



UCEDD Resource Center
A project of AUCD, in partnership with ADO, to strengthen and support the network of UCEDDs

Enhancing the Effectiveness of Consumer Advisory Committees (CACs)



June 26, 2013

- **Introductions**
- **Presentation**
- **Question & Answer**



- Submit questions throughout the webinar via the ‘Chat’ box. The moderator will read the questions after the presentation.
- Ask a question aloud by pressing the * then # key to request the floor. Questions will be answered in the order they are received.

- **Survey**



- Please provide your feedback by completing our short survey at the end of the webinar



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Panel of Presenters

- **Shannon Caldwell**
 - COCA, Lexington, KY
- **Tanisha Clarke**
 - AUCD, Silver Spring, MD
- **Harold Kleinert**
 - Human Development Institute UCEDD, Lexington, KY
- **John Maltby**
 - Westchester Institute for Human Development UCEDD, Valhalla, NY
- **Dawn Olson**
 - COCA, Minot, ND
- **Amy Sharp**
 - Center on Disability and Development UCEDD, College Station, TX
- **Ann Marie White**
 - Institute on Disabilities UCEDD, Philadelphia, PA

AUCD

Association of University Centers on Disabilities



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Recruitment & Membership

Ann Marie White - Philadelphia, PA



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- According to the Developmental Disabilities Act:
 - Majority of CAC members should be individuals with developmental disabilities and family members of such individuals.
 - Membership should reflect the racial and ethnic diversity of the State.





- Members must also include representatives from:
 - State Protection and Advocacy system
 - State Council on Developmental Disabilities
 - Self-advocacy organization
 - Other UCEDDs in state (if applicable)
 - Other organizations such as
 - Parent Training and Information Centers
 - Those carrying out activities of the State Assistive Technology Act
 - Relevant State agencies, and other community groups



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Recruitment

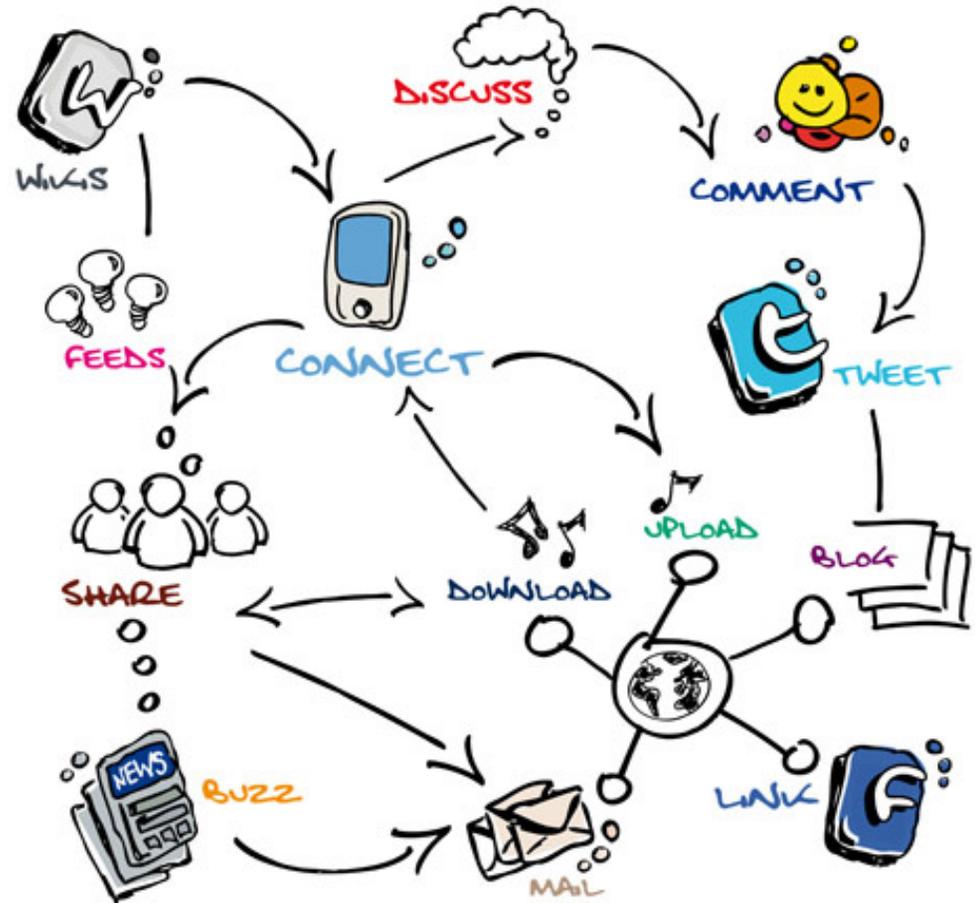
- Recruitment
 - Appointments
 - Nominations
 - Self-Nominating Applications

