

TELECONFERENCE ON STATE PLANS

December 8, 2004

State Councils participating: Florida, Indiana, Maryland, Delaware, Kansas, Tennessee, New York, California, Iowa, Hawaii, Idaho, Nebraska, Connecticut, New Hampshire, Georgia, Illinois, New Mexico, Oregon, Texas, Kentucky, Wisconsin, Vermont, Washington DC, Alabama, Maine, Missouri, Wyoming, North Carolina, Minnesota, Colorado, Pennsylvania, Utah, Oklahoma, Alaska, Michigan, Guam, Ohio, Washington State. NACDD staff – Phyllis Guinivan, Karen Flippo, Sheryl Matney and Susan Madison. From ADD - Mary Beth Greene and Margaret Schafer.

Welcome and thank you all for supporting this call today. We're taping this call and notes will be sent out to all the Council Directors. You can forward it to specific staff or Council members and then we also will post them on our website, under the technical assistance resource section. We're going to begin with Mary Beth Greene from ADD. There is an attachment to the call that I sent out, which is her handout on the DD Act and the requirements for the State Plan. Mary Beth - welcome.

DD Act Requirements for the State Plan - Mary Beth Greene with ADD (attachment)

I wanted to talk about the requirements that the DD Act has for the State Plan, and all this can be found in Section 124 of the DD Act. Please refer to my handout.

There are 5 main requirements of the State Plan according to the Act, and those are 1) establish and maintenance of a council; 2) identification of the designated State agency; 3) a comprehensive review and analysis of the services and supports that available to individuals with developmental disabilities; 4) the Plan goals; 5) the assurances.

I'll focus predominately on #3 and #4, the comprehensive review and analysis and the plan goals, because those are the needs of the State Plan. What we see that the DD Act requires is for the DD Council to do a review and analysis of what that service system is in their State. What that means is what are some of the unmet needs for services, specifically within federally assisted State programs such as medical assistance, maternal and child health, children's mental health services, comprehensive health and mental health services and institutional care options, etc. So there's a long list in Section 124 of those areas under federally assisted plan that you'll want to look at and see what you're responsible for in terms of doing an analysis.

Some other things there include job training, job placement, rehab, child welfare, aging, etc. Again I will refer you to that list to look and see what those services are that the Council should be reviewing as part of its State Plan.

It's also required to look at inter-agency initiatives that improve and enhance community services and support. So what kind of inter-agency initiatives are there in your State that are ensuring that there's not a lot of overlap? Or that are helping to take care some of the barriers in your State of unmet needs for services? We also need to look at the extent to which the community services directly benefit individuals, and that would be specifically in areas like eligibility, assisted technology, what is there in terms of waiting lists in your State. You're required to do an examination of healthcare to people in facilities and ICF/MRs, and through home and community based waivers. Again, I'll refer you to the specific language of the Act, but that gives you a highlight of those kinds of community services for an individual that are to be reviewed by the Council in its State Plan analysis.

It's also required to look at inter-agency agreements of the DD Act program. So you want to look at the network organizations and see what kinds of agreements or working documents you have with each other.

All that information is going to provide you with a variety of things to look at in terms of the unmet needs for services, any kinds of barriers that there are in your State to those services, and that will build you a rationale for your goals. So from all that information the Council develops its plan goals, and it clearly states within the Act that those plan goals are developed through data drive strategic planning. That essentially means what kinds of data you've looked at in your State, analyzing that data, analyzing the programs themselves, and developing your goals based on that data.

The one specific goal that is required in the State Plan is relative to self-advocacy. There's 3 components to it, one is establishing or strengthening a program for the direct funding of the State self-advocacy organization led by individuals with developmental disabilities. That's the first of the required goal. The second piece is to set a goal 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. Again, that's the second piece of that goal. And then the third and last required part of that goal is to support and expand participation of individuals with developmental disabilities in cross disability and culturally diverse leadership coalitions. And I know you've heard all that language before, but I wanted to emphasize that as being the required goal within the State Plan.

Obviously your other goals are going to come from what your needs are that you've determined through your State Plan analysis. Also, within those Plan goals it's required to determine the strategies that you're going to utilize, and the message to determine if the goal has been achieved. So the strategies are spelled out to you. If you look through Section 125, it talks about specific strategies of Councils such as outreach , training, informing policy makers, coalitions, those types of things that are all spelled out within the Act. Those are the strategies that we have listed in the State Plan that you will check off relative to each goal that you're going to work on. Then you have to have a method to determine if the goal has been achieved. That is through data, it's through whatever you develop as a Council to determine whether or not you've been able to achieve your goal.

The last piece of the State Plan requirements are the assurances, and those are signed documents that include a variety of things like how the funds are used, that 70% of the money is for the goals of the State Plan. They put the parameters around the costs for the responsibilities of the Designated State Agency. And it details information on conflict of interest, on interference, and there are other assurances that I'm sure you all are aware of within the State Plan requirements. We do require a signed document relative to those assurances that you will need to send along with your State Plan.

