

# **Association of University Centers on Disability COCA Work Group**

*Kansas City, Missouri*  
**June 21 – 22, 2004**

## **Introduction**

Ten years ago AUCD (then AAUAP) sought to increase participation of people with developmental disabilities at its annual conference and within its structure. To achieve this the Consumer Council (later renamed the “Council on Consumer Affairs” or COCA) was formed. This effort was a noteworthy success.

However, during the past several years members of the COCA along with others within the AUCD network have struggled with what appears to be a stagnation of the function of COCA. To address the sense that the COCA has lost some of its vitality within AUCD, an ad hoc work group assembled in Kansas City, Missouri June 21 and 22, 2004. This paper reflects the labor of the work group and presents its findings and recommendations to AUCD and its leadership in hopes of advancing the contributions people with disabilities began making to the association more than a decade ago.

Those who participated on this important work group believe that AUCD and its member affiliates benefit from and should guide their work based on the lived experiences of persons with disabilities and family members of people with disabilities. To achieve this the group believes AUCD should increase and improve meaningful involvement of people with disabilities and family members at its annual conference, on its Board of Directors and on councils and committees, and that such involvement should be funded by AUCD and individual UCEDDs. This paper is designed to advise AUCD as it strives to achieve this objective.

## **Core Questions**

The day and a half work group dialog considered the following questions. Some of these questions were answered while others were broached but require further refinement and resolution.

- ❖ Is there still a need for a Council on Consumer Affairs within the AUCD?
- ❖ If so, how should the Council be organized?
- ❖ Will the COCA have an AUCD staff person assigned to it?
- ❖ How will the COCA interface with the AUCD Board of Directors and how will it grapple with issues the larger organization is addressing?
- ❖ How often and where will the COCA meet?
- ❖ Shall the COCA be an internal organization? Or should it interface with other disability advocacy groups?
- ❖ Will the COCA (and/or Consumer Advisory Councils at individual UCEDDs) interact with Developmental Disabilities Councils and Protection and Advocacy agencies?
- ❖ How should the COCA work with the Administration on Developmental Disabilities?

## **Issues**

The Council on Consumer Affairs has evolved. Presence of persons with disabilities within AUCD has been achieved and now there is a drive to turn presence into more meaningful involvement. With this change has come a concomitant need to redefine the specific functions and roles of the COCA. And the reformulated structuring of the COCA should be a reflection of its redefined roles within the AUCD network.

At this time it is believed that some Directors and COCA representatives do not understand the function and role of the COCA. The COCA seems to have become an isolated group within AUCD. Uncertainty exists as to whether the COCA should serve as a nexus between AUCD and the larger “disability community” around the country or a centralized “voice” of people with disabilities whose members ought to disperse through other councils and committees advising AUCD on disability matters, or if perhaps a new function should be crafted.

Moreover, once a revamped COCA purpose and function has been established the need will remain for financial and staff support for the Council as well as means for educating new UCEDD Directors and other key stakeholders about the Council.

A pair of quandaries exists regarding membership to the COCA. First, when people with disabilities and family members participate on COCA, a kind of self-segregation occurs; yet when they disperse throughout other councils and committees, disintegration of a united constituent voice occurs. Second, some skepticism exists as to whether UCEDD employees who have a disability or family members of People with disabilities can accurately articulate or represent the lived experiences of the constituency, but UCEDDs are understandably hesitant to fund the recruitment of non-employees to travel to AUCD annual meetings and serve on the COCA. It is therefore difficult to secure an independent, community-based perspective without running the risk of appearing that input from People with disabilities and family members is “tainted” by close affiliation to individual UCEDDs. Moreover, determining whether a potential representative to COCA who is not employed by a UCEDD possesses the necessary expertise to speak to the needs of people with disabilities in general is more difficult to achieve than with employees. In addition, travel expenses for people who require attendant care are sometimes higher than for conference attendees without disabilities.

In recent years growing debate has begun concerning the merits of consumer involvement versus consumer control over disability-related matters. This debate is, of course, pertinent to AUCD and COCA.

Finally, there is a need for greater input from People with disabilities and family members who have a grasp of national concerns within AUCD and on its Board. Mandates of the DD Act are not always congruent with the needs of people with disabilities. And there are many factions within the so-called “disability community” whose perspectives need to be considered, hence the need for national perspectives.

It is for these reasons that COCA needs to be reformed, supported by AUCD and secure greater, consistent representation.

### **Issues in 2010**

In anticipation of important concerns that are likely to either remain salient or become more critical, the work group embarked on a discussion of predicted important matters AUCD, the COCA and other stakeholders will be addressing in the year 2010.

Choice, control, and flexibility regarding services to and legislation regarding people with disabilities by People with disabilities are sure to remain at the forefront of the field. In addition, decisions about the appropriate language to use are likely to attract considerable attention.

Universal design will demand increasing attention. Particularly as the “Baby Boomers” become senior citizens access issues will remain crucial. Also, far more knowledge will emerge concerning the myriad similarities there are between the needs of persons with disabilities and

the general public. Such similarities should be fodder for greater inclusion of people with disabilities throughout American and other cultures.