Marketing



Communication

Harold Kleinert &
Shannon Caldwell -
Lexington, KY





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Clear, Ongoing Communication

- Mechanisms for Insuring that CAC Members are Fully Informed of UCEDD and Network Activities:
 - Active CAC List-serve to insure that members receive ongoing communications, *AUCD Legislative Briefs*, *AUCD Resources*, and have the opportunity to communicate with each other
 - Quick member polls to determine important topics for future meetings and topics for Annual Joint Meeting with our DD Partners (Protection & Advocacy, Council on Developmental Disabilities)



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Clear, Ongoing Communication

- Periodically surveying (through phone interviews) all of our CAC members to make sure that everyone is included and that their voice is heard:
 - Asking members if the CAC is meeting their needs as family representatives and/or as self-advocates
 - Asking how they can be better supported at and between the meetings
 - Asking what additional things that the CAC meetings need to cover as a way of encouraging active and sustained participation from everyone
 - This is also a strategy that does not single anyone out!

Clear, Ongoing Communication

- Using a variety of formats to identify important priorities for our work:
 - Small group formats focused on specific goals in our Five Year Plan
 - Individual phone interviews so that individual members have time to reflect on those priorities and to make any follow-up comments.





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Roles & Responsibilities

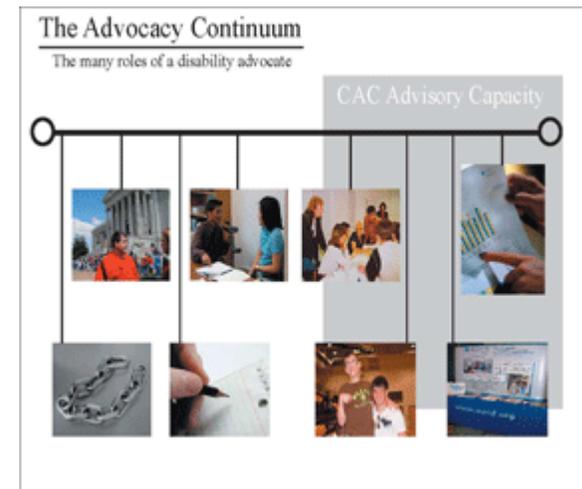
John Maltby - Valhalla, NY



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- High Expectations
 - Use the AUCD material to educate new members as to their role and responsibilities.
 - Make sure the CAC knows the UCEDD role is the core.
 - Chair should be non UCEDD member
 - Secretary should be UCEDD staff member





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Clear Roles & Responsibilities

- **High Expectations**

- Term limits. Typically 3 years, in a cycle such that a third of the board is either renewed or retires annually.
- Limit attendance through phone calls or video links. In –person makes a difference.
- If a member misses three consecutive meetings then they should retire.

**STRIKE THREE!
YOU'RE OUT!
NO SERIOUSLY...
GET OUT OF HERE**

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Committees that Work

- Encourage CAC members to support CAC activities year round
- Invite CAC members to UCEDD events, tours, presentations etc.
- Involve the Self Advocate members of the CAC intimately in the UCEDD concerns, locally and nationally.



