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**Consumer Advisory Committees:**

**Recommendations for Meaningful Participation of Individuals with Disabilities and Families**

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**Executive Summary**

The Association of University Centers on Disabilities (AUCD) and its Council on Community Advocacy (COCA) collaborated on a participatory action research project exploring meaningful participation and effectiveness of Consumer Advisory Committees (CACs) at University Centers for Excellence in Developmental Disabilities (UCEDDs).

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (The DD Act) requires UCEDDs to establish CACs that meet specific minimum requirements. One requirement is that a majority of members must be individuals with developmental disabilities and family members. However, beyond minimum requirements, supports are often needed for individuals with disabilities and family members to meaningfully participate on committees.

Some UCEDDs have developed innovative practices to support their CACs, while others are looking for technical assistance to improve practices.

The purposes of this project were to:



Joe Caldwell

1. Identify supports that enhance the meaningful participation and effectiveness of CACs.
2. Develop case studies on innovative or best practices in CACs.
3. Provide recommendations concerning the assessment of CACs.
4. Provide recommendations of possible areas to consider during the future

*(Continued on page 2)*

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*The DD Act requires UCEDDs to establish CACs to assist them in guiding their direction and planning.*

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*A participatory action research approach and qualitative research methods were used to achieve the objectives of the project.*

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#### Executive Summary (continued)

reauthorization of The DD Act.

Qualitative research methods were used that included a series of telephone focus groups, an open-ended electronic survey, and case studies of two CACs. Five general themes emerged concerning supports that contribute to the meaningful participation and effectiveness of CACs:

1. *Individualized Supports.* This includes such areas as accessibility and accommodations for meetings; cultural competency; child care, respite, and personal assistance services; and transportation.
2. *Financial Supports.* This includes coverage for travel and related expenses as well as stipends or honorariums for time.
3. *Communication and Coordination.* This includes UCEDD staff support to coordinate the committee and the development of effective, ongoing means of communication.
4. *Leadership Development and Orientation.* This includes strategies to foster the leadership development of less-experienced and new members of CACs, such as mentoring, opportunities to attend other meetings and conferences, and orientation.
5. *Values and Outcomes.* This includes the extent to which suggestions and feedback provided by the CAC is valued and leads to outcomes within the University Center.

The framework of five identified themes was incorporated into recommendations for the assessment of CACs. Furthermore, potential areas to consider during the next reauthorization of The DD Act were highlighted, such as using the word “consumer” and embracing a multicultural view of disability.

## Background

The DD Act authorizes funding for grants to entities designated as UCEDDs. In 2005, there were 64 grants to UCEDDs in every state and United States territory. The DD Act requires UCEDDs to establish CACs to assist them in guiding their direction and planning. Certain minimum criteria for CACs are outlined in The DD Act (see page 14 of this report). The DD Act specifies “who” should be on CACs: (a) a majority of individuals with developmental disabilities and family members, (b) representation from particular organizations, and (c) representation that reflects the racial and ethnic diversity of the state. The DD Act also specifies the purpose of CACs, which focuses on the UCEDD’s 5-year plan.

Beyond these minimum requirements, and in line with the spirit of the legislation, the Administration on Developmental Disabilities (ADD), AUCD, and UCEDDs are committed to enhancing the meaningful participation of individuals with disabilities and family members on CACs. Given the diversity across UCEDDs, many different approaches have been taken to support CACs. Some UCEDDs have developed innovative practices in CACs, while others have identified needs for technical assistance. There have been few opportunities for sharing information about CACs across UCEDDs, and perhaps even fewer opportunities for individuals with disabilities and family members to share their views about what works and what is needed. There were four primary objectives of this project:

1. Identify supports that enhance the meaningful participation and effectiveness of CACs.
2. Develop case studies on innovative or best practices in CACs.
3. Provide recommendations concerning the assessment of CACs.
4. Provide recommendations of possible areas to consider during the future reauthorization of The DD Act.

## Methods

A participatory action research approach was adopted for the project. AUCD staff collaborated with members of AUCD's Council on Community Advocacy (COCA). COCA is made up of individuals with disabilities and family members representing UCEDDs across the country. COCA was first organized in 1994 through an ADD Project of National Significance titled "Leadership and Choices." Initial work on this project was provided by Carl Calkins, Director of the UCEDD at the University of Missouri, Kansas City, and Bruce Eddy of AUCD. One of the initial technical assistance products of COCA was an orientation manual for individuals on CACs. As outlined in its mission statement, COCA aims to "build the capacity of local University CACs, including identifying needs for technical assistance, providing that assistance, and disseminating information about exemplary and innovative practices." COCA offers a wealth of experience and provides connections to individual CACs.

Qualitative research methods were used to achieve the objectives of the project. First, three telephone focus groups were conducted—one with UCEDD Directors and staff and two with individuals with disabilities and family members from CACs. AUCD staff and volunteers from COCA collaborated to develop a set of questions (see page 14 of this report). AUCD and COCA list serves were used to recruit participants for the focus groups. The first telephone focus group was held on 7/28/05, and 15 UCEDD Directors or their appointed staff participated. The second and third calls were held on 8/10/05 and 8/12/05, and 16 individuals participated on these calls (5 individuals with disabilities and 11 family members). Twenty-two UCEDDs (about a third of the network) were represented on the calls. Each call lasted approximately two hours, and calls were transcribed. All participants were provided with the questions before the call. This allowed participants to prepare for the call, particularly individuals with cognitive disabilities who may need this as an accommodation. For individuals for whom verbal communication on the telephone is difficult, written comments were obtained in advance and shared during the call.

In order to provide additional individuals an opportunity to comment on the questions, an

electronic survey was created based on the same questions used for the focus groups. This survey was distributed through the AUCD list serve and to CACs through COCA. Forty-nine individuals responded to this survey (11 individuals with disabilities, 18 family members, and 20 other individuals—a mix of UCEDD Directors and staff as well as other members of CACs).

