RESOURCES FOR DETERMINING COMPLIANCE WITH CONSUMER ADVISORY COMMITTEE REQUIREMENTS

The DD Act requires that the Consumer Advisory Committee be comprised of a majority of members who are individuals with developmental disabilities and family members of individuals with developmental disabilities. Members in the minority are individuals representing different organizations, including the DD Council, State P&A, and a State self-advocacy group. When indicating compliance with this component of the DD Act, the UCEDD needs to document a distinction between individuals with developmental disabilities and family members serving on the Consumer Advisory Committee from the organizational representatives serving on the Committee. Individuals with developmental disabilities and family members cannot represent both an organization and individuals with developmental disabilities and family members. This is not to say that the UCEDD cannot have CAC members who work for disability-related organizations. Instead, it needs to be clear whether A clear delineation in roles must be made between the majority and minority. Thus, when a UCEDD asks individuals with developmental disabilities and/or family members to serve on the Consumer Advisory Committee, they should communicate that they are there to represent primary and secondary consumers. In cases where such individuals work for self-advocacy and/or parent organizations, the UCEDD should clearly indicate to them that they are representing themselves as a consumer and they are not there to represent the organization. The chart below can be used to determine compliance with the DD Act. It is followed by a sample of a completed chart.

<table>
<thead>
<tr>
<th>Name</th>
<th>PRIMARY STAKEHOLDERS</th>
<th>ORGANIZATION REPRESENTATIVES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A majority of the members shall be individuals with developmental disabilities and family members of such individuals.</td>
<td>One representative is required for each of the groups below.</td>
</tr>
<tr>
<td></td>
<td>Individuals with developmental disabilities and related disabilities</td>
<td>DD Council</td>
</tr>
<tr>
<td></td>
<td>Family members of individuals with developmental disabilities</td>
<td>State P&amp;A organization</td>
</tr>
<tr>
<td></td>
<td></td>
<td>State self-advocacy organization led by individuals with developmental disabilities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other stakeholder organizations</td>
</tr>
</tbody>
</table>

Sample

<table>
<thead>
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<td>Family members of individuals with developmental disabilities</td>
</tr>
<tr>
<td>---</td>
<td>------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------</td>
</tr>
<tr>
<td>1</td>
<td>Jane Apple</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>John Ball</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Polly Casserole</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Peter Dairy</td>
<td>X</td>
</tr>
<tr>
<td>5</td>
<td>Susan Egg</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Sam Fig</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Tom Grape</td>
<td>X</td>
</tr>
<tr>
<td>8</td>
<td>Theresa Guava</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Jack Pancake</td>
<td>X</td>
</tr>
<tr>
<td>10</td>
<td>Susan Pickle</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Sarah Orange</td>
<td>X</td>
</tr>
<tr>
<td>12</td>
<td>Jim Cookie</td>
<td></td>
</tr>
</tbody>
</table>
The DD Act requires that the Consumer Advisory Committee reflects the racial and ethnic diversity of the State. The MTARS team will use U.S. Census data to determine whether the Consumer Advisory Committee reflects the racial and ethnic diversity of the State. The UCEDD might want to follow the same procedures in preparation for the MTARS review. Below is an example of how the MTARS review team will use the State Census data to determine compliance with this part of the DD Act:

<table>
<thead>
<tr>
<th>U.S. Census Data for State</th>
<th>Demographic Data for UCEDD Consumer Advisory Committee</th>
</tr>
</thead>
<tbody>
<tr>
<td>85% White</td>
<td>83% White</td>
</tr>
<tr>
<td>10% Black</td>
<td>10% Black</td>
</tr>
<tr>
<td>2% Asian</td>
<td>1% Asian</td>
</tr>
<tr>
<td>2% American Indian and Alaska Native</td>
<td>3% American Indian and Alaska Native</td>
</tr>
<tr>
<td>1% Native Hawaiian and Other Pacific Islander</td>
<td>3% Native Hawaiian and Other Pacific Islander</td>
</tr>
<tr>
<td>15% Latino</td>
<td>10% percent Latino</td>
</tr>
</tbody>
</table>
Program Operations and Practices Checklist
Administration on Developmental Disabilities

Consumer Advisory Committee
**Directions:** This part of the Program Operations and Practices Checklists can be completed with members of the University Center for Excellence in Developmental Disabilities (UCEDD) Consumer Advisory Committee (CAC). The **CAC Program Operations and Practices checklist is organized into the following 5 sections:**

1. **Member Supports**
2. **Financial Supports**
3. **Communication and Coordination**
4. **Leadership Development and Orientation**
5. **Values and Outcomes**

Each section has a series of questions. The UCEDD is not required to do all the things listed. The UCEDD may do some things that are not listed. The UCEDD may have suggestions of things that are not listed in the checklist.
1. Member Supports

The questions about member supports are separated into 4 areas:

A. Accessibility and accommodations for meetings
B. Cultural and linguistic diversity
C. Childcare, respite, and personal assistance services
D. Transportation

EXAMPLES OF MEMBER SUPPORTS:

- interpreters, alternative formats
- pre-teaching at meetings
- slower pace at meetings
- plain language, translated materials
- providing rides
Section 1: Member Supports

A. Accessibility and Accommodations

1. How does the UCEDD make sure that all CAC members can participate in meetings?

2. How does the UCEDD assess the needs of individual CAC members to ensure that meetings are accessible to all?

3. How does the UCEDD make accommodations to assist with communication needs?
4. Does the UCEDD provide sign language interpreters, closed captioning services, amplified hearing devices, or other assistive communication devices?