I will put in here that we're trying at some point in time to have an electronic signature. I'm not sure what the status of that is right now, but hopefully by the time the State Plans are due that will be developed. And finally, within the whole State Plan, there is a requirement to have public input and review into that State Plan. Councils will determine what the best way is for them to get that. There are a variety of mechanisms you can utilize, you can have focus groups, you can have public forums, you can ensure that people have an opportunity to provide information on a website if you have one, there's a variety of mechanisms you can use. But you have to identify that you have received public input and review into your State Plan.

And since my 5 minutes are up, I just wanted to take that time to thank you all for inviting us here, and that is our summary of what's in Section 124 for the State Plan requirements.

Thank you so much Mary Beth. The second portion is sharing different types of input that States have used, including the focus groups and public forums that Mary Beth just mentioned, the public input portion. The first speaker is Becky Harker from Iowa.

Public Input – Best and Promising Practices - Becky Harker – Iowa Council (attachment from compilation of list serve postings)

I was glad to know what Iowa does is an acceptable practice. Mary Beth called this summer and asked about input, and I talked about what we did. We do focus groups, town meetings, we're doing web polls, but we're doing them as a part of our contracts. We tend to have 3 or 4 long-term contracts, and we've developed a lessons learned, where do we go from here, and then a public input approach on an annual basis with those contracts.

I think the significant thing there is in it allows us to include the cost of those things in the priority money rather than coming out of our administrative costs. And so far, and we also in the Council are beginning to look at the use of that annual update as probably a better strategy for us to talk about what we've learned, what we need to change and what we're going to do for the next year more specifically, rather than more of a one time thing every 3 to 5 years.

In addition to doing the focus groups, the town meetings and the web polls as a part of the contract work plan, if it seems appropriate, then we may do additional web polls, or probably additional town meetings with individuals who haven't been touched by the contract. That just varies depending on what it is we're trying to find out. I think that's it.

Okay, and the web poll? Please expand on that a bit Becky.

We just put questions on the Website - on either the Council's or the ID Action website, asking with advocacy for instance: how do people want to receive information? What do they want included and then next year - what do they want to accomplish when they're at the Capitol? We receive some input online, we end up mailing to our newsletter as well.

Thank you very much Becky, our next speaker is Anna Lobosco from New York.

Public Input - Anna Lobosco – New York Council (attachments)

Hi folks. I think I was chosen because we used the most strategies in our last State Plan, and it kind of wore us out. But what we did do, was we learned a lot. I was fortunate enough to be able to have one of my graduate students go through all of the list serve responses and do a quick and dirty analysis. She had done this before this conference call was even under discussion. That's the first step for us in our plan development. And it appears that most everybody uses some kind of public meetings, focus groups, and surveys. Additionally, there are some informal meetings, use of the DD network, information from other agencies and organizations, and getting a variety of stakeholder participation in the strategic planning process.

In our last plan, we broke down the kinds of information gathering we did into 5 basic groups. General information gathering, which was public forums which we did in 11 areas of the State. But we did them not in major cities where other agencies always do their forums. We went out to the small cities to get additional information that we could supplement with what was collected from the larger agencies who went to the major cities. We also do a 1-page survey that was available on the web. (Attached) We sent it out with our newsletter and to our grantees. This is probably where we got the most information. It was just 4 or 5 questions and I'll get into questions in a minute, that people could respond to. We certainly got a lot of information on the particular problem they were having at that time, but we always get probably 500 or 600 more of those surveys back, and it's very helpful when we can read the writing, and when it's in English, although we did have some Spanish speaking staff who did translate a few.

We looked for some expert assistance who were speakers that we had at the Council and in our Committee meetings, the DD network folks, and we had some workgroups who provided input into the Plan.

We did what we called systemic information gathering. We had a series of meetings one-on-one with various Commissioners of State agencies and really talked through what they saw were issues within their agencies that could benefit by working with us. Obviously we did the State Plan reviews, we did some information gathering with our statewide organizations to get the provider and the consumer perspective. And then we did a public review at the end.

In terms of the questions that we found very useful to gather information, there were 5 questions. 1) What were your recent experiences? (and we put a 2 year timeframe on it). 2) We asked what services/supports were particularly useful, 3) What barriers or obstacles they encountered trying to get services, 4) What things do people think should be done differently so that it would be more helpful or more useful to them, and 5) What else should be available that would be helpful, in addition to what already is available.

This time I've been going to a series of seminars on the pricing of government, and one of the things they suggest is, how will you know...if we do something, how will you know it's better? And to actually allow the consumers to define what the measuring system might be for a task. *The Price of Government by David Osbourne and Peter Hutchinson (2004, Basic Books).*

Where did we find information? Obviously, we get a tremendous amount of information that just comes into our office from list serves, email, relationships with other agencies and organizations, people who just sent us stuff because they think we should have it. Doing focus groups and meetings with agency heads takes a lot more effort and a lot more planning to do, and then things like public forums really take a lot of effort to do.

I don't know that the amount of effort that we put into doing public forums actually brings us the input, but what it does do is get us out there, talking to people and being more visible so the people feel better about talking then sending us information.

