

2010 ADD Technical Assistance Institute; June 24-25, 2010, Arlington, VA

Transcript of opening message delivered by Sharon Lewis, Commissioner, Administration on Developmental Disabilities

## **OPENING MESSAGE**

**SHARI COOPER:** Sharon Lewis was appointed Commissioner of the Administration on Developmental Disabilities in March 2010. She's been an effective advocate for disability issues, working for a better quality of life and better outcomes. She has been working on disability policy for more than ten years both locally and nationally.

She originally came to D.C. to serve for the junior foundation public policy, working for Senator Chris Dodd.

In 2007, she joined the chairman as a senior disability policy adviser, where she advised members of the community on disability concerns related to education, employment, and healthcare.

She is the recipient of numerous awards, including the 2010 distinguished leadership for disability policy award and the consortium for citizens with disabilities chairman's award.

She has worked on public policy for developmental disabilities for the ARC. She served as the co-chair of the action coalition team founded by disabilitycompassion.org, working with individuals with disabilities and families to participate in policy decisions at all levels.

She is from Michigan. She graduated from Washington University.

Commissioner Lewis, you are a busy lady.

(Laughter.)

It is my pleasure to introduce Commissioner Sharon Lewis. Thank you.

(Applause.)

**SHARON LEWIS:** Thank you very much for that wonderful introduction, and thank all of you for being here. It is so exciting to see so many hands going up in terms of folks who have not been with us before. I'm excited to be here with you, and I'm really looking forward to a couple of days of great work, connections, and opportunities.

I wanted to start off by saying thank you to our own staff and to the staff at NACDD, who have made this possible, in particular, and I don't know where you guys are in the room, but if you want to stand up or wave or whatever is most comfortable, Sarah, Kathy, Jennifer, they have worked tremendously hard on behalf of ADD to make sure that this is a valuable two days for you. And this concert with Sheryl, where are you, Sheryl, who has just done yeoman's work to pull all of this together, as well as the members of the planning group. Thank you all for making a great agenda for the next couple of days.

Even though you just heard my bio, I thought I would take a minute to talk about my background because many of you I don't know. But I think what's important for you all to know about me is that I am standing here as proof positive of your work. The reason that I care so passionately about ADD and the programs is because the DD network, in particular the DD councils, changed my life. I know that sounds corny, but it's true. I came up through the network. As a parent, I ended up running the program. I worked for some of our local nonprofits doing grassroots organizing and advocacy work. And then ultimately with support from our council, our UCEDDs, several of our nonprofits, I

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ended up working on building a couple of statewide coalitions that were really focused on empowering individuals with disabilities and family members, not just serving them.

And when I came to D.C., first as a Kennedy fellow and then as senior disability policy adviser, the foundation of those values, which I learned from all of you, are the home base that I come back to every day. That's important for you to know.

And of course my family grounds me and supports me. Watching my daughter manage the challenges that we still face and that the world creates daily reminds me of how far we still have to go. Just within the last two weeks I found myself in an IEP meeting; once again, explaining that no matter how terrific that special ed classroom down the hall with all those wonderful children is, it's not the least restrictive environment. It's amazing to me that in this day and age; we're still having this conversation. That access to grade level content is paramount and that all kids, all kids benefit from differentiated instruction.

At the same time as the folks down the hall in the school are having discussions about how to ensure a culture of acceptance and interdependence among the diversity of students in the building. And while my kids get the connection between those two conversations going on in the building, the adults don't. That tells me a lot about how much work we have left to do.

I would argue that these attitudinal and cultural challenges are engrained across our culture, including in the federal government. At ADD, we are a small but powerful voice in changing that attitude.

As all of you know, I have been there for just over two months. It's been a pretty busy transition time for me and for all of the staff. They've been wonderful and welcoming me, teaching me about the bureaucracy, which has been a steep learning curve.

And there's a lot to do. You guys all know that. So I wanted to talk a little bit today about our agenda, and then some issues that are specifically of interest to the councils.

Our immediate agenda integrates both administrative activities as well as policy issues and the concerns of the administration. However everything that we're doing is grounded back in the DD Act, intended to support that mission, as stated in the statute, to ensure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms assistance that promote independence, productivity, and integration of all facets of life through culturally competent programs. The provisions of the DD Act support our work.