5. How does the UCEDD make sure that meeting materials are provided in format that everyone can understand?

   For example, are materials made available in Braille, large print, or in disk formats?

6. How does the UCEDD make sure that individuals with cognitive disabilities are able to participate in the meeting?

   For example, does the UCEDD provide materials in advance to allow members to understand information?
Does the UCEDD use support persons to help with preparation and understanding before and during meetings?

Does the UCEDD hold separate meetings before and/or after the larger CAC meeting for individuals to develop and focus ideas?

7. Does the UCEDD develop agendas and other meeting materials using plain, simple, jargon-free language that is easily understood?

8. Does the UCEDD use pictures or clip art to assist with understanding materials?
9. Does the UCEDD maintain a pace that accommodates individual styles? Is there enough time to ask questions?

10. Does the UCEDD make CAC members feel comfortable sharing their views?

11. Does the UCEDD use an outside facilitator to monitor and promote more inclusive meetings?

12. Are meetings scheduled at a time when everyone can be there?

   For example, does the UCEDD make sure that the meeting is scheduled at a time when everyone can be there?
13. Please describe any other strategies the UCEDD uses to accommodate CAC members.
Section 1: Member Supports

B. Cultural and Linguistic Diversity

*Note:* Cultural and linguistic diversity refers to differences such as those in language, race, ethnicity, and disability.

1. What strategies does the UCEDD use to ensure that the CAC reflects the cultural and linguistic diversity of the State?

   For example, does the UCEDD have relationships within a variety of diverse communities?
2. Does the UCEDD have a plan for recruiting members from diverse backgrounds? If yes, please describe.

For example, does the UCEDD have relationships with community-based organizations that are prominent in culturally and linguistically diverse populations to find new CAC members?

3. Does the UCEDD provide training for UCEDD staff and members of the CAC so they better interact with people from diverse backgrounds?

4. Does the UCEDD provide translated materials and interpreters, as needed, for members who speak a language other than English?
5. Please describe any other strategies the UCEDD uses with diversity.
Section 1: Member Supports

C. Child Care, Respite, and Personal Assistance Services

1. Does the UCEDD make arrangements to provide childcare or respite on-site?

2. Does the UCEDD provide financial supports (e.g., reimbursements or stipends) to cover the cost of child or respite care?

3. Does the UCEDD cover the costs of personal assistance services, including their travel and other expenses?
4. Please describe any other strategies the UCEDD uses.
Section 1: Member Supports

D. Transportation

1. How does the UCEDD find out if CAC members need help with transportation?

2. If needed, does the UCEDD provide rides to CAC members to ensure they attend meetings?

3. Does the UCEDD contract with cab companies to pick up individuals from home, bus stations, or airports?

4. Does the UCEDD use other ways to meet (e.g., conference calls, regional meetings)?
5. Please describe any other transportation strategies the UCEDD uses.
Section 2. Financial Supports

The questions about financial supports are separated into 2 areas:

A. Travel and other expenses

B. Monetary compensation

EXAMPLES OF FINANCIAL SUPPORTS:

- Hotel expenses
- Meal expenses
- Taxis, shuttles or other car travel
- Cost of missing time off of work to attend committee meeting
- Stipend or honorarium
Section 2. Financial Supports

A. Travel and Other Expenses

1. Does the UCEDD have written policies with regard to the kinds of travel and other expenses will be paid for?

2. What kinds of travel and other expenses are paid for CAC members?

   For example, does the UCEDD pay for hotel rooms, transportation, or food expenses?

3. Please describe any other travel and other expenses that are covered by the UCEDD.
Section 2. Financial Supports

B. Monetary Compensation

*Note:* Monetary compensation may be a stipend or honorarium.

1. Does the UCEDD offer CAC members any kind of monetary compensation for the time they take to attend meeting?

2. Please describe other monetary compensation strategies the UCEDD uses to support CAC member participation in meetings and activities?
Section 3. Communication and Coordination

The questions about communication and coordination are separated into 3 areas:

A. Staffing of the CAC

B. On-going communication

C. Informing CACs about UCEDD activities

EXAMPLES OF COMMUNICATION AND COORDINATION ARE:

- staff coordinator position
- listserv
- more than 2 meetings a year
- using conference calls or video conferencing
- coordinating forums on specific topics
- matching CAC members with specific projects within the UCEDD where they can play a more of a participatory role
Section 3. Communication and Coordination

A. Staffing of the CAC

1. Does the UCEDD have a staff person who plans the activities of the CAC?

2. If the UCEDD has a staff person, how is this staff person funded?

   For example, are core funds used to pay for the staff position?

