

## **Standing Grantee Call: Facilitating Productive Stakeholder Participation (December 1, 2005)**

### **Moderator:**

- Christina Neill, The Lewin Group

### **Presenters:**

- Allan Goldman, Georgia ADRC
- Phyllis Madachy, Howard County pilot site, Maryland ADRC
- Stephanie Hull, Maryland ADRC
- Nancy Day, New Jersey ADRC
- Dorothy Ginsberg, New Jersey ADRC
- Elizabeth Quinn, Merrimack Valley pilot site, Massachusetts ADRC
- Michael Winer, 4Results Together

### **Call Outline**

- I. Introduction by Christina Neill, The Lewin Group
- II. Discussion Questions
- III. Comments by Mike Winer
- IV. Questions and Open Discussion

### **Introduction:**

The objective of this call was to provide information about the structure, process and activities of advisory boards and other mechanisms to garner stakeholder input and buy-in to the ADRC initiative. Christina Neil introduced the topic by reviewing an ADRC TAE Issue Brief on Facilitating a Productive Advisory Committee. Christina's introduction included discussion of the broad goals of ADRC Advisory Committees, the grant requirements, and key design considerations. Her PowerPoint presentation is posted on-line at:

<http://www.adrc-tae.org/tiki-index.php?page=December05>

### **Topic Questions**

Questions posed to speakers during the call included the following:

- For advisory boards: How many members? What is the composition? How often do you meet? Who sets the agenda for the meetings?
- Are there other mechanisms you use to solicit stakeholder input? (e.g., subcommittees, specialized membership (consumers only, or employees only))

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- Describe a particularly successful strategy for meaningful input of advisory board members.
- Identify a valuable insight or direction the advisory board provided.

### **Alan Goldman (Georgia):**

AoA and CMS are very clear who you should have as your partners at a minimum, including the Medicaid agency and other categories they have identified such as consumers. Coming from an advocacy background, he thinks it is important to recognize that down the road you are going to need these people to get involved with advocacy – asking for money or changes in legislation. These members will build support for the initiative and assist with sustainability. It was clear that they needed a representative from the Governor’s Office of Planning and Budget, someone from the legislature, and other key agency staff. In Georgia, it was important to include the Division of Mental Health and members of the disability community (physical and developmental disabilities). They also included others who represented their partners in the local pilot sites.

In inviting members, they talked to the stakeholders to make sure they had realistic expectations of the job descriptions and what their obligation would be. They sent an invitation letter with the job descriptions ahead of time. Board members were asked to monitor the progress the ADRC makes, review materials, help with planning and marketing, and information dissemination. One of their biggest roles is to serve as an advocate for the ADRC in the community and support statewide expansion. You want your Advisory Board members to engage in inter-organizational collaboration and build networks. You need them to think about what will happen when the federal grant finishes.

Their Board has 16 members and meets quarterly. It is important to pick a modest number but include all the major players. They did not want to have too many meetings, which might place a big burden on members.

They also require their pilot sites to have local Advisory Councils and encouraged them to think strategically in picking their councils.

### **Phyllis Madachy (Maryland):**

Similar to many of the things they heard from Allan at the state level in Georgia, that is what they tried to do at the local level in Howard County. We assembled a group that is 50 percent consumer or consumer advocates. They originally tried to keep the group to 20 or 22, but it was not possible and now ranges from 23-28. Their meetings are open to the community. State level people attend and as the second pilot started up, they would also attend their meetings. Sometimes they have had a larger external audience than the Board itself.

In addition to what Allan talked about, their Board members review materials such as the marketing plan and figure out what the project measurables were. They also emphasize that their role was to be an Ambassador in the community. A lot of energy

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was needed to educate the Board up front - particularly about the disability and aging networks for those who came from one or the other. They also shared information about the basic resources and information already available that Board members and consumers may not know about. They wanted to keep the Board as productive as possible and make sure members were not suggesting things that were already out there.

The Ambassador role was one that their members could play even if they did not know all the details about the project. They encourage members to open doors to their communities - neighborhoods, churches, provider organizations - so that the pilot site staff could come in and talk about the ADRC. They have had success with this. One member of their Board, a consumer and community leader, has taken this responsibility to heart. They also tried to focus on critical pathways, so for example, their hospital representative opened up opportunities for training with discharge planners.