Among the administrative goals that we're working on right now, we are working to ensure that ADD is well positioned to support the network with knowledgeable staff and appropriate resources. To lead by example, by hiring individuals with disabilities on our staff and supporting the secretary's goal of having 2% of HHS staff be individuals with disabilities by the end of this fiscal year, by October 1st, to ensure that at least 2% across the agency are those targeted disabilities. And I'm happy to report that as of yesterday, we have two great new staff coming on board at ADD that hopefully some of you will have the opportunity to meet that will help us move along this that goal.

We want to create an open and receptive culture that allows real experts, people with disabilities, family members, and professionals who support them, to drive the priorities and the agenda. Not the folks here in Washington, D.C.

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We want to find ways, better ways, to find data and reporting to both improve programs and strengthen the support and resources for our efforts.

We want to build relationships and the infrastructure to support ADD and allow us to inform and support the broader policy goals of ACF and HHS and to capitalize on the strong level support we have within the administration. We have great opportunities right now. It's a really exciting time to be part of this administration and to serve as the voice internally for people with developmental disabilities. We're at the table on critical issues. I thought I would take a second to talk about some of the things that we're working on across HHS and interagency efforts. Probably first and foremost, the thing that is driving most of the conversation at HHS right now is the implementation of the health reform bill, the Affordable Care Act, which is a change. We're all engaged on that. We are the office responsible for working on, in particular, long term services and supports, including working on the implementation of the Class Act as well as improvements to Medicaid home and community based waivers. ADD has been forging relationships, which is something that hasn't happened a lot in the past, to my understanding. It's exciting to have those opportunities.

The Affordable Care Act has so many moving parts and so many good policy changes that will benefit people with disabilities and their families. For example, the law eliminates insurance company discrimination by eliminating children denied for preexisting conditions. Going forward, starting this year, the act will prohibit insurance companies for denying or charging someone more than another because of genetic information. We have banned insurance companies from dropping people from coverage for using the coverage. Amazing that we have to have that conversation. The act restricts the use of annual limits in all plans, in all new plans and existing employer plans, starting this year. And then in 2014, all annual limits are prohibited. So those caps for families that max out will be gone. The new law will provide access to health insurance to those without job based coverage and provide tax credits to those who can't afford coverage, significantly increasing access to choice of health insurance plans for individuals with disabilities. This is important so that people can keep their jobs rather than giving unemployment in order to access Medicaid.

And in a little known provision, the act requires accessible medical/diagnostic equipment, things like examining tables, X ray machines, the basic things that many of us take for granted that have been inaccessible for individuals with disabilities will now be required to be accessible, so that people with disabilities can receive routine and preventive care like mammograms. For a woman in a wheelchair, it's nearly impossible to get a mammogram right now. The Affordable Care Act will change that.

There's a lot of information about healthcare reform at a website that is [www.healthreform.gov](http://www.healthreform.gov), including a lot of state specific information. If you haven't checked out that website, I would suggest that you do so and you do it on a regular basis. It's updated nearly daily. Through that website, HHS has also been hosting weekly web chats on a range of issues. A few weeks ago, they targeted questions around what the Affordable Care Act means for people with disabilities, and I would anticipate that we will continue to have that kind of information accessible to people through that website. I strongly encourage you to spend some time there.

Another initiative that ADD has been involved in as been the community living initiative. A year ago on the anniversary of the Olmstead decision, President Obama announced

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an initiative related to community living, really focusing on Olmstead implementation. The Department of Justice, as you may know, we've been sending out notices on our listserv, has been gung ho, to say the least, in enforcing Olmstead, and we are excited to see that happening and should further your efforts in terms of community integration.

The community living council has been working on a variety of issues. The deputy assistant secretary, David Hansell, who will be here over lunch, will talk more about some of the efforts on the community living initiative, but I'm pleased to say that ADD is an integral partner in those efforts and has been working with our partners at the Centers for Medicaid as well as the Administration on Aging and HRSSA to really look at where are all of the federal components of community living and how do we ensure that people have access to living in the community.

On family and children's issues, as an agency within an agency, ADD is part of ACF. We are working on a lot of cross cutting policy issues, including looking at TANF and supporting nondiscriminatory support. You may be aware that OCR recently came to a settlement with the folks in Wisconsin around discriminatory practices in access to TANF. For those of you who track TANF issues, that is a great decision and there's great information there that may be helpful for you in looking at these issues in your state.