Based on information from the focus groups, two UCEDDs were selected that seemed to have innovative or best practices regarding their CACs. Visits to CAC meetings at the two UCEDDs were scheduled. AUCD staff and a representative from COCA jointly visited these Centers. COCA representatives from the host UCEDDs assisted with coordinating the visits. Opportunities were provided to observe the meeting of the CACs and interact with members, the COCA representative, and UCEDD Director during and outside of the meetings. The questions developed for the focus groups served as the springboard for interaction and further discussion. The first visit was made to the Interdisciplinary Human Development Institute (University of Kentucky UCEDD) on 8/18/05, and the second visit was made to the Wyoming Institute for Disabilities (University of Wyoming UCEDD) on 11/7/05–11/8/05.

Transcripts from the focus groups, data from the electronic surveys, and notes from visits to UCEDDs were analyzed qualitatively. A qualitative software package was used to assist with organizing data and coding. A grounded theory approach was taken to construct a framework of general themes associated with the meaningful participation of individuals with disabilities and family members on CACs. Members from COCA reviewed the themes and provided feedback. Information gathered during CAC meeting visits were developed into case studies to share with other UCEDDs (see page 11 of this report).

Five general themes emerged concerning supports that contribute to the meaningful participation of individuals with disabilities and family members and effectiveness of CACs: Individualized Supports, Financial Supports, Coordination and Communication, Leadership Development and Orientation, and Values and Outcomes.

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*What UCEDDs are  
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## Individualized Supports

### Accessibility and Accommodations

UCEDDs are skilled at providing individualized supports to individuals with disabilities and families. Therefore, some of the information within this section may appear to be business as usual to many UCEDDs. However, what UCEDDs are doing can serve as a model for other boards and committees. Also, the list of all possible accommodations is endless and, as one UCEDD Director observed, sometimes accommodations for one committee member might conflict with accommodations for another. Ensuring accessibility and accommodations requires ongoing monitoring. UCEDDs have developed some creative approaches, particularly concerning full inclusion of individuals with cognitive disabilities.

Meeting locations, and related transportation and hotel accommodations, need to be fully accessible to individuals with physical disabilities. In addition, environmental accommodations may be required for individuals with other disabilities, such as particular lighting or scent-free environments. Accommodations are often needed to assist with communication, such as sign language interpreters, closed-captioning services, amplified hearing devices, or use of other assistive communication devices. Meeting materials and other modes of communication need to be accessible. This might include providing materials in Braille, large print, or disk formats.

Accommodations for individuals with cognitive disabilities are often less understood and at times do not receive adequate attention. Individuals with cognitive disabilities may need materials in advance in order to process information. Also, some individuals may desire to use support persons to help with preparation and understanding before and during meetings. One UCEDD, for example, holds a separate meeting before the larger CAC meeting that could be viewed as a support for members with disabilities to develop and focus ideas. Agendas and other meeting materials should be written in plain, simple, jargon-free language that can be understood. As one self-advocate stated as a recommendation, “Get rid of acronyms!” Sometimes pictures or clip art can assist with understanding for individuals who do not read well. During meetings it is important to be aware of the pace and provide opportunities for questions. Also, every CAC member should feel comfortable to share their views and be listened to. Some boards and committees have also found it helpful to elect a person outside of the committee to serve as a monitor

and promote more inclusive meetings.

### Cultural Competency

CACs are required to reflect the racial and ethnic diversity of their state. Several UCEDDs reported having difficulty recruiting committee members from diverse backgrounds. UCEDDs should develop culturally competent strategies to develop relationships with and outreach to minority populations about participation on CACs. This may include engaging community-based organizations that are prominent in culturally and linguistically diverse populations, reaching out through faith-based organizations, and cultural competence training for UCEDD staff and members of CACs. Furthermore, in order for some members who have a primary language other than English to fully participate, translated materials and interpreters may be needed.

### Child Care, Respite, and Personal Assistance

Individuals with disabilities and families often face long waiting lists and difficulty obtaining needed supports and services, such as child care, respite, and personal assistance services. Therefore, for some individuals with disabilities and family members, UCEDDs may need to provide these services to ensure their ability to participate on the CAC. Some UCEDDs have developed arrangements to provide child care or respite on-site, while others have provided financial supports, such as reimbursements or stipends, to cover these services. For individuals requiring personal assistance services, UCEDDs often cover the costs of services as well as travel and other expenses for assistants.

### Transportation

The most frequently mentioned support needed by individuals with disabilities and family members on CACs was transportation. This is a constant struggle for UCEDDs in rural and large states that cover wide geographic regions. Some UCEDDs provide rides or contract with cab companies to pick up individuals from home, bus stations, or airports. Since transportation is a major barrier, UCEDDs may need to actively provide assistance and develop creative solutions so individuals can attend. As one UCEDD staff member stated:

*I think transportation continues to be one of our biggest issues, getting folks to and from the meeting. And so, sometimes we've got folks that will arrange transportation—sometimes actually give people rides home or get them to the meeting. We're pretty good about trying to figure out ways to get them to and from.*

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## Financial Supports

### Travel and Other Expenses

At a minimum, hotel accommodations, transportation, and food expenses should be provided to CAC members for their participation. While most UCEDDs reimburse for these expenses, it is important to recognize that many individuals with disabilities and families live on fixed incomes and may not have credit cards to make purchases in advance. Some UCEDDs budget money to cover these expenses using ADD core funds. At least one UCEDD provides a budget to its CAC and allows them to make decisions concerning expenses.