Clearly we've determined that the Plans have to be strategic, data driven, outcome oriented and responsive. And that means that analysis is really critical, and I think one of the points that our Council has made already in our planning process is that along with spending the time to collect the data and organize it, we really need to spend more time doing the analysis so that the information is actually leading to the goals and objectives that are included in the State Plan. Last time we did both quantitative and qualitative analysis. Most of our quantitative information came from other sources, but we did put it within a context. We did a huge amount of qualitative analysis using some qualitative research software which is very easy to use to come up with themes and trends in all of our focus group and public forum data. Again, it was definitely worth the effort, but we need to go the next step so that it really links more strongly into the goal development.

Things that our Council has asked for already, is to try and look at a more innovative planning process, to take a more careful look at the prevalence, particularly the finer breakdown to see where the less frequent conditions are and then to go out and see if those folks feel that they are well served or not well served. We have a great reliance on our partnerships and our collaborative endeavors to bring us information. In particular, we're looking at the Alliance for Full Participation in bringing us a lot of good information that will help to develop the next plan.

They've also asked us to use more innovations in technology in terms of collecting information, and as always they want us to do things so that we can reach culturally diverse populations.

Excellent Anna, thank you. There was an attachment from NACDD for that section by the way, that many of you had input into. I want to thank Sheryl Matney for putting that together. It was from the list serve where there was recent discussion around gathering public input.

(Attachment)

The planning process has a timeline, etc. This came from our Staff Day that we had last June in DC from one of the program planner sessions. Sheryl Matney is going to cover that.

Note: After the call, Anna sent New York's Information Gathering Survey, their Planning Process and Strategies for Public Input taken from Council's input on our list serve (attached)

The Planning Process - Sheryl Matney (attachment)

If you don't have this attachment, it is also posted on the NACDD website as the document from the Staff Day session after the 2004 TA Institute. There was diverse information in this section because Councils are unique as all you well know. So, the one thing that we do agree on is those planning nuggets: plan early, plan often, plan backwards, and implement forward. Use clear, concise contract and outcome language. Your expectations need to be described consistently all the way through, and have that outcome consistency throughout the process. The planners that participated in this event last summer thought that the starting point would be the Council adopting a timeline. The timeline ranged from an 18 month planning process, for the larger States, 12 months for your medium allotment States, and 9 months. I'm sure Anna Lobosco in New York would love a 9 month planning process, but I'm sure she's not going to do that.

The Council adopts a timeline. You're going to gather your information, your public input on issues of importance to your State, and of course, then your staff will be reviewing issues and selecting areas of emphasis for review from your Council. So 4 or 6 meetings prior, you would hold a meeting of your Council or your Planning Committee of your Council to determine the goals and objective topics.

Three to 4 meetings prior to the Plan being due, depending on your length of the public comment period that your State is required statutorily to use, it was felt that 90 days was the longest period of time that Councils were mandated to use, others may use 60 days or 45 days. So 3 to 4 meetings prior to that being due, your Council will approve a public review draft of your draft date plan. Between those meetings, getting it out there for public input with the allowance of whatever mandated time period you're required to have. Then give your staff time for compilation of all of the comments.

Two meetings prior to the Plan being due, your Council would, of course, review those public comments, determine if any modifications would be made, and then one meeting prior to the Plan being due, Council approves the final plan which leads me to: **When is this Plan due?**

August 15, 2006, for all Councils.

That is a brief planning process review with the various timelines and public input. We are going to address, during questions and answers, what you do when you have substantial comments on your draft date plan, and redoing public input if there's substantial changes made to your draft plan.

Determining Goals and Objectives – The Process with Sandy Ryan-Illinois

Thank you. I just wanted to start this out by mentioning that we have a unique situation here in Illinois. If some of you know Illinois, you probably aren't surprised by that. But one of the things that will be heavy duty for us in developing the goals and objectives for this plan is going to be working in a collaborative manner with our Council members, Council and staff together. We have a unique situation in that over half of our appointed membership has just started with the Council in the last 2 months. And we also have a new Chair, and in the input part of the process our Division of Developmental Disabilities has just conducted a significant number of focus groups for input into their strategic plan. There's going to be a lot of collaboration not only among our Council, but also using that information from the Division of Developmental Disabilities.

That being said, what we are doing for this State Plan is providing a lot of education, particularly for these new Council members. We're looking from January until March working with our Committee Chairs, our Council Chairperson, on education, an education process on best practices or promising practices from across the country. We feel this is very, very important for us in order to get a plan that is based upon and looking forward to using best practice. Then we expect that our committees will begin working from March through August in educating themselves on developing recommendations in the particular life areas that are within the purview of their committee. We expect goal development to be done at our annual September retreat, and then performance target development in our committees between September and December, all leading to a draft plan being developed by January of 2006.

Council and staff roles in this: we see staff as instrumental in helping to facilitate the education process within each of the committees. We also see the staff role being one of helping the Council and Committee members in developing performance targets which are measurable. I think that tends to be an area that we have found in the past is a little difficult for people to really grasp, so we see staff's role being very much of a facilitating role there. But the actual content is definitely going to be Council member driven. They will be the ones who are determining what will go into the Plan and the various strategies that all come through the committee structure.