We are participating in and supporting the President's initiative on early childhood learning across environments, including pre-K, head start, interdepartmental, HHS, with a summit scheduled for August. We're looking at foster care with our partners at the administration on children, youth, and families and we're participating on the interagency autism coordinating council, in particular looking at bringing a much needed voice related to policy perspectives on supports and services, not just treatment and cure.

In terms of my two major priorities at ADD, really I have two things right now that I wanted to focus on and talk about. First, we need to strengthen our outreach and public input efforts to better understand state and local priorities and utilize this information and prioritize our discretionary spending using our internal resources incorporating this information into policy decisions. To this end, we are implementing several outreach efforts, including two in particular that I want to talk about today.

Next week, we will be unveiling a web based public survey asking for ideas and feedback related to projects of national significance. We need your ideas and your thoughts. I am not interested in being a commissioner who decides that this is what I want to fund and spend money on. I need you to engage actively in our prioritization process.

(Applause.)

I hope that as we get that link out, you will forward it broadly. I want to see it popping up all across the country, because we need a broad cross section of folks to participate in that survey to ensure that best information to inform us as we move forward.

Also to improve our communication and outreach efforts, so that all of you know about these great things happening within ADD and ACF and our relationships with the Department of Labor and what's going on in D.C. in general, we're establishing a new email list available to anyone who wants the information. In the past, ADD has really only sent out information to executive directors and to the point of contact for our

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grantees. We are actually -- we want to get the information in the hands of council members, in the hands of staff, and go beyond that. I know a lot of you as executive directors do a great job of sharing that information with your councils, but we want to make sure that anybody who wants the information can get it. We will be sending out an email in the next few days to the EDs and to the emails that we do have with that email address so that people can subscribe to this list. And again, I would encourage you to distribute it widely so we can build a really great information flow out of ADD and through the network.

And my second priority, and we will be continuing additional outreach and communications efforts over the year, but those are the first two things we'll be working on.

Secondly and probably my most important priority is really I am hoping to complete a DD Act reauthorization that really reflects the principles of the act. As all of you know, we don't get many chances to reauthorize. Congress has shifted. I was looking at the history of the DD Act reauthorization. Once upon a time, it was done on a regular schedule. We actually had DD Act amendments and reauthorizations every couple years. We've now been sitting since 2000 without a reauthorization. This is not about the DD Act, however. We have huge reauthorizations sitting up on the Hill that are very, very overdue. The Workforce Investment Act has not been reauthorized since 1998. The Child Abuse Protection and Treatment Act is many, many years overdue. The Childcare Bureau Act development grants is way overdue. So we are part of a long line of overdue legislation. That makes our task of reauthorization that much more difficult. All of us in this room care passionately about the DD Act, but in congressional views, it is small potatoes. I hate to say it, guys, but we live and breathe this stuff every day, and there's not a lot of people in Congress who do. So it will not be an easy push.

I don't want to miss the opportunity to get it right. I'm not interested in just tinkering around the edges on reauthorization. I think since this only comes along at this point once every ten years, I really want to get it right. I believe we should ensure that self advocates are a critical component of the DD network, reinvigorating and defining family support and taking it in new and exciting directions, strengthening the role of the DD network and systems change efforts, improving data collection, evaluation, and reporting, acknowledging and enhancing our relationships with our state DD directors, and of course providing adequate resources for the work.

As such, we'll be embarking on a series of activities over the next year to prepare for reauthorization. This is not going to happen in the next few months, but it will happen quickly in terms of starting this public engagement and really trying to figure out what are the priorities in the DD Act reauthorization. One initiative that we're looking at is really some very focused conversations about the federal and state role in supporting the self advocacy movement and honing in on what we need to do there. So stay tuned for more information about that. Sneak preview. But we will be talking a lot about how do we all engage in a reauthorization process.

Finally, I wanted to touch upon some very specific issues and concerns for the councils, especially here at the TA institute. As we talk about state plans, data reporting, and evaluation efforts. By way of context, I think it's really important that everyone in this room understand that the days of federal financial support with little accountability are gone. They're just gone. It's not about who is in the political leadership. The politics

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have fundamentally shifted with the loss of Senator Kennedy. Senator Jeffers and Senator Kennedy for many years were our champions. We don't have them right now.