They met at first monthly, now quarterly. They also provide information through email to members. They did not set up a work group framework. They recruited people that were worried about time commitment, so in deference to that they decided not to do work groups. But they did break the groups down into small groups at the meetings so small group process could be part of it. Then as work groups were formed at the State Level, they linked people at the pilot level into those work groups. Many of their members took advantage of that.

They also have an internal advisory group. In the fall of 2003 and early 2004, they worked with an organizational development student focusing on what they needed to know about their own agency and staff in order to develop the ADRC. In spring of 2004, they formed a staff advisory group that included the information specialists and others in the entire agency. They wanted this to be something that would change the way the agency operated - the way that clients flowed through the different divisions. They had amazing products come out of that including a new protocol for the entire department to use for walk ins. They developed and got county government support for a 10 hour work day. They made recommendations to change the physical lay-out of a waiting room to make it more accessible for people with disabilities. The stakeholder development was not just external - it was internal.

### **Stephanie Hull (Maryland):**

They have a 20-25 member Statewide Advisory Board. Maintaining membership in a balanced way is a challenge. They have to continue to recruit people who will be active. Meet every month, until just recently when they moved to quarterly. Their Board has all the same functions talked about, but they also have five work groups of community members and local members.

- The "no wrong door" committee provides recommendations to the state to explore streamlined eligibility, presumptive eligibility, and the integration and cooperation of four state agencies.
- Employment and workforce works to define what kinds of information that would be needed in those areas. Very important to disability community.
- Website work group developed a draft RFP for a statewide website.

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- Evaluation work group really defined the evaluation plan and works closely with local sites.
- Marketing and outreach group to help identify critical pathways, identify the name and logo of the project.

They also have an Interagency Executive Committee where all of this work is folded up; this group is now exploring presumptive eligibility and on-line applications. Their work at the state level has been slower than the local level. They have to make sure to get and keep representation from the key departments and get as transparent as possible between the agencies. They have struggled with keeping a balance between aging and disability communities. This has required more effort with the disability community, which is younger and busy with other kinds of advocacy priorities.

### **Nancy Day (New Jersey):**

New Jersey has broken down their advisory groups into three levels. At the state level they have an Advisory Council that is a collaborative effort with all the New Freedom Initiative Grants in the state. It is 50 percent consumers and meets quarterly. It is always a challenge to get people to come regularly and travel is a challenge for people with disabilities and older members. They try to do a lot of work through the web.

The second level is a 10-member state management team that includes the director of the Medicaid office, the Division of Disability Services, Aging and Community Services Division. They meet monthly. They can make the overall policy decisions on things like single point of entry, presumptive eligibility, clinical and financial eligibility determination. They have learned that coordinating all the parts of their fragmented system is very important.

The third level is made up of 11 work groups. They operated these groups 6-8 months into their grant. They recruited people statewide to participate, identified by the partner agencies and local level. The meetings were conducted by conference call or through websites so people did not have to travel. Each work group was responsible for creating a product or protocol – they are the resource and development part of the projects that developed all the products being tested by the pilot counties. Over 250 people participating statewide and co-chaired by state staff. They launched the work groups with state level staff, meeting weekly with the group leaders to establish agreement as to what the goals were of each subcommittee so it was very well defined up front.

### **Dorothy Ginsberg (New Jersey):**

The group leaders met regularly in the beginning with the state leaders to make sure they understood the project. It is always a challenge to get people to participate. They worked hard at emphasizing that the group was responsible for developing a specific product – not just to bounce ideas around. This was the most helpful thing they did. Members felt truly valued and engaged from the beginning, with specific assignments and responsibilities. Each group had its own blend of people with different expertise and different perspectives were encouraged.

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People participated fully to a point for a limited time, to accomplish a set of specific goals. They met in person sometimes and on conference calls. When the bulk of the work was finished some of them stayed on to implement the ideas – like the website.

### **Mike Winer:**

In his experience, what really engages people is when they have a clear sense of what their responsibilities are and when things get done – seeing demonstrable progress and success. This is what he heard from the speakers. In Georgia, they were clear they wanted members who could make policy change so they brought people they knew could make that happen. Maryland brought people in as Ambassadors with a clear sense of what their role would be. New Jersey is incredible to have 250 people involved, but they had a charter – people knew what they had to do and what was expected of them. And it was for a limited time! This was not an ongoing commitment. Once their product was developed, they were applauded for their success and let go – only some of them stay on for implementation. His hunch is that when people talk about the challenges of getting members to participate, and having to replace members with more participatory members, it was because their roles were not clearly defined. They did not know what was expected of them personally. It is important to have a picture of where things are headed and aligning responsibilities around that – for a limited time. You should tell your board members, “you are free to renew, but we want your time for 6 months or 1 year to get these particular tasks done.”