### Stipends and Honorariums

Many UCEDDs provide stipends to individuals with disabilities and family members. Stipends or honorariums recognize the time individuals provide to participate on CACs. Some individuals may need to take time off from work to participate in meetings. Stipends pro-

vided by UCEDDs generally ranged between \$50 and \$200 per meeting. As one UCEDD Director explained:

*We pay a \$100 stipend per meeting. Our meetings are three hours. We base it on what we would pay professionals to provide consultation to us. So, basically we're kind of viewing it as consultant relationship.*

Stipends and honorariums communicate respect and value. As one family member on a CAC illustrated:

*I think it just kind of makes you feel like you're valuable. You know, often for parents and family members, folks always want you in the room. And professionals are there and they are getting paid but you've not only taken a day off from your job but you've arranged child care and all the other things that go along with being away from your home. So it's nice to have that acknowledgement.*

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*The most frequently mentioned support needed by individuals with disabilities and family members on CACs was transportation.*

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## Coordination and Communication

### Staff Support

Many UCEDDs have created paid positions that help coordinate and facilitate the activities of the CACs, and this support seems to significantly contribute to their effectiveness. Most positions have been filled by individuals with disabilities or family members. The positions often incorporate other duties within the UCEDD, such as community outreach, training, and community advocacy. Some individuals serving as paid coordinators of CACs were once members of the CAC the UCEDD decided to hire.

Most often these individuals view themselves as supporters of the CAC, rather than voting members. However, some individuals question if this should be seen as a conflict of interest. As UCEDD employees, they may have unique perspectives to offer about the employment of individuals with disabilities or family members within the UCEDD. They typically also have broad-based advocacy experience and passion. As one such individual stated:

*Sometimes it's hard for me to be an ex-officio member because I'm a family member and I'm opinionated about some stuff and I have to leave that hat in the background when the*

*committee meets because it's really their committee.*

Members of CACs tend to feel strongly that having a paid coordinator or facilitator within the UCEDD is very helpful to ongoing functions of the CAC, as indicated in the following two quotes:

*I think that having a coordinator is very important to connect and go over any questions about the agenda for the meeting coming up, and then follow up after the meeting just to make sure that questions have been answered, and they are really clear on the issue, and they feel more comfortable at the meeting.*

*I think that the support that we get from our liaison is wonderful. She is always very, very helpful in recruiting members, or helping with minutes and agendas, and things like that. So I think that's working out very, very well, having a person like that in place at the university Center.*

### Ongoing Communication

As indicated above, paid coordinators or facilitators from within the Center can be one way to maintain ongoing communication with the committee. This is particularly important

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*I think that effective committees are able to be informed about what is happening in the centers and have some say so in how programs are administered.*

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#### Coordination and Communication (continued)

due to the infrequency of face-to-face meetings. Most CACs tend to meet about four times a year. However, some UCEDDs in rural or widespread geographic areas have as few as two meetings a year. In response, some UCEDDs have created task forces within the CAC to work on issues between meetings. One UCEDD recommended taking advantage of other statewide meetings, where CAC members may be gathered. Other UCEDDs use conference calls, and a few are beginning to experiment with video conferencing. Sometimes it takes creative ways to accommodate everyone, as one individual with a disability illustrated:

*We need more frequent communication and ways to communicate other than conference calls. We use e-mail and are in the process of creating a website with chat and a message board. It is difficult to find one way of communicating that is accessible to all members. For example, one of our consumers uses an augmentative communication device, and I have impaired speech, so phone conversations are not our best forms of communication.*

Some UCEDDs are using e-mail and the internet to aid communication. However, this may require Centers to overcome access barriers to technology that many individuals with disabilities and families face, as one Center staff indicated:

*I guess one of the things that we do, that could be called a support, is we manage a list serve for our consumer advisory council. We put all of the materials out through the list serve and the group has an opportunity to ask questions that way. They get into some pretty lively discussions! There have been a couple of*

*people who didn't have access to technology, and so we've supported them in figuring out how to get them computers and online.*

As one family member on a CAC stated, "Centers live and die by grants!" She emphasized the importance of having effective streams of communication to meaningfully involve the CAC in providing assistance when decisions need to be made in a timely manner:

*One thing that decreases effectiveness is when decisions have to be made in a hurry, and I think that's probably inherent at the Center all of the time. And I think that's where we fall short because we're not apprised of the decision that needs to be made because there's not enough time. Sometimes I think that it would be better if we met more than quarterly, although now we're leaning more towards meeting only twice a year. But I think that's part of the issue is that some decisions need to be made right away, and there's just not enough time to contact everyone, or maybe we need to develop a better mechanism for doing that, that's been my observation.*

In addition to developing effective modes of communication, CACs need clear information about the activities of the UCEDD. As one CAC member stated:

*I think that effective committees are able to be informed about what is happening in the Centers and have some say so in how programs are administered. A "token" committee is just in place to be compliant with the grant requirements and just meet due to specific requirements of the grant. This type of committee is not an informed one and makes no decisions.*

## Leadership Development and Orientation

### Leadership Development

One of the most consistent things heard from Centers concerned having difficulty recruiting new members for CACs. Many UCEDDs echoed that there are a handful of strong advocates in the state, but they already serve on many different committees. As one UCEDD staff member stated:

*Recruitment has been an issue for us. We have people with disabilities in the state who*

*are really involved in what I would call high level advocacy efforts with legislatures and other important policy kinds of things. And they tend to already be serving on some type of board or within some type of advocacy consortium. So they are really very knowledgeable and meet all of the requirements, but we have a hard time recruiting those folks. They are pretty booked!*

In response, some UCEDDs have developed strategies for more active recruitment. For example, one UCEDD has discovered that their statewide self-advocacy conference, where hundreds of self-advocates gather annually, is an excellent venue for sharing information and recruiting individuals for the CAC. Another UCEDD simply asked the more seasoned advocates who are already on a lot of committees for their recommendations:

*When I first looked at the board there were several that were involved in other committees. They were spread out thin. Everyone wanted these one or two parents who were big advocates to be on their committee. So, I went to them and I sat down and got input about who they would recommend. The good part about that is that I found some rather wonderful parents, but other agencies stole them away and now they work full-time for other agencies in the disability field.*

Several UCEDDs have begun actively recruiting younger individuals with disabilities for their CACs, sometimes high school and college students. They expressed that this has worked very well, adding refreshing new perspectives that rejuvenated their CAC.