The members who will prioritize our issues are few and far between. I believe the DD councils are the heart and soul of the DD Act. And it's critical --

(Applause.)

-- that councils have strong relationships with our political leadership. In addition, for us internally, when we look at information for the councils, it's clear to me that we need to strengthen our technical assistance and training efforts. When councils are struggling with basic operations and compliance issues, I have grave concerns. Guys, some of this stuff that I'm seeing concerns me deeply. If we can't show that these basic foundations in terms of meeting the requirements of the act are strong, it will be even harder to move forward in a performance discussion, strengthen our opportunities, and improve our funding resources. The questions that I receive from Congress and from federal staff make it clear that we have a lot of work to do in ensuring that people understand the value of the councils and that we have measurable performance outcomes that can demonstrate the value of a federal investment. Recently I had a conversation with a high level political appointee who commented to me about the councils, 40 years of planning? Haven't we planned enough? Are these just permanent task forces that have outlived their utility?

That scares me. I care deeply and passionately about the councils and the work that we do. Complacency is not an option right now. Leveraging additional resources, measuring performance, and demonstrating sustainability are issues we all need to think about. It is no longer adequate to collect and report output information, how many people came to a meeting or are trained. We have to move to focus on meaningful, valid, and reliable data. We have to demonstrate the good work that I know all of you do. And we know that the tools and the processes that ADD uses are often part of the barrier to demonstrating these outcomes. This is a partnership. We have to figure this out together.

So that being said, several initiatives that we hope will move us along a path towards the demonstration of outcomes: First, I want to talk a little bit about the Westat evaluation. I know it's been a lot of work. Thank you for participating. I know it hasn't always been pleasant. But I appreciate your willingness to participate.

Yesterday we mailed out a letter that for those of you who are executive directors will be in your boxes when you get home that talks a little bit about Westat and where things are. I wanted to explain a couple of things that I talk about in the letter.

At this point, nearly five years into the process, additional significant changes to the study protocol would be cost prohibitive. We know that the study is not perfect. We know that the study does not get at program impact the way that we would like to. But no additional savings could be recovered from terminating the evaluation early. Additionally, the vast majority of grantees participating in the study have already completed the time consuming work and changes to the process would have an adverse impact without saving any time for the participants.

As the study has unfolded, ADD has received consistent feedback about the difficulty of utilizing a quantitative framework, using numbers, for understanding and assessing program impact. The study design has shifted substantially from this original concept

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and is now using a descriptive, a narrative, words to talk about and collect information through on site interviews, surveys, and review of documents as a way to document program effectiveness and achievements through qualitative information, not quantitative.

We've been working to re-conceptualize the original evaluation as a national study that demonstrates program achievements and effectiveness. We're changing the statement of work. We're renaming it. National independence study of the administration of developmental disabilities programs. It will include suggested qualitative performance criteria based on narrative descriptions as opposed to quantitative measurement systems. This will include interviews with stakeholders, including many of you, for validation purposes, and then revised according to your feedback but will not include program targets for explaining the impact. We're moving away from that assumption.

(Applause.)

The project is no longer concerned with measuring program impact using those quantitative performance standards. The criteria will be used to describe over all program effectiveness and achievements across the country but will not represent an evaluation of any individual grantee or any individual state.

In order to truly reflect the partnership between the ADD and all of the grantees in implementing the DD Act, I believe ADD itself should have been included in the study.

(Applause.)

As such, the project is being expanded to include ADD, including technical assistance provided to grantees, in order to better understand how we support and create barriers for grantees in achieving the purposes of the act. One component of this assessment will include surveying all of the DD network grantees, not just the study participants, about ADD's efficiency and effectiveness. I hope you all will participate and provide us with your honest input.

Finally, I do think at the end of the day we will all benefit from the distribution from an independent source providing in depth information regarding the activities of the DD network. We see this as a good tool for policy makers to demonstrate the excellent work done throughout the DD network, as well as some of the challenges experienced by the grantees. So thank you for participating and know that this is where we're taking things.

Secondly, we are revising the state plan template.

(Applause.)