Finally, some speculation was introduced as to whether the future will bring about regional councils, more meetings, and greater transportation for persons residing in rural communities.

### **Role of COCA**

The discussion of the work group evolved into some decisions as to what the role of the COCA ought to be. Members agreed that the primary responsibility of the COCA should be to present a united voice of the “disability community” by advocating priorities that should be adopted by ADD, AUCD, individual UCEDDs and other disability organizations.

Additional functions the COCA should serve include providing technical assistance to AUCD and member UCEDDs on disability-related subjects, fostering the recruitment, development and mentoring of potential leaders within the disability community, and informing new UCEDD Directors on the role of the COCA as well as on utilizing consumer expertise as the framework for projects.

Another duty of the new COCA should be to serve the network as experts on full participation, dispersing members to the other councils and committees, and promoting interaction between COCA members and other AUCD participants.

### **Recommendations**

Rather than recommending to disband the Council on Consumer Affairs, the work group decided to suggest a restructuring of the council. Restructuring of COCA to enhance participation of people with disabilities in all activities of the AUCD is the principle aim. Specifically, the work group would like to see people with disabilities advising AUCD and

member affiliates on strategic planning efforts, program development for UCEDDs, and leadership development for individuals with disabilities and family members,

The work group devised the following recommendations for AUCD and its program directors to consider. The recommendations are divided into categories and are in no certain order of importance.

***Recruitment:***

People with disabilities and family members often have expertise on subjects such as inclusion, services, universal design, and so much more. This is a body of knowledge AUCD needs to tap as much as it can.

- 1) To achieve this AUCD and its affiliates need to redouble efforts **to identify and recruit talented and informed individuals with disabilities and family members.**
- 2) **Leadership training and mentoring** is not only an enticement for those who will be sought but will prove invaluable to UCEDDs when their COCA representatives return with embellished leadership skills.
- 3) Both AUCD and its member affiliates will benefit from **consistent participation** of new leaders, as well as from the presence of more of these leaders. **Regular attendance** at AUCD conferences is likely to contribute to addressing disability issues at a national scope. And as leaders are identified and emerge they will discover areas of interest and pursue these within the network, thus spreading the COCA expertise throughout AUCD's councils and committees.

As a result the COCA will play a key role in framing the influence AUCD has on legislation and other activities that impact people with disabilities throughout the country.

### *Logistics*

- 4) At the annual AUCD conference, the **COCA should meet prior to the rest of the network to assess priority disability issues**. Then, individual representatives will have opportunities to participate in and advise other councils and committees.
- 5) The **mission statement** the COCA will use to guide its activity needs to be **further refined** (see the “Mission Statement” section below).
- 6) The **role each COCA representative will play** both for AUCD and for the UCEDD from which he or she comes needs to be **carefully considered and clearly defined**.
- 7) **UCEDD Directors should collaborate with COCA representatives in setting agendas** for AUCD conferences and for activities the network will undertake between meetings.
- 8) **Greater reliance on video conferencing, teleconferencing and e-mail chat rooms** should be considered for improved communication within the AUCD network.
- 9) **Travel expenses**, even for people with disabilities who use personal care attendants, must be a **high priority**.

### *Membership*

The work group identified a serious conundrum facing the COCA. Membership is not increasing and is at the same time largely transient. In other words, there is a core membership of representatives who attend the AUCD national conference each year coupled with individuals who might attend once then not be heard from again.

This might be a direct result of the current definition of COCA being based upon the characteristics of its members (People with disabilities and family members) rather than the purpose it serves. A second conundrum discussed is the question of who COCA should recruit

into its membership. Sometimes a UCEDD appoints the Chairperson of its Consumer Advisory Council to represent it on the COCA while others have staff (People with disabilities, family members, etc.) who choose to serve. Moreover, legitimate arguments for appointing UCEDD staff or persons not employed within the network need to be weighed.

Input from individuals not employed at UCEDDs is requisite information to the network yet it necessitates UCEDDs to incur travel costs of stakeholders not on the payroll. (A determination as to whether UCEDD staff ought to serve on Consumer Advisory Councils or whether independent community representatives should constitute CACs is faced by member affiliates).

A third quandary faced is that of isolation. COCA members are essentially segregated from other councils and committees yet they have the expertise that is needed and sought by these groups.

- 10) The **involvement of people with disabilities and family members needs to be beneficial** to the individuals, the UCEDDs from which they come and to the AUCD network as a whole.
- 11) For membership to have maximum effectiveness, **individuals with expertise and experience related to the important disability issues the nation faces need to be recruited.**
- 12) These individuals will need **early mentoring from veteran members** and should **serve one or two 3-year terms** on the COCA. These members should benefit from membership and be better poised to serve their affiliate program as a direct result of COCA membership.
- 13) Furthermore, **limiting the maximum number of COCA representatives** ought to be given serious consideration so as to keep the group at a manageable size. Such a limitation will

necessitate some UCEDDs not having a representative on the council but this might keep affiliates' costs down in the long term.

### ***Resources***

AUCD, ADD, MCHB, and other national organizations benefit from the advice they solicit from people with disabilities and consumer advisory councils.