One of the things that we are hoping to do a better job of this year is really looking at our State Plan in trying to tie everything to some sort of systems change within Illinois. And I think what we found from our last plan, it's easy to develop performance targets or objectives that might be more one time activity kinds of things, but then tying it to and getting measurable outcomes for real systems change is a challenge, and we're hoping to do a better job on this State Plan for the systems change piece.

Washington, D.C., Mary Brown, you just had your annual retreat, and I understand you had an outside facilitator, it was partially paid for through the technical assistance contract. Mary will talk about that process for DC.

Determining Goals and Objectives – The Process with Mary Brown – DC Council

We did hire a facilitator to assist us with this annual retreat. And our vision for this particular retreat was to start the planning process for the development of the State Plan. And we

made sure that those persons participating in the retreat this year were representatives of the principle State agencies who really had the authority, full authority, to speak and make some commitment on behalf of those agencies. We had participating the Director of our Designated State agency, and her deputy for programs, as well as the representatives from the DD network, and the regular membership. We also extended invitations to local self-advocacy groups. We had a fairly large group. Most of these people have been involved with us over the last couple of years, either in some of our projects and project activities, and our different advisory committees and parent groups. We had going in, a group of people who have already been privy to many discussions about some concerns, specific issues, and the trends in this area.

So with the facilitator, we were able to engage a group discussion that allowed us to come up with some areas of interest. After we came out with this larger list, we were able to focus down into 4 areas of interest. And we established 4 working groups, and they in turn were able to actually establish some goals and objectives and a specific task as a beginning. We decided with those 4 working groups, (there's only so much you can do within a 3 day period that we had) come back with some specific tasks and continue to work, at least once a month, through March.

We have other means of data collection. We plan to engage in community focus groups, in some public forums, so we will be gathering other information. We will also be collaborating with other agencies within the city that were not a part of this process. In addition to that, in one of our projects we had already begun engaging in training some of our self advocates and parents in the conduct of consumer satisfaction at the service agency here within the District of Columbia. We have established a survey instrument that we will disseminate to other agencies and provide services here within the District of Columbia.

So for us that's the beginning process. I think we've done very well in terms of coming out of the retreat with having identified 4 major areas of emphasis, and some direction in terms of goals and effectives. As we gather other information, we'll be able to refine and make some other decisions about what actually will go into the plan. And that will be done by our smaller group, our program review committee.

The next section is collaboration within the DD network, and also with other agencies. Through the TA contract we did a large report. Sheryl compiled that report so she will now discuss that collaboration report that we generated with information from the Councils.

Collaboration – DD Network/Others with Sheryl Matney-NACDD

This report can be found under the TA section of the NACDD website under Collaboration Report. I pulled out from the States who reported some of their collaboration activities, activities that could be used in developing your State Plan. Many of the States are on the call, so if you have questions about some of this collaboration, just jot them down and then you can address the State.

Oklahoma meets on a monthly basis with each of their network partners, they meet as a team. They have also participated in a joint planning retreat with the Board of the other agencies, the P&A and the UCEDD, with their staff. Holly Riddle just reported prior to the call

that they are contracting with their UCEDD in North Carolina, and partnering up with the P&A to do data collection and some State Plan development and analysis of information. In Maine, the Directors of the P&A and the UCEDD with the Chair for their statewide self-advocacy group all participate on the Council's Planning Committee, and so they ensure integral involvement with the planning of Council activities by putting most folks together.

You just heard from Mary Brown in DC. They include their Protection and Advocacy partner and the UCEDD on their Council program subcommittee, and DC's reporting that their input is invaluable because it offers their perspective insofar as the recommendations for any focus on areas of emphasis.

In Louisiana, the Council holds joint forums with the State's P&A and the University Center twice a year. They move forum locations to different parts of the State in order to gather comments for public use in developing planning goals, objectives and strategies. That is on an ongoing basis, I think you saw Roger Webb's (TX) comment on the list serve that's included in your attachment that states that data collection and input of issues really should be an ongoing process, and you can see it with Louisiana.

In Oregon, the ADD network meetings 2 to 4 times per year to update each other on agency projects and initiatives. That way they can explore opportunities for collaboration, plus it gives them the opportunity to see if the issues and initiatives are similar.

In Tennessee, they hold monthly conference calls with the P&A and the UCEDD to discuss issues that they can address as a network. In Idaho, the DD network partners collaborate on an ongoing basis through shared joint memberships on each other's Boards. They also collaborate on planning efforts through shared membership in the P&A annual planning process and the UCEDD annual planning process. They plan to collaborate on focus groups for information gathering and they also meet monthly on public policy issues as part of their Consortium of Idahoans with Disabilities.

In New York, a forum has been created to discuss planning of collaborative efforts, and they actually have a workgroup comprised of at least one member from each of the relevant organizations. It is convened quarterly, by conference calls, or face-to-face meetings.

In Missouri, they prepare a joint quarterly newsletter, and the benefit is sharing their contact lists so they can reach a broader audience. I'm sure if any of you do written surveys, that would be a great tool to use each other's newsletters to be able to gather more input from a broader audience. They also cross reference each other on their websites, so that might be another way to use Becky Harker's idea of using a web survey.