Pretty timely and relevant for this conversation the next couple of days. The current template requires that goals are set by areas of emphasis, and in the past, ADD has directed the councils to set goals for every area of emphasis. The law does not require this. So the law actually does say that the goals need to relate to the areas of emphasis, but it does not include a section to provide the requirement planning to include -- excuse me -- for the grant -- the template needs to include a section to provide the requirement that the plan include a goal for each year of the grant to establish or strengthen a program for the direct funding of state funding organization to support opportunities for individuals with developmental disabilities who are considered leaders, to provide leadership training to individuals with developmental disabilities who may become leaders, and to support and expand participation of individuals with developmental

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disabilities and cross disability and culturally diverse leadership coalitions. These need to be built into the state plan and the process in terms of the template.

ADD proposes to make changes to the following sections. We'll be looking at the comprehensive review and analysis, the goals, budget, and evaluation planning. We are going to start with a draft template that will be used as a starting point for discussions. It aligns well with the requirements of the DD Act, and yet it should be reviewed, evaluated, and revised based on the feedback that you will provide.

So in working with our TA contractor, ADD will convene a group of council representatives, including council executive directors, to engage in a dialogue to propose revisions to the template and evaluate it for usability and effectiveness. We will be doing this over the next two and a half months. The goal is to have this completed by the end of September so that you have a usable state planning template to go forward with in this next year.

The third piece of news, because we know there are many challenges in using our favorite tool, OLDC, for data collection and reporting, we're looking at alternatives. We don't have to use OLDC.

(Applause.)

I'm excited to announce that we are embarking on a process that will allow councils to use DD suite for data collection and reporting. We're in the early planning stages of this change, but we've run the traps in HHS and ACF, and this is something we can do. We've had some conversations with the DD suite developers and our friends up in Massachusetts about what we need to do moving forward, and we think this holds great potential for saving time, money, and providing us all with improving tracking and reporting tools. For those of you who love OLDC, you can stay with that option. We're not taking it away. But for those of you who are planning to use or would like to use DD suite, we'll do everything we can to make this possible.

Finally, we are also going to restart the process of revising the PPRs. Back to my original point around ensuring that our members of Congress, that our political leadership, and the public at large, understand the work that we do, we need more effective reporting. We will be convening work groups on this topic as well and using all that we know from the field. Looking at the work that has already been done. I know many hours have been spent on this task already by many of you. Looking at what we're learning from the Westat national study, looking at what we can learn from efforts, looking at work that other councils are doing to measure your efforts, to measure systems change and measure the good work that you're doing so we can propose new annual reporting methods that are valid, meaningful, and useful in demonstrating all of your accomplishments.

So a little bit of work laid out in front of us. Pretty ambitious agenda, both short term and long term. I will need your help and support, and our staff will need your help and support. You so far have been incredibly generous and welcoming and accommodating in providing that support, and I want to thank you for making it an easy transition for me to come into this role. I look forward to our time together in the next day or two, and I look forward to our continuing partnership. Thank you.

(Applause.)

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**JEANNIE ELKINS:** Thank you very much. We'll take our break and be back in 10 minutes.

**MELISSA SWARTZ:** She finished quickly and has offered to take questions.

**JEANNIE ELKINS:** Oh, I'm sorry. If you have questions, we have microphones in the room.

**SHARON LEWIS:** It looks like we do have a couple of questions. The problem with offering a break versus listening to me some more, people are heading through the doors.

**AUDIENCE:** Good morning. I'm Sandy from Louisiana. First I just wanted to say thank you so much. Your comments are just such a breath of fresh air. With that, my question is, with the Westat evaluation, we are one of the states that did participate. I totally understand that the information is just going to be in the aggregate, but is there any way that we can receive our information, just to come from us? Because I'm just curious, you know, as to how we individually fare.

**SHARON LEWIS:** I'm going to punt this one. Jennifer, do you want to comment on that?

**AUDIENCE:** Hi, everyone. Jennifer Johnson with ADD. At one point in time in this process, we had talked about that actually occurring if states were interested in receiving the information back, knowing that it would just go back to you, it wouldn't be shared with anyone else or ADD. I don't see any reason why we can't make that happen.

**SHARON LEWIS:** So if you are a participant and you are interested in that, Jennifer would be your point of contact in expressing your interest on that.

**AUDIENCE:** Many of us know, in the last reauthorization in 2000, OMB wanted to see an independent evaluation of the DD Act programs. If Westat does not satisfy OMB or will not be their criterion, will we still expect some kind of another -- I don't know the right word -- evaluation, and how will we go about setting that up? Because the projections on reauthorization right now, I've heard everything from, it will happen in 2011 or stretched out to 2013.