Developing the next generation of leaders with disabilities and family members is critical. UCEDDs have the opportunity to play a key role in leadership development of advocates, similar to the role Centers play in the professional development of students and trainees. As one family member of a CAC challenged:

*You put some parents on panels because they fit or just because you are already comfortable with this parent. So, everybody puts them on the committees and then burns them out instead of reaching out to parents who might come in for counseling or call for help. You need to reach out to other parents. I would like to see organizations use grassroots parents, and not parents that are professionals, or fit into that little mold, but pull in grassroots parents that have a lot of advice and information and can train professionals on what's happening in the disability community and use the committee as training for them to be a chair person. We all need to get out of that comfort zone and really reach out. It's not fair to other parents who could be on committees and who have a lot more input and advice that they could give*

As another family member reinforced:

*I think it is valuable to develop leadership in people who haven't had an opportunity to see the broader perspective, or the global picture even if we're only talking about the global picture statewide. Parents are at the beginnings of their careers, perhaps, as activists or advocates. I think this is a wonderful opportunity for them. And, you know, had somebody not taken a chance on me at the beginning and brought me along I don't know that I would be where I am today.*

Some UCEDDs have also supported leadership development of advocates through formal trainings to build skills, such as models based on Partners in Policy Making. As one UCEDD staff member stated:

*And we've had a number of members participate who have maybe real limited educational experiences or background even in the field of developmental disabilities, although they might have a disability. And so we've had to become innovative developing some materials to help people participate, you know, on an equal basis with members who might have advanced issues. That's been a challenge for us.*

Some UCEDDs are experimenting with mentoring new members who may not have had a lot of previous experience on boards or committees. So far, this has mostly been done on an informal basis through pairing new members with more experienced members:

*One of the things that we're starting to work more with is kind of a mentoring for people coming on to advisory committee. This is because we're getting people that have not been really too involved in the disabilities field. We're trying to pull in some people that will give us some different perspectives. And so we're doing a peer-mentoring program on the committee to get these people so that they understand what we're doing, and so that they feel comfortable with what we're doing. And also so that they can feel comfortable giving us their opinions no matter what those opinions might be.*

However, individuals with disabilities and family members should not be viewed as the only parties in need of leadership development. As one family member indicated, CACs can offer the pathways to collaborative leadership development, where everyone gains new perspectives and skills:

*I think that you have two group dynamics*

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Leadership Development and Orientation (continued)

*coming together. Those who work in the area of serving, or doing research, or education for persons with disabilities, and then those who are family members or consumers. I know that we're talking about leadership from the perspective of the consumer advisory board, but I think that the function of the consumer advisory board would provide some leadership learning opportunities for those people that are new to the university Center as professionals, because some of those people come into those positions with limited knowledge from all perspectives around the table. So, I think that we need leadership training for consumer advisory members, but I think that it also needs to be somehow done collaboratively with folks that are professionals working within the Center.*

Orientation

Finally, a common area where many individuals from within and outside UCEDDs saw a need for technical assistance was orientation for new CAC members. Many UCEDDs handle orientation of new members informally. However, some indicated they would like better materials to provide a

foundation for new members:

*One thing that I wish our Center would do is to have a real meaningful orientation so that you get a foundational knowledge base about the different laws that have caused, you know, the UCEDDs to be in place, in the first place. And just so people have kind of a context, you know, so that they understand what they're getting involved with.*

Another excellent way to provide orientation and leadership development is through supporting participation in activities of the broader network of UCEDDs. About a third of UCEDDs have appointed representatives to AUCD's COCA, which consists of individuals with disabilities and family members and promotes meaningful participation across the network. Some UCEDDs are committed to sending representatives with disabilities and/or family members of individuals with disabilities to national meetings, such as the AUCD Annual Meeting and the Disability Policy Seminar. These are wonderful opportunities to build skills and network that often, in turn, benefit UCEDDs and their CACs.

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## Values and Outcomes

Values

Perhaps the most important support from the perspective of individuals with disabilities and family members is attitudinal: the value placed on the CAC. As one CAC member explained:

*I think that is the most important thing, and I don't know if this is considered a support or not, but I think that people need to feel that their input is valuable, and that they feel that whatever they have to say is important. I think that's the most important support that can be given to the members.*

Another family member on a CAC also emphasized the importance of feeling valued and not as a "token," there to field the requirements of a grant:

*I want to emphasize that it is important to make family members feel like a significant part of the committee, making them feel welcomed and that their advice and recommendations are, indeed, taken into consideration. Because a lot of people are from organizations, and they network in many different places where family members sometimes don't. It is important to make them*

*really feel like they're not just a token person, or they're there because you have to field some numbers on the grant. But that they're really needed and their advice is really taken into consideration.*

Still another family member stressed that staff may need to weigh their personal desires and career motivations with the value they place on input from the CAC:

*There is a stated value in having the input from the consumer advisory group, but on the flip-side what's driving them forward is their own personal desire, which is not bad. I don't mean to say it negatively, but that can really impact the perceived value of the consumer advisory group. Because if you are trying to always gain more and more grants or do more and more published research, sometimes the input from this group might be at different levels of value.*

Some individuals feel that the leadership of the UCEDD, particularly the influence of the UCEDD Director, contributes to the difference between a "token" CAC and one that is valued:



*I think what we've been very fortunate in that we have a great director. I worry that when he leaves us that will truly impact the focus and function of this group. Because I think that he is a lot of the power and the initiative behind how we're so meaningfully involved. I think that we could be much more meaningfully involved with projects that are going on, but I think that he has tried very, very hard in a leadership position. That's why I am so excited about this project—putting things into policy and practice and evaluation will probably help to maintain things once people pass out of different positions.*

One CAC member with disabilities stated that you can tell a lot about a committee by simply observing the interactions that take place during meetings. He suggested looking at who is doing the talking during the meeting.