Again, you can find that full report on our NACDD.org website.

Next Steps: After the Plan is Finalized

After the draft plan has been presented for public input, what constitutes a significant change to warrant a change to the draft plan? And does any change to the draft plan then go back out for public comment again?

Mary Beth: There's no definitive answer to this, and I know you might want one, but there's no way to examine every Council's particular situation and provide an answer that fits all. My particular belief is that if you're going to change the goals in your Plan you need to get public input to that, and if you're going to do that you need to put that back out and make sure that the changes of the goals are acceptable. Because the goals are ultimately based upon your examination of your service system.

I think when you get down to more of the strategic part, activities and the strategies, that's going to change. As an organization, you're expected to be able to change those things without necessarily having to get more public input. I believe that the goals, in particular, if you're going to change the goals, you need to go back and make sure that you get the public's input on that, and then you can address any particular comments that you might be given relative to those goals.

The law does say specifically that the Council shall revise the Plan to take into account and response to significant comments. And that's with your first round and your first round of public input. But again, if the Plan is going to be revised in any way relative to your goals, I believe you should go out and get public input into that revision.

Does anybody have any comments or anything they want to share on that, because I would like to hear any specific concerns you have and I can always take it to my counterparts here, and see what their comments are on that.

Q: I can certainly understand why a big piece would be to go back out for public review, but what happens if that comes late in the process and you're just flat running out of time? I think it's really kind of a non-issue, most of the big issues in the system, the big issues that derive out of that would be identified pretty early on in the process. But should we be blindsided by something late in the process that requires a substantial change, and the clock is ticking on the due date, how to do you reconcile those 2 things?

A: I guess, my feeling would be, and I'd like you all to give me input to this, but wouldn't your putting it out from public comment and review be one of your final steps in the process?

It would probably be paced 2 months out, something like that.

It depends on your timelines I guess, but even if something happened after that and you'd have to change your goals relative to that I'm going to honestly say the best thing to do is talk to ADD staff on a case-by-case basis. Because I don't want to sit here and answer for my colleagues about what they might do in their particular situation. That's the best way to go with it.

A suggestion for Marilyn would be, if it's something where change is warranted and it's real late in the process, you may be better off waiting and doing it as an amendment in the next year, to give yourself time.

Q: I just have a question relative to what Becky said, and I'm a small State with minimum allotment. Am I understanding that if we contract with our UCEDD to do the survey focus parts, that that has to come out of Administrative money? And if so, how do we do that?

What have you done in the past?

Well, typically we've given it out as a grant, and we've put it under one of the priorities like quality assurance. The last time we did a major one like that where we actually contracted, was for the 1990 report. (No, those were very different kinds of things).

When you're a small State and you have \$460,000 and you can only use 25% of that for Administration, for your Council operating costs, it really limits the ability to really access a lot of information.

A: I'm not prepared to give an answer relative to that. Because I don't know that we've actually talked about how to delineate that money and made a specific policy on it, so I'm not really comfortable saying that right now, but can I look into that Mary and get back to you?

Yes, because it could actually be split up between the different goals. I'd appreciate some kind of response. (Others agree that they would like a response on that question)

The answer would be good to go out to everyone. We can put an amendment to the notes on this perhaps. Please comment Mary Beth as a follow-up.

Q: I didn't hear anything about terms of the sign off by the States on the Plan, and involvement. Who exactly does have to sign the assurances? The problem that we had the last time was getting a paper copy of the assurances and then figuring out who had to sign off on them. Is it our State agency head?

A: Yes. The agency, because they're the ones that have to ensure it, since they're the ones that are actually receiving the money for the Councils. Ultimately we had our designated State agency do it. But I just want to make sure that that's what we're supposed to be doing.

In Tennessee, we have our Governor do it. It's actually been a useful thing for us to have the Governor sign those assurances, because it creates some really good understanding with the designated agency about what those assurances are. They seem to pay more attention to them when the Governor signs them, rather than when the state agency signs it.

Approving officials for assurances - the Chairperson for the DSA not Council, so I would assume that would be your person from your DSA who's your representative there. But I will try to get some sort of clarification on that. (Mary Beth)

In the Act itself, in Section 124, right at the end of that, it talks about consultation with the Designated State agency. Just make sure that you're consistent with State law on what that is. You might want to look at that section, Section 124, at the very end, it's the next to the last paragraph of that Section.

Q: Why are we doing a new 5 year State Plan about the same time that we are working on reauthorizing the DD Act for 7 years and will be submitting a 5 year State Plan just about the same time that we will be submitting, or getting a reauthorized DD Act for perhaps 7 years? That 5 year plan may contain elements that are not in the reauthorization, so doesn't a 1 or 2 year extension of what we're currently doing make more sense?

Could this group submit that as recommendation? Ed is the Chair of the Reauthorization Committee. This is something they're planning for us to do prior to us getting reauthorization. I think one thing we could easily do is just take it to the Board and ask the Board to write a letter to the Commissioner.