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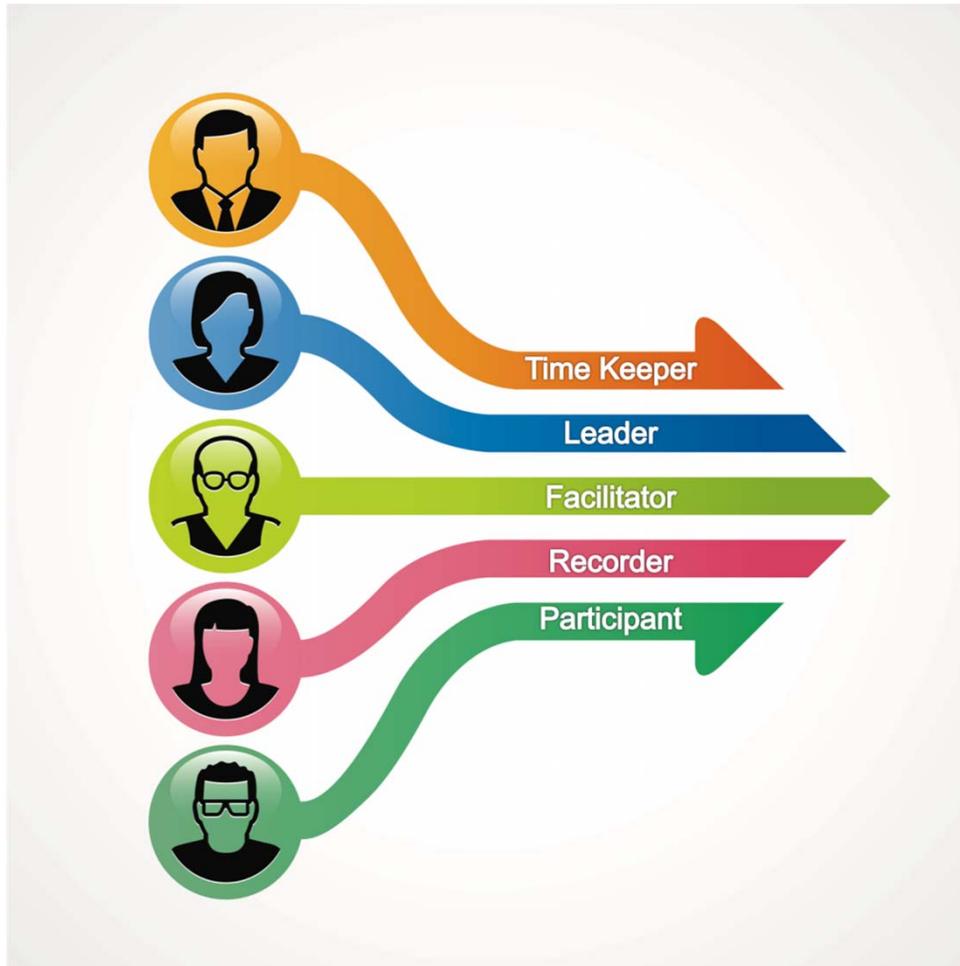
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- Create small, diverse, standing committees, for example
 - Membership and recruitment
 - Organization of the five year plan
- Committees to fit your own UCEDD, e.g.
 - Fund Raising
 - Scholarships
- Choose the sub committee chairs with care
 - Ensure there is always a vice chair who is expected to succeed the chair.
 - Annual rotation, including Self Advocates.
 - Ask CAC members committee preferences but ensure balance.





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Meeting Organization

Amy Sharp -
College Station, TX

What are the goals of the meeting?

- Ensure meeting goals are meaningful and the CAC is not meeting for the sake of meeting.



- What tools and/or information do people need to achieve meeting goals?
 - Do Action Items require support/background materials?
 - Send these in advance of the meeting.
 - Would participants benefit from a pre-meeting call to discuss the agenda items?
 - Will speakers utilize A/V tools that need additional accommodation preparation/attention?





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Meeting Facilitation

- Typically the CAC Chair will facilitate the meeting. Ensure that this person has the skills to facilitate conversations, ensure participation of the full CAC, perhaps appoint a ‘Keeper of Respect’. See [AUCD CAC Orientation Curriculum](#), Module V.
- Be mindful of the time allotment for meetings by attending to a provided agenda/ schedule.
- For discussions it is often good to appoint a ‘Devil’s Advocate’ to ask the hard questions.



Timekeeper



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Meeting Facilitation

- Ensure that self advocates are involved and active members.
 - This may require additional supports and time but the pay off is invaluable.
- Often committees are a good way to provide meaningful participation for all members.
 - Although, these committees must have real goals/ purposes.
- Keep it Interesting!
 - Ensure everyone gets time for input, but keep it lively.



- Avoid dominance by staff or the chair
- Avoid the “Expert” voice
- Be conscious of any “power” relationships (e.g. employer or provider relationships)
- Limit the “ramblers”, or the repetition of the same issue.
- Create an environment of respect, no interrupting, cordial disagreement.
- If you have to reference Robert’s Rules too often you probably need to rethink the whole committee.
- Provide a cheat sheet of acronyms used by your state and Center.



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Agenda

- Clearly state the agenda with times attached to each item
 - This allows the CAC to see when they are getting delayed.
- Identify Action Items on the agenda.
- Establish some regularity to the format of your meetings for committee reports, etc.
- Share who will be speaking on specific topics and how long.
- Include “feature” items introducing staff and projects from the UCEDD. Opportunities to learn more about the Center activities.
- Circulate the agenda ahead of time
 - Allow members to contribute an item from time to time

- Establish meetings dates/times annually so all can get them on everyone's calendars.
 - Hold the meeting as much as possible at a set time to inconvenience the least amount of people.
- Start on time!