14) **AUCD, ADD, MCHB should allocate funds to support the persons with disabilities and their personal care attendants** to present their knowledge.

15) **As core UCEDD funding increases so too should budget line items for COCA.**

UCEDD Directors must be able to observe and benefit from outcomes of sending representatives to the COCA. COCA meetings at which representatives of other councils and committees present synopses of the work they are doing might help to generate outcomes Directors will find valuable.

16) **Establishment of a “co-learner” experience for COCA members** might also prove beneficial to individual UCEDDs.

### ***Outcomes***

A reconfigured COCA has potential to yield positive outcomes for the AUCD network. First, the development of leaders who are educated and skilled systems advocates will bolster the work the network and its affiliates undertake. Second, a set of guidelines for research and practice more congruent with the real needs of people with disabilities and family members will emerge. Third, a more realistic portrayal of the daily lives people with disabilities and their families live will, when presented to ADD and legislators, translate into prioritized action steps coupled with funding streams directed at those actions. Finally, a reformulated COCA will

improve communication between people with disabilities and family members within AUCD that will in turn strengthen strategies the organization embarks on for engineering positive change.

### ***Priorities***

The COCA work group identified the following priorities for change within AUCD:

- 1) Increase efforts to **recruit talented and knowledgeable individuals** to serve on COCA.
- 2) A **commitment to participate** should be garnered from these individuals and from the UCEDDs for which they work.
- 3) The **schedule for the annual meeting should be modified** so that the COCA can meet prior to the regular meeting.
- 4) **COCA should be consulted and/or participate in framing priorities** the network will address. The COCA will present its list of priorities to the Board of Directors of AUCD.
- 5) When COCA members participate on other councils and committees they **will report back to COCA** afterwards.
- 6) A decision will be made concerning **replacing the word “consumer”** as a referent for persons with disabilities.

### ***Suggested Name Changes***

The ambiguous word “consumer” has fallen out of favor with many people with disabilities. Therefore a few moments were devoted by the work group to brainstorming potential replacement names for “Council on Consumer Affairs.” No decisions were made, but following are the names the group produced:

- ❖ Council on Community Access through Universal Design
- ❖ COCA plus
- ❖ Quality Council
- ❖ Coalition for Community Participation
- ❖ Reality Council
- ❖ Futures Council
- ❖ Quality Assurance Council
- ❖ Partnership for Universal Participation
- ❖ Hacket's Council (in honor of David Thomas' wonderful guide dog, Hacket)

### ***COCA Mission Statement***

The current mission statement for the Council on Consumer Affairs is vague. Members of the work group agreed that a more specific mission statement reflecting a reformulated purpose and function of the council is needed. Brainstorming was undertaken to produce ideas for what should be included in the new mission statement. Some of the important factors members suggested are that COCA is part of the fabric of AUCD, advancing policy and practice for and with people with disabilities, futuring, partnerships, universal design and access, and diversity.

The work group generated the following phrases in an attempt to encapsulate its notions of the mission of the reconfigured COCA:

*The mission of COCA is to.....*

- ❖ ...enhance the involvement of individuals with disabilities in AUCD and individual UCEDDs...
- ❖ ...establish a mechanism for partnerships....
- ❖ ...partner with individuals with disabilities, family members, and professionals to build the capacity of AUCD and its member organizations and thereby...
- ❖ ...build organizational supports that will define policy and practices for future direction based on the partnership between individuals with disabilities, family members, and professionals.
- ❖ ---define future directions for AUCD and member organizations based on the partnership between individuals with disabilities, family members, and professionals.
- ❖ ...provide organization supports for AUCD and its members based on the partnership between individuals with disabilities, family members, and professionals.
- ❖ ...ensure that PWD and family members are integral partners at every level of the AUCD network...

### **Conclusion and Next Steps**

A great deal of thought was given to the Council on Consumer Affairs, its history, its current state, and to means for improving its contribution to the AUCD network by the work group. Many excellent ideas were yielded during the day and a half in Kansas City. The thoughts and recommendations of the COCA work group are presented in this concept paper but there remains a great deal of work to do.

Members of the COCA work group will be asked to review this document to ensure accuracy of the representations of the work done in Kansas City. Moreover, this document will be considered by members present at the AUCD Directors meeting in July, 2004. At this meeting it is hoped the ideas presented in this paper will be considered and refined. A revision of this paper will be drafted based on feedback offered by both Directors of UCEDDs and participants on the COCA work group.

At the annual AUCD conference in Fall of 2004 a plenary session where this work will be presented will occur. Audience members will have opportunities not only to learn about the process that went into reconfiguring the Council on Consumer Affairs but will have a chance to offer suggestions and to pose questions.

There is no question that involvement by people with disabilities and family members within the AUCD and its member affiliates is crucial. AUCD made a commitment to welcoming input and participation from this constituency more than a decade ago. The work reflected in this paper is the next, major step the network must undertake to improve the solicitation of input and participation of people with disabilities and family members within the network. In turn, the network will be strengthened and the work it does advanced once these recommendations are refined and put into action.

Respectfully submitted by David M. Thomas

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