One thing you have to remember though, this is Mary Beth, the law requires you to have a 5 year State Plan. If you'll remember last year in terms of the reauthorization or the last time we had the reauthorization, it didn't get reauthorized in the year that it was supposed to get reauthorized. So there's no guarantee that that's going to happen at that point in time anyway, so what if that doesn't happen? Do you keep extending things or do you go ahead and do the 5 year plan, based on what the law requires now? The law specifically requires a 5 year plan. The last time the law was supposed to be reauthorized was '99 I believe, and it didn't happen until the year 2000. You run into issues like that when you just want to do an extension or something. I'm sure that's going to get brought up.

I wonder if then in reauthorizing, we can have some language and if it would make our next 5 year plan make sense? Since we're doing the 5 year plan before the reauthorization.

If you have a 5 year plan and 7 year reauthorization cycle, they're never going to be the same. No, the issue would be if there are major changes in reauthorizing, you've developed your plan on certain areas that are identified in the statute and then it changes, you need to still be able to grandfather those areas. What if our reauthorization doesn't include a State Plan?.

I think whether or not it was a requirement, we would want to have in place a strategic plan for advancing our mission and then identifying measurable goals. I think we'd want to be doing, in Oregon anyway, something similar to what we're required. It may not look the same if it wasn't a requirement, but I would still want to do a strategic planning. I'm actually not looking forward to the work involved in developing a new State Plan, but I am looking forward to taking a fresh look at how to build a plan that is measurable. We keep amending and amending, it starts to feel a little bit like a patchwork.. I'm looking forward to having a new whole plan that we agree on, and apply what we have learned.

Q: We submit a 5 year plan, reauthorization goes through in a timely way, then is there any way through law or through regulation, that we could continue with our existing 5 year plan even though there are substantial changes with reauthorization? Or would we have to start all over again? Or could we amend our existing plans?

I think what we would like to avoid is what happened last time which is the reauthorization got held up, so we were told you've got to do another 3 year plan but don't worry, it'll count. And one year later we are told do a whole new plan. And that was frustrating for all concerned. And expensive.

I remember many years ago, we actually did what someone was recommending. We were in the middle of a 3 year cycle when the Act was reauthorized. Additional things were added, but we actually did not do anything to our plans until the following August when we amended them, and then we agreed we would do certain things by a certain time.

The major change to me that happened between the writing of the Plan in 2000 and the reauthorization later, was the inclusion of the self-advocacy goals, which I give you, is important work., but none of our planning had related specifically to how to address self-advocacy. With all of the planning and analysis, that was a peripheral issue, not a central issue. And so we've planned very badly for these last 4 years to work on that, because from the get go we didn't have the right data. I understand the law but I'm going back to the comment about regulations, does a 5 year Plan have to be in law, could that be a reg., rather than a law, and we can use language of strategic plan, defined by ADD?

Why couldn't we seek to have the sponsor of the legislation preauthorizing the Act? Write into that legislation, a deadline of 2 years following passage for a 7 year plan so that we have the State Plans matching up to the reauthorization, then everybody's State Plan matches the federal reauthorization cycle.

Q: Mary Beth, is there any way that any Council is going to be able to not do a 5 year plan due August of 2006?

A: Not that I know of. I'm not sure why there would be. If we sent a letter to the Commissioner, it is not going to change because it's law, is that what you just said?

Yes.

But looking at it for a potential change in the process of reauthorization is always possibility?

Yes.

And there is a call coming up on that, right?

On December 21st.

Q: I do have 2 Plan related questions. The first is: ADD preferred to see a little done in each of 9 areas of emphasis, which if you take into account that there's really 3 separate pieces to quality assurance, you're talking about 11 areas. Or to try to say we can't be everything to everybody, this is where we want to make a more focused systemic change, so that's question #1. Question #2 is what we heard articulated in the Institute was that when ADD had its audit, it was clear that OMB considered that it isn't 3 separate programs that they funded, it's one program - all 3 are supposed to work together. Someone from ADD said it would not be considered network collaboration if it did not involve all 3 partners, you couldn't work with one or the other.

A: The collaboration piece is something that Faith's going to have to answer here in our office, because she had taken on the responsibility of the whole collaboration piece, so I have to talk with her about that.

In terms of the other one, I think I understand what you're saying, do you develop something in every area or do you kind of focus yourself more in specific areas of that, but just in terms of your State Plan? And I think a couple of things come into play here. One is what does your State analysis say? You know, what does it say that those areas are in your State? Based on that and the problem with the service system, etc. Based on that information, what does the Council think it can handle. So that if you tell us in your State analysis that one of the major issues in your State is a lack of a direct care workforce. And if you say that 3 or 4 or 5 times, yet there is no goal and objectives relative to that, I think that we have a responsibility to say how come there's nothing addressed to it?

If you tell us that employment is a huge area in your State, and lack of employment for people with disabilities, yet there no goal in your Plan relative to that, I think we have a responsibility to ask why that hasn't been addressed. So I think you know, we don't have a preference, we want you to tell us what the barriers are in your State, what the needs are, and then how you, within your budget, can address those things. And if that sounds reasonable, then that's what we'll look at, the reasonableness of those decisions. I think if you put all your money in a formal and informal community support, that's going to have a good explanation as to why it's only there and not into the other areas of emphasis, given that that's not supposed to be a catch all for a lot of things. I do also want to say that I know we are working on some guidelines relative to those things. I know that a lot of you have asked for some specific guidelines about what goes into each area of emphasis, and we are working on that. Hopefully we'll be able to help you with that in those decisions.

