

# UCEDD Tip Sheets

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ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES  
THE LEADERSHIP, EDUCATION, ADVOCACY & RESEARCH NETWORK



A project of AUCD, in partnership with ACL, to strengthen the network of UCEDDs

## Admin Essentials Meaningfully Engaging Your Consumer Advisory Committee (CAC)

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### What is Addressed in this Tip Sheet?

This tip sheet discusses creative strategies and promising practices for meaningfully engaging a consumer advisory committee (CAC). It summarizes a roundtable conversation on the topic held on September 9th, 2020 and archived [here](#).

The Admin Essentials series brings together UCEDD directors and business managers with content experts, often retired UCEDD directors, to address pressing administrative challenges. These virtual roundtables provide an opportunity to share resources, troubleshoot challenges, and brainstorm creative solutions to a broad range of administrative topics.

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### Why is this Important?

The Developmental Disabilities Act (P.L. 106-401), hereby referred to as the DD Act, requires centers to establish a consumer advisory committee (Section 154 (a)3(E)).

### The advisory committee should be made of:

- i. individuals with developmental and related disabilities
- ii. family members of individuals with developmental disabilities
- iii. a representative of the State protection and advocacy system
- iv. a representative of the State Council on Developmental Disabilities
- v. a representative of a self-advocacy organization
- vi. representatives of organizations that may include parent training and information centers, entities carrying out the Assistive Technology Act, and other community groups concerned with the welfare of individuals with developmental disabilities and their families

The DD Act specifies that the CAC must be a majority people with developmental disabilities and family members of such individuals and that the committee must reflect the racial and ethnic diversity of the state.

### The roles of the CAC as defined by the DD Act are to:

- consult with the Director of the Center regarding the development of the 5-year plan
- participate in the annual review of and comment on the progress of the Center in meeting the projected goals contained in the plan
- make recommendations to the Director of the Center regarding any proposed revisions of the plan that might be necessary
- meet as often as necessary to carry out the role of the committee, but at a minimum twice during each grant year

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## What are some Promising Strategies?

UCEDDs must center the voices of those most impacted in order to truly understand the needs of the local disability community and the impact of the center's work. The CAC is designed to make sure that people with disabilities and their family members are a part of the work that impacts them.

In order to function well, CACs need to include a diverse representation of the broader community, especially reflecting racial and ethnic diversity. Directors might also consider how they are representing the entirety of their region, including rural areas, and how they are having a mixture of new and old voices on the CAC. UCEDDs may consider setting term limits as a part of their CAC's bylaws and setting aside funds to promote accessibility, in order to facilitate further diversifying their CAC.

Some UCEDDs have noticed that in their CAC meetings, the staff actively participate, but people with disabilities and families might not. In order to further diversify their CAC.

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## **Some promising strategies to spark engagement:**

- Having CAC members interact with other parts of the center. For example, have CAC members work on a project team in order to learn more about what the UCEDD does and provide direct, topical input.
- Consider having CAC meetings centered on a timely topical issue.
  - For example, last year the Nebraska UCEDD had a CAC meeting focused on emergency preparedness. They invited guest speakers and created opportunities for groups to get together and talk about the current landscape in the state.
- Have a person with an intellectual disability facilitate CAC meetings.
  - You may have a person dedicated to supporting that person by taking the minutes or handling administrative tasks, but leadership by people with intellectual disabilities is vital to effective CAC engagement.
- Have CAC members plan events.
  - For example, in Rhode Island, CAC members planned an event focused on transportation access. They also created a community grant to promote accessibility of arts and leisure activities and CAC members served to review the applications.
- Ask CAC members to listen to stakeholders between meetings and then bring the things they notice to the next meeting.
- Offer a stipend and reimburse expenses for CAC members.
- Center accessibility in CAC meetings.
  - For example, always provide materials in advance and in easy-to-read formats.
- Involve CAC members in policymaking
  - For example, Nebraska's UCEDD's community advisory board wrote a letter to a national consulting team that was examining long term supports and services under managed care. They shared their key points with the consultants and state leadership and their comments were included into a final report.
- Bring in outside guests.
  - For example, you may consider having someone from COLA provide advice or guidance to your CAC or have a CAC member actively attend COLA meetings and then report out about COLA during your CAC meetings.
- Identify meeting dates a year in advance to ensure they are on the calendar.
- Attend other groups meetings (eg. The Arc, self-advocacy organizations, parent trainings) to see who is participating in similar groups and initiatives. Participate as a representative of your UCEDD and consider recruiting from these new connections.
- Invite participation outside of CAC meetings by reaching out via email or phone call to members who may not participate as actively during meetings

## **Promoting Virtual Engagement:**

Within the environment of COVID-19, engaging your CAC may be even more challenging. COVID-19 may have added to the isolation already felt by some members of your CAC and finding ways to engage over a virtual platform while prioritizing accessibility can be challenging.

You may try making use of social media, breakout rooms in zoom, making use of outside speakers, or hosting social hours virtually to encourage further engagement.

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## Recommendations

CACs are critical to the functioning of UCEDDs and the inclusion of people with disabilities and their family members in the work that impacts them. The promising strategies outlined above are just some of the ways that network members are working to further engage their CAC.

There is not a one-size-fits-all solution to meaningfully engaging a CAC and each state or territory will have its own needs and landscape that impact how the CAC functions. Directors need to consider their specific context, as well as the requirements defined in the DD Act, when working to improve the engagement of their CAC.

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## What are the Relevant Resources?

- [Webinar: Meaningfully Engaging Your CAC Admin Essentials](#)
- [Webinar: Enhancing the Effectiveness of Consumer Advisory Committees \(CACs\)](#)
- [CAC's Recommendations for Meaningful Participation of Individuals with Disabilities and Families](#)
- [Webinar: Involvement of People with Disabilities in the Operations of the UCEDD](#)
- [Checklist for the CAC to Assist with Program Compliance](#)
- [CAC Orientation Curriculum](#)
- [MVMPMB Curriculum](#)

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## For More Information

Sarah DeMaio, MSW  
Association of University Centers on Disabilities (AUCD)  
1100 Wayne Ave., Suite 1000, Silver Spring, MD 20910  
301-588-8252; [sdemaio@aucd.org](mailto:sdemaio@aucd.org)

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