#### Outcomes

Directly assessing the value a UCEDD places on their CAC is difficult. However, there seemed to be a lot of consensus that looking at outcomes of provided input is a good marker of value and the role of the CAC. As one UCEDD Director noted:

*Is the advice utilized? Is there a way to track the advice given and then what happened? People say that their greatest need is transportation. Well, then what is the Center doing about it? People say their greatest need is in-home support, so what is the Center doing about it? You can connect the dots logically, so that the council feels like they're contributing, and so you know where it came from. I know that for us we've got a number of initiatives going on that we would never have embarked on if it wasn't for this group telling us that this*

*is what they wanted us to pay attention to.*

Meeting notes may be helpful to check back and see if suggestions were taken into consideration. Some UCEDDs have added time to their meeting agenda to reflect on how input is being used. They feel that two-way communication promotes accountability and a better understanding of the role the CAC is playing. As one family member on a CAC stated:

*I would say it is important to get the information flow from the ways that our members inform our programs that are featured at their meetings. Have those that are presenting sort of share back in how they took the feedback from our members, and how it informed their work, and how they made changes. So, that information flow I would say is one of our major support needs.*

In addition, CACs could be interviewed by peer reviewers and asked to self-assess whether they feel they have the supports they need and whether they feel that their feedback and guidance is making a difference. Ideally, both CACs and UCEDD staff should be able to point to some specific examples of how their guidance has led to outcomes. As one CAC member suggested:

*In interviews conducted by someone other than a staff member, ask whether consumer advisory committee members feel they have given input and whether their advice has been considered and used by Centers. Ask university Center staff what consumer advisory committee advice has been acted upon and how advisory committee members have contributed to university Center activities, other than attending meetings.*

## Recommendations

#### Assessment of CACs

One mechanism to assess whether UCEDDs are meeting requirements under The DD Act is the Monitoring Technical Assistance and Review System (MTARS) conducted by ADD. The *UCEDD Program Operations and Practices Checklist* (see page 15 of this report) is used during the MTARS process. This checklist is intended to provide suggestions to UCEDDs about their practices. One of the objectives of this project was to provide recommendations concerning this checklist and the assessment of CACs.

There are currently eight items on the *UCEDD Program Operations and Practices Checklist*. Half of the items seem to concern the “form” of the CAC: (a) the CAC has by-laws, (b) the members represent people from different regions across the state, (c) the CAC is chaired by a consumer or family representative, and (d) the CAC meets often enough. There was a lot of agreement among participants in the project that assessment should look more at the “function” of the CAC rather than focusing on the “form.” As

*(Continued on page 10)*

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*I think that people need to feel that their input is valuable, and that they feel that whatever they have to say is important. I think that's the most important support that can be given to members.*

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*There was a lot of agreement. . . that assessment should look more at the “function” of the CAC rather than focusing on the “form.”*

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*The concept of a self-assessment seemed to resonate among many participants in the project.*

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Recommendations (continued)

one UCEDD Director stated:

*I think that the checklist format really makes it look like bean counting. And in doing that, the process gets lost over who’s filling what role. And really the critical issue is “What function is the consumer advisory council doing?” So what meaningful role are they playing in the organization?*

Items concerning the form of CACs, beyond what is already required in The DD Act, do not necessarily seem to indicate meaningful participation of individuals with disabilities and families or that the CAC is substantially contributing to the guidance of the UCEDD. Perhaps illustrative of this point, the one item that produced the most debate was the item on by-laws. As one UCEDD Director described, their particular CAC “lives and dies” by the by-laws.

However, other UCEDDs feel that by-laws are not absolutely necessary to the effectiveness of the CAC and prefer to do things more informally. As one CAC member stated:

*The one item on that checklist that seemed arbitrary was the article about by-laws. We don’t have them and our committee doesn’t want them. If it’s a board, there is more need for by-laws. But when it’s an advisory committee, you know, by-laws can bog you down I think.*

One suggestion to reform the *UCEDD Program Operations and Practices Checklist* and assessment process could be to structure it within the framework of the five themes identified in this report concerning meaningful participation and effectiveness of CACs: Individualized Supports, Financial Supports, Communication and Coordination, Leadership Development and Orientation, and Values and Outcomes.

For the first four themes, UCEDDs could be asked what they are doing to provide supports in each area. Ideally, UCEDDs should be able to demonstrate that they are providing some type of supports within each area. However, specifics will likely be different for each UCEDD based on the particular needs of the CAC. Things other UCEDDs have done, such as the examples contained within this report, could be bulleted and serve as prompts. While allowing for flexibility, this format would provide suggestions based on activities of other UCEDDs. Similarly, UCEDDs could also be asked to identify how feedback and guidance from the CAC is being used and if it

has led to specific changes or outcomes in the functioning of the UCEDD.

In addition to assessment from the perspective of the UCEDD, the concept of a self-assessment by the CAC seemed to resonate among many participants in the project. CAC members could similarly be asked to assess whether they feel they have needed supports from the UCEDD to meaningfully participate and to identify how their feedback and guidance has resulted in specific changes or outcomes.

Reauthorization of The DD Act

During the project, some additional issues emerged concerning CACs that may be important to consider during reauthorization of The DD Act. Concerning terminology, many individuals with disabilities and family members feel the term “consumer” is outdated and demeaning. In fact, within the past year COCA elected to change its name to eliminate the word “consumer.” One CAC member stated he disliked the word because it implies that a “consumer” is someone who takes or receives, while he feels his role on the CAC is to do just the opposite: to offer his perspective and give guidance.

Another issue that caused a great deal of debate is the interpretation of The DD Act concerning the “counting” of individuals with disabilities and family members on CACs who also represent organizations. The current interpretation is that, for the purposes of assessing whether there is a majority of individuals or family members on the CAC, individuals with developmental disabilities and family members cannot represent both an organization and be “counted” as individuals with disabilities and family members.