But you know, I doubt if there's one State that's going to tell you that they don't have employment issues, or education issues or housing issues, everything is an issue in formal and informal community support. You have to base it on what your State analysis has shown us. Then based on that, lead it with data driven strategic planning. Data, that information you collect, should help you develop your Plan goals.

Comment: I wanted to add something to that, because I think another part of the analysis is looking at opportunity. In terms of your State, if a particular area is a big problem, but we have limited resources and we look for where we have opportunities to make the greatest change and get the biggest bang for our buck. Transportation may be an issue, but if we don't see a good opportunity for the Council or a niche for the Council to make significant change in that area, we do not prioritize. So I think that needs to be a big part of the analysis, not just the need.

A: I think that's a good point, and I think that kind of opportunity should be included in your analysis.

Comment: This is Janet again, and one of the things we do include as part of our analysis is not only where are the needs, but who is supposed to be tending those needs. It is just a question that you need to do some systemic advocacy to get the right people to step up to the plate that are supposed to be there anyway.

Q: In crafting the strategies, I think it's always been difficult for us to walk the fine line between getting something that is measurable, and not tying the Council's hands. I think very few Councils can predict 5 years down the line what kind of initiatives or projects they're going to fund. We can constantly amend those strategies, but I wondered if anybody had any thoughts on that. It's been a real issue for us, particularly since it's often staff that are crafting strategies that are measurable and it becomes a very fine line for staff to avoid actually determining what an RFA release is going to look like before the Council's had time to deliberate.

Comment: We've had a little bit of conversation, our plans vary, one of the planning nuggets is plan backwards implement forward. And I hate to bring up a sore subject, but if you look at the PPR measures, and they're pretty consistent under each area of emphasis, if as you're building your goals, we identify on the front end, is this a policy change or improvement, is this something for training, people facilitated in systems advocacy. Those are the ways we're instructed at this point to measure outcomes. So if we keep those in the fore front of our thinking as we develop strategies, we can make the links.

Comment: This is Anna in New York and I will say that one of the things that we are not very good at is target setting. We basically achieved all of our targets in our State Plans within the first 2 years of implementation, and we're just not real good at it. We're getting better at helping our grantees do target setting, but we're not good at doing it ourselves. And that would really be a great technical assistance issue for the contract to work on in the near future. (NC, CA, NM, Florida concurred)

Q: With regard to the data driven strategic planning, in Hawaii one of the areas where we're really having problems is housing obviously, with costs and just lack of available housing, especially affordable accessible housing. We went through the 5 year HUD planning process here and tried to gather resources to buy questions on the survey specifically relating to individuals with disabilities. We were unable to do that given the narrow window we had to buy our way in. And every time we go, whether it's consolidated planning meeting for the counties or for State issues, they say how many people are you talking about? What kind of setting are they in now? What kind of setting would be more appropriate?

Coupling this with massive weight list for all the public funded housing issues, our best goal would be to just work on getting the data over a 5 year process. But barring that which we don't have in there right now, I would love to hear suggestions on States that have been able to really analyze the housing situation. I guess the more philosophical point is, if you're doing data driven strategic planning and you have absolutely no data, that process becomes very difficult.

A: That sounds like a good question for the list serve actually. Absolutely. Why don't you throw that out to the list serve and see what you get.

Comment: One of the things actually attempting to obtain data last planning cycle, it actually pointed up as a systemic barrier right there, which is in this area of databases there is not consistent data, so you look at our Department of Developmental Services, and the fields and the way they have that information named, and then you go look at the Department of Rehabilitation, you can't even cross reference.

The other key piece to the housing issues is, if people were able, assuming available space, if people were able to move into that, what kind of support do they need? We have that data to our planning process for those receiving services from our DD division, but if we use the prevalent numbers that's a very small portion of the DD population that's out there, so we don't have the data. We have data from about 3,000 people, and we're talking about 22,000 people statewide. And the population that's already getting services are in some cases those that probably aren't going to be able to get to complete independent living without a lot of support. So the heavy support needing people we've got some data on, but the rest of the people who may already be out in the community, that group we have absolutely no data on.

Q: When we're writing goals and strategies, I'm assuming that we're writing goals and strategies for funded activities of the Council, not for nonfunded systems change activities, correct or incorrect? For example, I go into a meeting and something good happens, but it didn't cost anything other than what the salary is.

I'm not sure Holly what you mean by nonfunded? Are you talking about staff activities? (Correct.)

A: You can put them in your State Plan.

Q: Do you anticipate any changes to the State Plan format? Relative to this new computer system ADD has and also just components of, or layout of the Plan?

A: Not that I know of right now, but I'll have to talk with the tech people here to see if there's going to be any changes because of this new system. My understanding is that from your end, things should not be any different, but let me take some time to review that and get back with you guys on that.