It was wonderful listening in and he wishes everyone continued success in this work.

### **Alan Goldman (Georgia):**

It is important to have clear defined roles. One of the reasons they’ve had success in Georgia is by keeping in contact with board members in between their quarterly meetings. They also used them to set up meetings for us to go and make presentations, who we are and what we do, see where overlaps are. This will help you to take advantage of resources you might not be aware of.

### **Phyllis Madachy (Maryland):**

One of the things they struggled with was that sometimes it wasn’t always clear to them what the board members role should be. It wasn’t always clear to them what they wanted to do – the newness of it. You want to be open to opportunities that Board members bring that you might not have thought about. One example: one of the people they recruited to be on the board heads up a local foundation that takes recycled hardware (computers) and give them back to non-profit organizations. They recruited him for his technical expertise. With his help, they found ways to improve the look and usability of their partner’s database. Not something they had anticipated.

### **Elizabeth Quinn (Massachusetts):**

Massachusetts has a separate Consumer Advisory Board. They put out an application for both participants from ILC and AAA and recruited 11 members – people with a wide variety of disabilities (physical and mental illness) and consumers that were caregivers or participated in Advisory Boards in their housing complexes. A couple of them have

moved on to participation in outreach and marketing activities, using their knowledge of where to go and who to talk to. This board helps them make sure they're getting the word out, and that services are accessible. They offer a stipend and reimburse travel.

**Q: For Elizabeth, why did they choose to have a separate consumer board?**

**A:** That was done in the grant proposal. Massachusetts has always had a strong disability consumer voice. They wanted them to have their own voice and not be intimidated by participating with providers and other stakeholders.

**Q: For any of the grantees, do you intend on keeping your advisory board in place when the pilot period of the grant is over?**

**A:** In Georgia - Yes, but they also expect it to change as well. The state and two pilot sites meet among themselves and work closely together. They have a budget request in to their assembly to expand the ADRC and they will expand this partnership to those communities. They will be expanding the populations they target, so that will bring in new partners.

**Nancy Day (New Jersey):**

Just a comment to follow up on what Phyllis said - this has really been an evolving process. When they got the grant they didn't really understand what they had gotten themselves into, but this is a systems change process and a cultural change. They are continuously revising their thoughts. It is important to have the flexibility to change and have the input from people with a wide range of perspectives. Some days you have it right and the next day it might not fit. You have to roll it out slowly; it is a continuous process.

**Phyllis Madachy (Maryland):**

One of the things that surprised them was that people in their own agency did not really understand fully the consumer referral path. They had overestimated what they knew. The employees identified training as something they really needed, and so by going down the training route they realized there were other people in the agency that wanted that training, too. The systems change starts internally.

**Nancy Day (New Jersey):**

Their pilots have said they used the ADRC as the excuse for making needed changes internally. Being involved with the larger systems change efforts has given them the chance to serve as the innovators, the creators, leading the way. But it is not easy to change normal business protocols!

**Alan Goldman (Georgia):**

He encourages grantees to call the speakers on this call, follow up with questions. He's learned a lot from working with others through this process.

**Q: Jeff Anderson from DC asked if any of the ADRCs are doing level of care determination within the ADRC? If so, what kind of participation they may have had and any barriers they faced?**

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**A:** Nancy Day - Yes, in New Jersey LOC is done through the ADRC. The AAA had been doing assessments for Older Americans Act and the state had been doing assessment for Nursing Home. This was one of the biggest changes with the ADRC. Now the ADRC's goal is that one assessment will be done for all long term care - letting them know about all of their options. The state will still review these assessments to determine if the person meets nursing home LOC. The biggest barriers are changing or adapting state regulations and policies.

### **General Announcements:**

There are peer work groups coming up in December - more information on the website. Upcoming deadlines: 2005 grantees have updated work plans and budgets due to AoA/CMS by December 31.

The resources for this call and materials referenced on this call will be posted on the ADRC website at:

<http://www.adrc-tae.org/tiki-index.php?page=December05>