Many people with disabilities and family members feel this is demeaning. As one individual with disabilities stated:

*That is ludicrous because the more good information you can bring to the consumer advisory committee the better. How better to do that than with an agency representative that happens to be a parent or consumer? If you are a parent, or you are a consumer, and you are very involved in your state as an activist, advocate, and you work for an agency, it doesn’t matter—you bring more to the table.*

Many people objected to the one-dimensional view of individuals with disabilities and family members. As one individual explained,

being an individual with disabilities or a family member is part of their identity:

*Well, if you can tell me how to take that away from the person when they are there, then I'll tell you that's a good thing. But until you tell me how to do that, I don't know.*

Instead, some individuals would like to see a multicultural view of disability taken. The field of disability studies has advanced a cultural view of disability. Within this perspective, disability is a valued identity among many other identities and roles that individuals may have.

There may, however, be valid issues surrounding the interpretation of The DD Act that could be expressed differently in the reauthorization. For example, one UCEDD Director suggested that the issue could be framed around potential conflicts of interest:

*I think that the important question is not "Are you part of something else?" but the important*

*questions in any board or advisory group are "Do we understand potential conflicts of interest?" and "Do people acknowledge those and declare those when they are in a potential conflict of interest situation?" On any board, there's no problem of having a conflict of interest on paper unless you don't disclose it or deal with it.*

Furthermore, as discussed earlier, the heart of the issue might deal with a desire to create more leadership opportunities for individuals with disabilities and family members not already connected with organizations. If so, perhaps the issue could be reframed in a better way during the next reauthorization of The DD Act, while valuing the diversity and multiple roles and identities individuals with disabilities and their families can bring to the table.

## Case Studies of Consumer Advisory Committees

### Interdisciplinary Human Development Institute, University of Kentucky UCEDD

The CAC at the Interdisciplinary Human Development Institute (IHDI) at the University of Kentucky consists of approximately 20 members. The majority of members are individuals with disabilities or family members. Consistent with requirements from The DD Act, there are also representatives from the Kentucky Council on Developmental Disabilities, the Kentucky Division of Protection and Advocacy, and Kentucky Self-Advocates for Freedom. Representatives from several other relevant state agencies are also included, such as the Division of Mental Retardation Services and Vocational Rehabilitation. The CAC meets approximately four times a year. They have grown in recent years in order to pull in people who represent the State of Kentucky geographically and ethnically. Due to this growth, they now tend to hold their meetings at space outside of the university. They typically hold meetings at a hotel conference center because this is easiest for people traveling from across the state who have to stay overnight.

The CAC consists of very strong advocates

from diverse backgrounds and areas of expertise. As one member stated, "We are not a rubber stamp!" When it comes to developing and approving the 5-year plan for the UCEDD, they take their job very seriously. They will not approve things until they are able to hold a discussion on issues and reach an agreement.

The CAC operates through by-laws. As they have grown, they have found a need for some of the things they used to do informally to become more formal for consistency. CAC members serve 3-year terms and they can serve two consecutive terms (a total of 6 years). The CAC has wonderful leadership. They also have a representative appointed to the COCA at AUCD that keeps them well-informed about activities at the national level. Kentucky has also made an effort to support members to attend national meetings. They recently passed a motion to provide funding to send both their CAC Chair and their COCA representative to the AUCD Annual Meeting each year.

Kentucky provides stipends to their CAC

*(Continued on page 12)*

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*I think that the important question is not "Are you part of something else?" but the important questions in any board or advisory group are "Do we understand potential conflicts of interest?" and "Do people acknowledge those and declare those when they are in a potential conflict of interest situation?"*

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IHDI (continued)

members. They provide \$100 stipends that show appreciation for the time commitment members make to the CAC. They also help arrange and cover transportation and hotel for people who travel. In addition, many accommodations are made for members with diverse disabilities and needs. For example, accessible agendas and materials in Braille are prepared ahead of time. One member with hearing impairments uses a microphone and hearing amplifier. During meetings, if someone does not understand something that is being said they will take a moment to better explain things before moving on.

One of the reasons many CAC members feel they are able to be as effective as they are is the support they have from their UCEDD Director. He is at the center of the CAC meetings and sets a respectful and inviting tone. The CAC laughs, jokes, and truly has a good time when they are together. However, the Director also knows when to take a back seat and allow the CAC to do their business. For example, he started out a recent meeting by stating that it would be very hard for him to do, but his role was to “sit back and listen” on that day. One CAC member emphasized that it is important for UCEDD staff to be supported in their careers and work, but to balance this with meaningful involvement from the CAC. They said their Director sets an expectation of excellence for his staff and demonstrates that involving individuals with disabilities and families is “the way we are going to do things at this Center.”

In addition to influencing the work of the UCEDD, the CAC also stays informed about policy issues in the state and takes action on issues, such as making recommendations, writing letters, or participating in coalitions. One of the most exciting projects the CAC has initiated is a recent joint collaboration between the advisory boards of the three state agencies authorized through The DD Act in Kentucky: the Kentucky Council on Developmental Disabilities, the Kentucky Division of Protection and Advocacy, and the IHDI at the University of Kentucky.

Approximately 60 board members from the three sister agencies came together for a joint meeting in August of 2005. The meeting was historic. It was the first such meeting of its kind in Kentucky, and is part of an emerging practice of network agencies across the country. Prior to the meeting, the agencies collaborated to develop a joint newsletter and

website. They also developed a joint needs assessment in order to collect information from individuals with disabilities, family members, professionals, and policy makers about the most pressing areas of need for individuals with developmental disabilities and their families in the state. Staff from the UCEDD took the lead on analyzing the needs assessment and presented the results at the joint meeting of the three agencies. This information provided a foundation for participants at the meeting to select one priority area where the three agencies could focus on a joint project.

In order to select one area, participants at the meeting were divided into five workgroups based on areas of interests that were determined before the meeting. The five areas were: Education, Quality Assurance, Health, Transportation, and Employment. Each workgroup was instructed to jointly develop an idea for a project. Workgroups spent most of the day developing ideas, and then they were instructed to develop a poster presentation to pitch their project to the larger group. After each workgroup presented their project, everyone was given the opportunity to vote on the top project. In voting, individuals were asked to consider if the project: (a) reflects the needs of people with disabilities and families based on the needs assessment, (b) would make a real difference in the state, and (c) is a project that can be done through the collaboration. In the end, the project that received the most votes was a self-determination mentoring project targeted towards youth with disabilities in middle school.