- Clearly state location and time of the meeting or call in information.
 - If the meeting is a conference call, offer a test call to ensure that all participants are able to connect efficiently.
- Ensure accessibility of meeting location.
- Ensure there is enough space for the CAC needs.
- Provide light refreshments





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Accommodations & Meeting Support

Dawn Olson - Minot, ND



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Accommodations & Meeting Support

- Member Support Committee relay any accommodations requested to UCEDD.
- UCEDD staff ensure all meeting materials are in the requested format
- Members are invited to participate in an additional phone conference to discuss any questions in regards to the agenda.
- Use technology such as Interactive Video Network (IVN) for non face-to-face meetings

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Accommodations & Meeting Support

- Financial Support
 - Members receive a stipend for meetings they attend
 - For Face-to-face meetings...
 - Travel expenses reimbursed
 - Travel expenses for PCA also provided





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Resources & Opportunities

Dawn Olson - Minot, ND & Tanisha Clarke - AUCD





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Council on Community Advocacy (COCA)

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- Under the DD Act the CAC must be made up of people with disabilities and family members and members of state organizations such as Protection & Advocacy, and members of the State DD Council.
 - The makeup of COCA is much the same.
 - COCA is at the Federal Level.
 - COCA is charged with providing technical support to the CAC's
 - The CAC's have the opportunity to participate with COCA and bring the concerns from their state to COCA.

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Resources

[Council on Community Advocacy \(COCA\)](#)

- AUCD along with the co-chairs and the committee members at large, have been requesting that UCEDD Directors consider identifying a self-advocate or a family member from either their CAC or UCEDD staff to represent their UCEDD and state's interests on COCA.
- If a representative from your UCEDD is not yet on the COCA listserve, this is where you or they can subscribe.





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Resources

[UCEDD Resource Center](#)

URC

- Linked on left navigation panel of the AUCD home page.
- The URC provides UCEDDs with up to date information that will support the implementation of the AIDD core grant.
- Explore the navigational tabs on the left side of the page for topics that address issues you face at different times throughout the year at your Center.

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Resources

[UCEDD Resource Center: Inclusive Practices](#)

- On this page you will find resources related to the consumer advisory committee (CAC), UCEDD needs assessment and other information gathering, and information for people with disabilities to use when becoming involved in research and training.



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Resources

UCEDD Resource Center: Inclusive Practices

- Reports:
 - **Including People with the Most Significant Disabilities** - The full title of this report is "Strategies to Incorporate the Voice of People with Significant Disabilities in UCEDD Information-Gathering and Operations". This report gathered information from experts across the network on how UCEDDs can better hear the viewpoints and address the needs of people with the most significant disabilities who may have been traditionally challenging to involve in UCEDD activities requiring community engagement.
 - **CACs: Recommendations for Meaningful Participation of Individuals with Disabilities and Families** - AUCD and COCA collaborated on a participatory action research project exploring meaningful participation and effectiveness of CACs at UCEDDs. This report includes examples of supports that enhance the meaningful participation and effectiveness of CACs, provides case studies of innovative or best practices in CACs, and gives recommendations concerning the assessment of CACs.



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UCEDD Resource Center: Inclusive Practices

- Archived Webinar:
 - [Involvement of People With Disabilities in the Operations of the UCEDD](#) - The webinar addressed the involvement of people with disabilities in the operations of the UCEDD through their own experiences and stories. Topics of the presentation included: the perspectives of people with disabilities on their work in the UCEDD, some examples of successful family involvement, and experiences working with the CAC and COCA.

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UCEDD Resource Center: Inclusive Practices

- CAC Orientation Curriculum

- The purpose of this curriculum is to provide UCEDDs with resources that will assist in the orientation of CAC members. Whether they are potential, new, or existing CAC members, this serves as a way to introduce them to their role in advising the UCEDD. The curriculum consists of 5 modules, each containing slides and an instructor's manual, along with a number of useful appendices. Most importantly, the curriculum was deliberately designed to be customizable by each UCEDD.



- **Ready to Ask a Question?**

- You can ask a question aloud by pressing the * then # key on your phone to request the floor. Questions will be answered in the order they are received.
- Type your questions into the ‘Chat’ box below the slides and the moderator will read the question.



Contacts

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- **Ann Marie White**
 - Institute on Disabilities UCEDD, Philadelphia, PA (amwhite@temple.edu)



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THANK YOU

Additional questions about the Webinar?

Tanisha Clarke

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Please take a few minutes to complete our survey!