**SHARON LEWIS:** So a couple things. As I said to some of you, the politics driving the original evaluation have shifted, and that is politics. I mean, the difference between this administration and the previous administration in focusing on what was called the part, that was a tool developed under the last administration, utilized across many program areas in the federal government to determine ratings of programs, is not a tool that the current administration is continuing utilization of. So that is one piece of the question that you asked, Sheila, around what are the politics, is OMB going to come back and say what we've done is inadequate. I don't have any indicators from OMB about improving in terms of the concerns about independent evaluation. I think that we do have issues in terms of GPRA in our reporting. We'll talk about that in session tomorrow. But for example, we have a couple of measures that we have to report out to OMB through GPRA, and one of them this year, we had to throw it out because it was so unreliable and so invalid because we had data going like this because everybody uses different definitions and the information coming in to us doesn't make sense. On this particular measure, all of you would have had a target of 100% next year on this particular measure, which we thought was a little ridiculous.

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So the question is, are we going to wait until OMB and the political shifts are going to demand performance measures, established by other entities, or are we going to take the bull by the horns and make sure that we have a robust accountability system that is defensible so that as we're moving forward, both in terms of our advocacy with the legislative branch and our internal advocacy, regardless of political leadership, we can talk about the strengths of our programs. And that's why we're embarking on these different components ranging from the conversation on PPRs to what do we do about the state planning template to what do we do about reporting and using tools that make sense to all of you so that your time and energy is well spent.

**AUDIENCE:** Good morning. I've been with the Ohio DD council for 24 years but this is my first time here so I'm a newbie.

I have a question. You talked about restructuring of PPR. Are you talking about having that completed in time for the next five-year plan, or will it be changed during this cycle?

**SHARON LEWIS:** Well, so there's two parts to that question. We are going to change the state planning template right now so that you can use it for this planning cycle. One of the concerns we this is that the PPRs are driving too much of your work. So one of the reasons we wanted to change it is so we're focused on the components of the state plan, because to answer your question, we cannot -- I don't see that sequencing-wise we're going to be able to complete and get through OMB clearance a revised set of PPRs to go hand in hand. In an ideal world, we would, and we will move the process forward as quickly as we can and align it as quickly as we can, but I think it would be unrealistic and unfair to all of you, because we would essentially have to have those revised reporting requirements in clearance, you know, in the next few months in order for the process to play itself out and have that be a relevant tool for FY11 reporting.

**AUDIENCE:** Good morning. Holly Riddle from the North Carolina council on developmental disabilities. In the 20 years that I've been directing that council, I've worked our field develop sophisticated instrumentation for outcomes reporting. We mentioned the national core indicators who work with the council or quality leadership to measure outcomes for individuals, et cetera.

I hear you talking about and am heartened deeply by your commitment to performance outcomes, meaningful, measurable performance outcomes for councils on developmental disabilities. I would like to ask you if you would commit during your administration to the release of a competitive request for proposals to develop such an outcome reporting system for the 55 councils on developmental disabilities.

**SHARON LEWIS:** Thanks, Holly.

(Laughter.)

**AUDIENCE:** You know I'll be here for another 20 years and I'll get this.

**SHARON LEWIS:** So the short answer to the question is I can't commit to that standing in front of you today. I wish I could, but I cannot, for lots of different reasons. First and foremost being that, you know, our funding priorities for the next year have to be driven by lots of considerations, and to make good on my other commitment in terms of where are we going and what are we spending time and energy on.

Now, that's not to say next week when the survey comes up, if the number one response we get is -- I'm just kidding.

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(Laughter.)

I think it's something we have to talk about and look at. I think we need to start these conversations internally in terms of the work groups, state planning template, PPRs. If it looks like we need to engage in a contract, then we'll talk about engaging in a contract. Okay? I mean, that's what I can say right now.

On that, on the note of funding priorities, the other thing that I would just remind all of you who hopefully read the newspaper and pay attention to some of these things, you know, we are currently operating with the President and soon to be departing director under a requirement that we look at a 5% cut in domestic spending. Okay? We will be affected. I can't say whether the councils will be affected or P&As or what, but we will be affected. We are currently doing the analysis and going through the process internally in terms of where those cuts are going to come from within HHS, but this is why this conversation is really important, because when I walk into a meeting and say, no, don't cut the DD councils, and people say, well, why, aren't they just planning task forces that have been around for 40 years, I need to be able to have data to support my argument. So funding is not going to be -- it's going to get worse before it gets better. Let me tell you that. That's just real. For those of you who know me, I'm pretty direct. I wish I had better news, but that's where we are.