While one project was selected for the three agencies to focus on in the next couple of years, the meeting energized interest in future collaborations. All of the projects developed by the workgroups were extremely creative ideas, and as the meeting ended representatives from the three agencies were already strategizing about how they could incorporate ideas within other projects and continue collaborations.

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*One of the reasons many CAC members feel they are able to be as effective as they are is the support they have received from their UCEDD Director.*

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**Wyoming Institute for Disabilities, University of Wyoming UCEDD**

The Wyoming Institute for Disabilities (WIND) CAC consists of approximately 20 members. About half of the members are individuals with disabilities and family members. As outlined in The DD Act, there is also representation from the Wyoming Governor’s Planning Council on Developmental Disabilities, the Wyoming Protection & Advocacy System, and People First of Wyoming. Also included are representatives from various provider and other state agencies, including the Department of Health, the Division of Vocational Rehabilitation, the Developmental Disabilities Division, and the Department of Education. WIND is in the process of developing an undergraduate program in disability studies. Therefore, members from within the University of Wyoming are also present, such as the Deans of the College of Health and Sciences and the College of Education and the President and Vice President of Research.

WIND provides many excellent supports to individuals with disabilities and family members. Wyoming poses many transportation barriers. WIND actively figures out ways for people to get to meetings, having staff provide transportation if needed. WIND provides expenses for travel, accommodations, and meals. They also have provided stipends to individuals for their time. Perhaps the greatest support WIND provides is a paid CAC coordinator. He assists with arranging and facilitating meetings as well as coordinating travel and other arrangements. He also keeps communication flowing. He discusses specific activities and projects at the Center with members of the committee so they are better informed when they come to meetings. Communications between the meetings is where the real work seems to take place. In addition to supporting the CAC, he fills many other roles at WIND and serves as the COCA representative to connect with the larger network of UCEDDs.

One of the innovative practices at WIND concerns mentoring of new CAC members. There are no formal time limits in place for CAC members. However, perhaps out of necessity due to the relatively low population of Wyoming, WIND has actively taken a role to bring on new CAC members that may not have a lot of experience serving on boards or committees. Within the past year, they have brought on two new CAC members and have tried to partner them with other seasoned members.

The tradition of mentoring within WIND has been passed on. As the CAC coordinator stated:

*Actually I was the guinea pig for it because I came up from being a member of the advisory council to being consumer activities coordinator. And so when we got a new member on right after I started as a consumer activities coordinator, my Director came to me and said, "Okay, get this guy up to speed so that he knows what he is doing and work with him on the committee." So it just got to the point that it seemed like it made sense to have other people that were already on [another subcommittee] work with folks.*

Another practice at WIND is a subcommittee of the CAC known as the Consumer Program Advisory Council (CPAC). This committee consists solely of individuals with disabilities and family members. When WIND originated, CPAC was the only advisory committee. However, WIND saw a need to expand the committee to better connect with the university structure, community providers, and state agencies. As the CAC was expanded, members of CPAC wanted to continue meeting separately. They chose to focus their efforts more specifically on disability awareness issues, particularly in the school system. One very successful initiative they have led is the creation of disability awareness coloring books. They worked with a graphic artist at the University of Wyoming to develop two books that have been widely distributed. They are now developing creative ideas to raise disability awareness in middle and high schools.

Members of CPAC indicated that their work on a specific advocacy project, such as disability awareness in the schools, energizes them. Seeing outcomes of their work maintains their commitment. CPAC also fills the more traditional role of providing input and feedback to the Center regarding its 5-year plan. In some ways CPAC could be viewed as an accommodation in this regard. CPAC meetings provide much more time to share information about the Center activities and develop ideas for guidance. For example, CPAC was far ahead of the larger CAC in reviewing the goals of the Center and thinking about the next 5-year plan. They plan to select one goal that they as a group would like to focus on more.

The commitment of WIND to full participation

*(Continued on page 14)*

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*One of the innovative practices at WIND concerns mentoring of new CAC members.*

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*Seeing outcomes of their work maintains their commitment.*

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*Ideally, both CACs and UCEDD staff should be able to point to some specific examples of how their guidance has led to outcomes.*

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*An excellent way to provide orientation and leadership development is through supporting participation in activities in the broader network of UCEDDs.*

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#### WIND (continued)

of individuals with disabilities is evident within the environment created by the UCEDD Director. Walking the halls, one is constantly reminded of this message through artwork and posters that brand the mission of WIND. Furthermore, actions speak even louder. For a relatively small UCEDD, WIND makes a significant commitment to support individuals with disabilities and family members from its Center and CAC to attend national meetings, such as the AUCD Annual Meeting and Disability Policy Seminar. The Director sees impact and change as people gain new knowledge, leadership skills, and energy from these experiences. 🌟

## Supplemental Materials

### Requirements for UCEDD CACs in The DD Act

(Public Law 106-402)

The majority of the members must be individuals with developmental disabilities and family members of such individuals.

- The CAC must include:
  - Individuals with developmental disabilities and related disabilities;
  - Family members of individuals with developmental disabilities;
  - A representative of the State Protection and Advocacy system;
  - A representative of the State Council on Developmental Disabilities;
  - A representative of a self-advocacy organization; and
  - Representatives of organizations that may include parent training and information centers, entities carrying out activities of the Assistive Technology Act, relevant State agencies, and other community groups concerned with the welfare of individuals with developmental disabilities and their families.
- Membership of the CAC must represent the racial and ethnic diversity of the state.
- The CAC must do the following things:
  - Consult with the Director of the Center regarding the development of the 5-year plan;
  - Participate in an annual review of, and comment on, the progress of the university Center in meeting the projected goals contained in the plan;
  - Make recommendations to the university Center Director regarding any proposed revisions of the plan that might be necessary; and
  - Meet as often as necessary to carry out the role of the committee, but at a minimum twice during each grant year.