3. Describe other staffing strategies the UCEDD uses to support the coordination and communication of the CAC.
Section 3. Communication and Coordination

B. Ongoing Communication

1. How does the UCEDD tell members about upcoming meetings with the CAC?

   For example, does the UCEDD send out information about the time and location of the meeting?

   Does the UCEDD provide members with an agenda and other materials before the meeting?

2. How does the UCEDD communicate with the CAC in between meetings?
For example, does the UCEDD schedule conference calls to communicate in between meetings?

Does the UCEDD use video conferencing to communicate between meetings?

Does the UCEDD have a listserv for the Committee?

Does the UCEDD have a website for the Committee? Does the website have a message board?

3. How does the UCEDD find out about the preferred communication strategies of CAC members?

4. Does the UCEDD have more than two meetings per year?
5. Does the UCEDD have task forces within the Committee to work on issues between meetings?

6. Does the UCEDD take advantage of other statewide meetings, where CAC members may be gathered, to meet with the CAC?

7. How does the UCEDD make sure that all members have access to the technology that used for communicating with the CAC?

8. Describe other strategies the UCEDD uses to communicate with the CAC.
Section 3. Communication and Coordination

C. Informing CACs about UCEDD Activities

1. How does the UCEDD inform CAC members about UCEDD activities related to the goals in the five-year plan?

   For example, does the UCEDD schedule regular staff presentations about projects at committee meetings?

   Does the UCEDD organize interactive poster sessions to allow CAC members and staff to interact around projects?

   Does the UCEDD have meetings on specific topics?
2. Is staff trained on universal design principles and how to make presentations accessible?

3. Does the UCEDD schedule retreats where staff and CAC members can get to know each other, share information, and develop ideas for the future?

4. Does the UCEDD match CAC members with specific projects within the UCEDD where they can play a more of a participatory role?

5. Describe other strategies the UCEDD uses to inform CACs about UCEDD Activities.
Section 4. Leadership Development and Orientation

Leadership Development and Orientation is separated into 2 areas:

A. Leadership development

B. Orientation

EXAMPLES OF LEADERSHIP DEVELOPMENT AND ORIENTATION:

- mentoring
- opportunities to attend other meetings and conferences formal orientation
- informal opportunities to meet with staff
Section 4. Leadership Development and Orientation

A. Leadership Development

1. How does the UCEDD offer leadership development opportunities to CAC members that are emerging leaders?

2. How does the UCEDD identify and recruit emerging leaders as members of the CAC?

   For example, does the UCEDD utilize self-advocacy conferences to share information about the Center and recruit individuals for the CAC?

   Does the UCEDD asking more “seasoned” advocates for their recommendations?
Does the UCEDD actively recruit younger individuals with disabilities, sometimes high school and college students?

3. Does the UCEDD offer and/or support participation in formal trainings to build leadership skills? If yes, please describe.

4. Does the UCEDD mentor new members with limited experience on boards or committees? If yes, please describe.

5. Does the UCEDD offer collaborative leadership development opportunities where UCEDD faculty and staff as well as CAC members gain new perspectives and skills? If yes, please describe.
6. Does the UCEDD support member participation in other national activities and events? If yes, please describe.

7. How does the UCEDD structure meetings to build leadership skills of the CAC members?

8. Describe other strategies the UCEDD uses to build the leadership skills of CAC members.
Section 4. Leadership Development and Orientation

B. Orientation

1. How does the UCEDD plan for the orientation of new and current members of the CAC to the structure, program, projects, and activities of the UCEDD?

   For example, does the UCEDD offer formal orientation sessions for new members, using appropriate and accessible materials?

   Does the UCEDD utilize informal opportunities to provide information to new members about the UCEDD?

2. If the UCEDD offers a formal orientation session, does the orientation:

   a. Outline the roles and responsibilities associated with membership on the CAC?
b. Introduce members to the DD Act and requirements for UCEDD programs?

c. Provide information about DD Council and P&A programs?

3. Does the UCEDD create opportunities for new and current members to interact either formally or informally with members of the P&A Board and DD Council?

4. Does the UCEDD schedule time for members to spend time with UCEDD faculty and staff to learn more about UCEDD projects and activities?

5. Describe other strategies the UCEDD uses to orient CAC members.
Section 5. Value

Value Placed on the CAC is separated into 2 areas:

A. Use of suggestions from CAC members

B. Feedback to the CAC

EXAMPLES OF VALUE:

- showing importance of member feedback
- giving many opportunities for members to see how their input is being used in the work of the Center.
Section 5. Value

1. How does the UCEDD show members that their input is important to the UCEDD?

2. How is the input from the CAC used by the UCEDD?

   For example, are CAC members able to draw a link between their input and the activities of the UCEDD?

   If recommendations have not been used, does the UCEDD offer tell the CAC why the feedback was not used?
3. Does the UCEDD add time to meeting agendas to talk about how input is being used?

4. Describe other strategies utilized to demonstrate the value of CAC members.