**AUDIENCE:** Commissioner Lewis, I'm from Missouri.

**SHARON LEWIS:** Change your name.

**AUDIENCE:** That's my question. I kind of wanted to ask about the 5% cut. I thought you would probably address that and you just did, so thank you for that.

And then seriously, we've talked about our name before. Not very much as a council but amongst the directors. And I know several councils have changed their names because of that very reason, and even in our state at time it's can be a bit challenging to describe who you are and what you do. Should we invest the funds to come up with a new name and change our logo and everything?

**SHARON LEWIS:** I think that's a decision you have to make at the state level. I think it's important to hear that comment that was made to me. I mean, that's -- here in D.C., and I can say all of this to you, as somebody who came out of a state, very engrossed and enmeshed in DD efforts, coming to Washington, D.C., where on the Hill there are over 10,000 staff, I bet you out of the 10,000 staff, there are three to five who could actually describe to you what a DD council is. And when all they hear in the tens of thousands of issues that they're dealing with is DD planning councils that have been -- that just celebrated their 40th anniversary, the question arises. I know it sounds rudimentary, but it's something you should know.

**AUDIENCE:** Good morning, Commissioner. Bill Lynch from the Oregon council. I think we've met once or twice. I was smiling throughout your comments. Just happy to hear about the initiatives that you're launching.

Just wanted to address one thing. Unlike Holly, I won't ask for a commitment, but I'll encourage you to consider something. I think one of the barriers for having robust accountability for measuring outcomes has been that lack of link between PPRs and state plans. So much work sat at the staff level to make that link, and it's absolutely vital. So I was really happy to hear that you're embracing the DD suite as an option for states, and I don't know exactly where DD suite is at in terms of trying to develop that link, but I

Transcript of opening message delivered by Sharon Lewis, Commissioner, Administration on Developmental Disabilities

know it was on the agenda for a long time but pushed out as other things were being put in place. So if you, your staff, and your resources could be added to that effort, I think it would be great.

**SHARON LEWIS:** And I can tell you that we are committed to putting some resources out of ADD to support DD suite and make this work. We're not going to just take what we have right now and make everybody run with it. I think we need to talk about the state plan template issues, centralized database issues in terms of our overall access. There are several technical components that I know our friends will have to work through in order to make all this work, and we literally just got the word within the last two weeks in terms of the legal requirements of moving away from OLDC and so forth. It's helpful feedback in terms of what we need to be looking at.

**AUDIENCE:** I'm Laura with the Virginia council. We do not have the word "planning" in our name. I think that's a good thing.

As you look at state planning and recording and so forth, I hope you will also look at the requirements regarding DD network collaboration, which of course is really important but I think a lot of the focus on ADD in the past has been how many meetings have you gone to together, how many phone calls you have had, versus the real meaningful work that some of us do. There may be only one or two issues that we focus on in a year but they're really important issues and we have some great outcomes. When we get questions like, but how many times did you talk on the phone, it's a little frustrating.

**SHARON LEWIS:** I hear that. And you're right. I mean, that's not the measures that we should be looking at. I think there are a couple of things we need to do. One of the easiest in the reauthorization is fix the cycles so that everybody is on the same planning cycle.

(Applause.)

So you guys can get to meaningful collaboration in planning and throughout a five-year cycle, because I mean, I get that. Especially when you're talking about annual measures. It's not about the number of phone calls; it's about the sequencing of the process in terms of the different roles that the network entities play. In enforcing systems change, providing the research and data and so forth to support and document systems change. Yes. I think that we have to change that. I think it is a question around what do we measure and talk about when we're looking at collaboration, because frankly, it is easier to talk about how many meetings did you go to together, which is an output, not an outcome, versus here's what we all did and here's how we worked together to achieve this outcome and we'll need your help to get to that.

Anything else?

Okay. You guys are very patient. Thank you and I look forward to seeing you in the next -- throughout today and tomorrow.

(Applause.)

**JEANNIE ELKINS:** Thank you very much. Our break will end at 10:30. Return to this room at 10:30. Thank you.