSCLC.org and I suspect DREDF will put them up as well. And this presentation was recorded, so we'll have the recording up as well. Several people have asked about that.

I think we've pretty much run out of time. Eric, do you have any other questions that you think we really need to address? We can also, if you have questions that you've already written, we can try to respond to you offline. If any questions come up, particularly after you've had a chance to look at the tool, we all are available and we'd be more than happy to stay in touch with you.

**ERIC CARLSON**: Let me mention a couple of things. We got a comment that pointed out that the National Disability Leadership Alliance has developed principles for providing coordinated quality healthcare and Medicare managed care programs that include 16 principles. It would be worth it for folks to take a look at that, the principles put out by the National Disability Leadership Alliance.

Also a good suggestion, saying what about suggested language for managed care contracts. That's maybe the next step beyond the toolkit we have for our organizations and for others to develop more specific language, because obviously advocacy is a lot easier if there's already developed language, specifically if we can point to states where language is already in use and being used successfully.

Everything else I think can wait. So I'll turn it back to you, Georgia.

**GEORGIA BURKE**: OK. Thanks, Eric. Yes, we are hopeful that over time we can have more and more specifics available to help folks. If you will check back on the duals demo advocacy.org site, as we see language coming out of states and we're trying to really share the wisdom of state advocates who are involved in these proposals in different states so that we can all learn from each other.

So I urge you to check back on that site frequently, and also again we're more than happy to work with any of you individually.

Thank you all so much for joining our webinar. And we appreciate everybody's time and patience. Thanks so much. Bye-bye.

[Ended at 3:04 p.m. eastern time]