### Focus Group and Survey Questions

1. Each UCEDD Consumer Advisory Committee is different. Please share a little about how

your Consumer Advisory Committee works.

2. What is the best thing about your Consumer Advisory Committee?
3. What would you like to change about your Consumer Advisory Committee?
4. What supports are needed for meaningful participation of individuals with disabilities and family members on CACs?
5. What do you think contributes to the difference between effective and ineffective or “token” advisory committees?
6. How do you think CACs should be evaluated?
7. Please review the Administration on Developmental Disabilities’ (ADD) *UCEDD Program Operations and Practices Checklist*. This checklist highlights things ADD has identified as important to CACs. What suggestions do you have to improve this checklist?
8. The Developmental Disabilities Act requires that CACs consist of a majority of members with developmental disabilities or family members. Do you feel it is a conflict of interest for these members to also represent organizations, such as a self-advocacy organization or DD Council? (Please explain why or why not.)
9. The Developmental Disabilities Act will be reauthorized by Congress in the near future. What changes concerning UCEDD CACs would you like to see?
10. What technical assistance do you think would be helpful to UCEDDs concerning CACs?

#### UCEDD Program Operations and Practices Checklist Excerpt

(ADD Monitoring and Technical Assistance Review System)

Consumer involvement and input is a critical component of any UCEDD program. The UCEDD must involve consumers, in the form of a committee, who represent individuals with developmental disabilities in the state, including those who come from culturally and linguistically diverse backgrounds.

- The Consumer Advisory Committee has by-laws.
- The UCEDD supports member participation on the Consumer Advisory Committee.
- The members represent people from different regions in the state.
- The Consumer Advisory Committee is chaired by a consumer or family representative.
- The Consumer Advisory Committee knows their roles and responsibilities as outlined in The DD Act.
- Members are knowledgeable of The DD Act.
- The Consumer Advisory Committee meets often enough.
- Members of the Consumer Advisory Committee are knowledgeable of the goals in the 5-year application for core funding.

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*The field of disability studies has advanced a cultural view of disability. Within this perspective, disability is a valued identity among many other identities and roles that individuals may have.*

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### About the authors:

*The lead author of this report, Joe Caldwell, conducted this project while serving as the 2005 AUCD Policy Fellow. Since 2000, AUCD has provided a unique fellowship opportunity that offers a significant experience in national level activities related to policy and program development, systems change, advocacy, capacity building, and technical assistance.*

*Sharon Hauss and Gordon Richins contributed to this project and report during their terms as co-chairs of AUCD's COCA. Bethany Stark also contributed to this project and report as a member of AUCD's COCA. COCA, which is made up of individuals with disabilities and family members from each university Center across the AUCD network, assists AUCD to advance policy and practice for and with people with disabilities, their families, and communities.*

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## About AUCD

AUCD is a national, 501(c)3 non-profit organization representing a number of national networks of interdisciplinary, university-based Centers dedicated to research, education, training, policy development, and direct service for people with disabilities. AUCD has at least one member Center in every US state and territory. Established in 1971 to represent and support the collective interests of these national networks, AUCD's mission is to advance policy and practice for and with people living with developmental and other disabilities, their families, and communities by supporting our members as they engage in research, policy development, education, and service that further independence, productivity, and a satisfying quality of life. The AUCD networks of Centers promote the principles of self-determination, family-centered care, and cultural competence in disability supports across the life span.

AUCD's largest member network is the University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs), authorized under Public Law 106-402, and whose core funding is administered by ADD. This network of 64 UCEDDs is committed to accomplishing a shared vision in which all individuals with disabilities participate fully in the social, economic, and educational life of their communities.

AUCD's second largest member network is the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs, funded by the Maternal and Child Health Bureau (MCHB) within the Health Resources and Services Administration (HRSA) to ensure that health professionals have the necessary knowledge and skills to address the unique needs of children and adolescents with special health care needs and their families. Currently, 35 LENDs operate in 29 states.

AUCD's third largest member network is the 19 Developmental Disabilities Research Centers (DDRCs). These Centers, established by Congress in 1963 as "centers of excellence" for research in mental retardation and developmental disabilities, represent the nation's first and foremost sustained effort to prevent and treat disabilities through biomedical and behavioral research. 🌟

## Acknowledgements

This report is the result of a number of individuals and organizations working together who have a sincere interest in significantly increasing the full and meaningful participation of persons with disabilities in the guidance and planning of the UCEDDs and for that matter full participation on all boards and advisory councils that work at local, state, and national levels. This effort would not have been possible without the financial and programmatic support of ADD. Patricia Morrissey, Commissioner for ADD, and Jennifer Johnson, Project Officer at ADD, provided timely and invaluable guidance and suggestions that helped to shape the overall effort and to sharpen the focus and procedures that were used throughout.

Thanks are also due to members of AUCD's COCA and members of UCEDD CACs who participated in the project, along with UCEDD Directors and staff who shared their experiences, thoughts, and suggestions on how to address the needs of persons with disabilities and the critical elements needed to make their participation an integral part of the strategic operations of a Center. Furthermore, the following UCEDDs deserve particular acknowledgement for the support of coauthors of the report and collaboration with case studies: Tarjan Center for Developmental Disabilities (University of California, Los Angeles), Center for Persons with Disabilities (Utah State University), Indiana Institute on Disability and Community (Indiana University), Interdisciplinary Human Development Institute (University of Kentucky), Wyoming Institute for Disabilities (University of Wyoming) and the Institute on Disability and Human Development (University of Illinois at Chicago).

Lastly, the ongoing efforts of Maggie Nygren to coordinate this effort within the AUCD Technical Assistance Contract from ADD helped to make this project a network wide effort. Additionally, her edits and work with production staff helped to ensure the quality of the final product. We all hope that this publication will be of value and assistance to all those who strive for the full participation of persons with disabilities in the advisement and guidance of our society's social organizations. We all hope that this publication will be of value and assistance to all those who strive for the full participation of persons with disabilities in the advisement and guidance of our society's social organizations. 🌟

~George Jesien, Executive Director