Q: Anna described a pretty thorough process of gathering public input for their last 5 year Plan. It feels like gathering public input on need is an interesting exercise that educates people about what the Council does, and gives the Council verification of what it already knows in terms of the need. I would much rather spend our time and our resources gathering ideas for addressing those needs, looking more at the strategy level that what is the need, because I think most of us know what the primary needs that people bring up in meetings and forums over and over. What we really need to do is talk about how do we address those. Does anybody have any thoughts on that?

A: We try to do some of that in our public forum. It's a tough facilitation process because it's a process of getting input that's realistic, like how can we address these needs and especially with special needs children and moms, it's hard to help them sort through and start over and get them to more functional approaches. But I agree with you because when we hear it, we hear the same thing over and over again, and I also agree that it's more important to just try and talk about ways that different sectors of all of us can work on them, because otherwise it does feel like a rerun.

One of the things that I'm finding really helpful is, I'm been working on a couple of list serves that are not the people that we typically hear from, there's an augmented match list serve

that just by reading what's going on there, we can ask about needs that we really haven't been all that aware of or that focused on, for example: the fetal alcohol syndrome list serve. It's mostly parents who are on it, and that's been interesting, and I'm also getting some geographic differences, but it's a different viewpoint, it's a more specific personal viewpoint, and that's been helpful for me.

Q: How are you going to take that information and document it in such a way that you feel like you can weigh in how great the need that is?

A: It's helping me figure out what types of questions we need to be asking in places that we need to be going to ask them. While I'm there, I can ask questions and follow up. Because I really have found the best way to do continuous quality improvement and make sure you're on track is not really through surveys, it's through building relationships, and having conversations with people, so the more that you can reach out and do that, the better. I also take any opportunities when I meet people in different places, and even just in my own life quite frankly, like if I'm going to the dentist or to a financial advisor asking them what their experience is working with people with disabilities. Getting input outside of our area and that leads me to what kind of questions I need to be asking, what kind of data do I need to go out and look for.

Regarding surveys, regardless of maybe the value of the outcome, it would be nice if we were using some kind of uniform instrument, and then we would be able to compare among States if we're asking the same questions. I don't know if somebody has a tested survey that they're using already, that maybe that could be the basis for a general one that we use. But you know, I think that a lot of the stuff we report on the PPR, there's so much interpretation that we're not, even if we're reporting for the same performance measures, we're not necessarily asking the questions to come up with those results. If we were somehow use a more uniform or universal survey, I think we'd be getting something to find out really who's doing well, who's not doing well, and then maybe being able to borrow strategies to better address that issue.

Yes, I would agree that some questions and I urge you if you haven't, to look at the core indicators project, which quite a few States have been using. I know that Human Services Research Institute, HSRI, has been working with a number of States, and there's some data there that can be compared on quality of life. But one of the things that we find is that the questions themselves are different for different groups of people, and different expectations, and it's hard to make them broad enough that people can respond. You can't just ask people if you are satisfied with the services you're getting, because the quality of life is much more than that. We have worked with people where independence for young women is not a goal. And it has very little to do with disability and more to do with culture.

Q: For ADD, regarding our need to do a comprehensive review and analysis of the particular discreet funding streams. The one I have a question about is children's mental health. The intent there is what? Are we looking for dual diagnosis, unmet need, are we looking for kids at risk of developmental disability? That one's always kind of baffled me, what am I supposed to be fishing for there?

A: I think the best you can do is to contact the organizations in your State that would work in that regard. Maternal and Child Health is a member of your Council, so they may be

able to provide you with some information relative to that, or maybe lead you in the direction of where to go to get some information relative.

Q: Is it a DD nexus with a link?

A: Yes.

My name is Toni from Florida, and we have done a strategic plan on mental health and done a lot of work in that area, and I'd be happy to send that to you.

I'm be very interested, thank you Toni.

Q: I notice that the PART performance outcomes that were given OMB go as far as the year 2007. And I guess my question is, is there any thought to sharing with us what outcome measures you're using to Councils? Hypothetically, what if all of us would eliminate from our plan, a particular measure that you're depending on, to report to OMB. We really don't know what measures you're using at this point.

A: Thanks Mary, I will talk with the Commissioner about that. But I can tell you that when we worked with OMB on that, we used a lot of the measures. It's not just one here or one there, it is a significant number of the measures. Like all your 01 measures in each of your areas of emphasis are used, the training measures are used, I can't remember off the top of my head because it was last year, but I don't see any reason why we can't share that information. But I will tell you that it wasn't just one thing, there were significant numbers of measures, and we wanted to do that because one of our concerns was just what you said. You know, what if one measure is not used a lot by Councils in a certain year? What does that do to our data, so we were very careful about working with OMB to let them know that we felt a variety of measures needed to be utilized for those...for the ones that they were collecting.

Anything else? I think this has been a great call, and I appreciate the East Coast people's patience and perhaps working after so we could accommodate Guam. We appreciate everybody's time. We will be getting out notes and they'll also be put out on the website. So again, thanks to all of you for participating, and particularly our speakers.