

## Commissioner's Message

Because behavior, beliefs, priorities, and decisions are rooted in culture, it is imperative that disability services be culturally responsive. I strongly believe in the necessity for culturally competent approaches—programs that work from the inside, using the values, traditions, institutions, and strategies which individuals with disabilities and their families identify for themselves as being the most productive.

One of the strengths of the DD Network is that the system recognizes the fact that there is no one-size-fits-all solution to the challenges faced by individuals with developmental disabilities. ADD's grantees in each State are positioned to understand the unique needs of their communities, and to work with partners and community leaders to meet those needs in ways that work for the people that live there.

Understanding culture helps us to understand how others view themselves and their environment. Culture may influence belief systems; attitudes towards disability and health care; family structure; attitudes and behaviors; and how an individual interacts with his or her community and the outside world. Culture shapes individual and group values, including ideas about what is helpful and what is not, and what makes sense and what does not. I strongly believe that these cultural characteristics should be preserved, not ignored; these characteristics are important both to individual identity and to the diversity that is one of our Nation's greatest strengths. However, sometimes these cultural differences can create barriers to effective service delivery, especially when dealing with minority populations whose cultural perceptions may be at odds with the majority worldviews often used to shape service delivery systems.

Cultural competence is achieved when we take the time to learn about the culture of an individual or group, and then use that knowledge to shape our interactions, approaches, and programs. Our programs should value diversity, be conscious of cultural dynamics, and enable adaptations to maximize effectiveness.

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Cultural competence increases effectiveness of disability services and programs and improves communication. It ensures that individuals' preferences and beliefs are taken into account, and that individuals have the information they need to choose services and supports that are right for them. Cultural competence builds a bridge between programs and consumers, ensuring that all individuals with disabilities have access to the supports and programs they need.

This issue of the ADD Update is intended to facilitate the sharing of ideas and strategies to increase our capacity to design culturally competent programs and approaches.

## Spotlight on Self Advocacy



“To me,” says Tom Owens, “self-advocacy means to do things for myself, to take care of my life and live it to the fullest, regardless of disability.”

For Tom, living life to the fullest includes a wide variety of activities, involvement with several self-advocacy organizations, lots of time with friends and family, and a commitment to making his own decisions and finding ways to share his point-of-view.

In particular, Tom has found self-expression through photography,

“I love photography.” Tom says. “A few years ago I purchased a digital camera. I love the mountains, hiking, the ocean- so naturally, I wanted to take pictures of the things I love.”

Initially, Tom, who has cerebral palsy, had difficulty operating his camera without assistance. Then, through a program called Northeast Passage in his home State of New Hampshire, Tom was able to order a custom-made device that allows him to operate his camera unaided. The device gave Tom the independence to explore photography on his own, and the ability to take pictures that show the way he sees the world.

“I pushed (the remote),” says Tom, “and at that moment, in my 50 years of life, had taken my first picture independently. Amazing, incredible, unbelievable are not strong enough words to describe the way I felt at that moment.”

In addition to photography, Tom enjoys working on his computer, hiking, bowling, and spending time with his girlfriend.

“I am very happy with myself,” says Tom. “I...choose to live my life to the fullest even though I am disabled. I will never just sit around and be unhappy. Life is too short.”

## Network Collaboration

The following article, describing collaboration both within the DD Network and with other organizations, was submitted by the New Jersey UCEDD.

**Top Down and Grassroots Up: Two Initiatives in Cultural Competence by  
The Elizabeth M. Boggs Center on Developmental Disabilities-UCE  
University of Medicine and Dentistry of New Jersey-Robert Wood Johnson Medical School.  
New Brunswick, NJ**

Over the past five years, The Boggs Center on Developmental Disabilities has played a central role in two strategic initiatives to enhance the capacity of disability services to address the increasing cultural diversity of New Jersey. As framed in the title, one has been “Top Down,” working with statewide organization partners to develop a series of educational and training initiatives. The second has been “Grassroots Up,” helping to develop a New Jersey Statewide Network in Cultural Competence to bring together people and organizations to share ideas, expertise, and commitment to cultural competence.

### **Top Down**

In 2001, following a Boggs Center Developmental Disabilities Lecture Series on cultural competence, The Center hired an African American seminarian to work on linkages with faith communities as part of a project with The Brain Injury Association of New Jersey. That led to a decision to hire several part time consultants to help our UCE determine some ways it could reach out several ethnic communities in New Jersey: Latino, Arab, Korean, and South Asian as well as African American. We hired people from those communities, whether they were familiar with disability or not.

When the findings and recommendations of the consultants were presented to The Boggs Center Consumer Advisory Council, they sparked a discussion and suggestion that all three of the ADD partners in New Jersey should work together on this, for we each had been doing things, but none of us very satisfied with the results. That led to a committee call the Cultural Competence Collaborative. After several months of brainstorming and discussion, that committee came up with the idea of a series of Cultural Awareness Days (based on the model of The Boggs Center DD Lecture Series), planned in collaboration with leaders from various ethnic communities, to ask them to teach the disability community about their cultural communities in New Jersey.

Around the same time, The Boggs Center made contact with Celia Abalos, Esq., Vice President for Multicultural Affairs, for our parent institution, the University of Medicine and Dentistry of New Jersey (UMDNJ). She was very supportive of this initiative, quickly promised some funding, and even more importantly, invited a number of Latino leaders to an initial luncheon meeting to talk about our hopes and ideas. That approach led those leaders to say, “We need to learn about disability services in New Jersey. Can we do a two day conference instead of one, with one focused on disability service providers and the second on Latino families and organizations?” The Latinos

and Disabilities Planning Task Force was thus born, and worked about eighteen months to plan a first Latinos and Disabilities Conference in September, 2004, with primary coordination provided by The Boggs Center. Each of the ADD partners contributed funding along with UMDNJ. It was a smashing success, with a wonderful spirit, simultaneous language translation, a real desire for information, and excellent coverage in Latino print and television media.

Out of that conference, a Latinos and Disabilities listserv began. The same collaborative contacts were then utilized by the New Jersey Division of Disability Services, Department of Human Services, to plan and coordinate a conference on employment for Latinos with disabilities in the fall of 2005, and a conference on African Americans and Employment in November of 2006.

Meanwhile, in the last year, The Boggs Center and Celia Abalos, the university representative, worked with the original Cultural Competence Collaborative to initiate a similar process with the South Asian communities in New Jersey. Planning is now underway for a first South Asians and Disabilities conference on June 15, 2007.

Thus, top down, statewide agencies worked together to reach out to leadership within ethnic communities to collaboratively plan training events and other activities.

### **Grass Roots Up**

In 2002, The Boggs Center also worked with the New Jersey Department of Health and Senior Services, to host a two day training and consultation event on cultural competence led by Tawara Goode and staff from the National Center on Cultural Competence at the Georgetown UCE. The focus was on early intervention and transition services, but part of the consultation was to determine future directions. A small committee came out of that event with a dream of establishing a statewide network on cultural competence, to find out who was doing what, to share ideas and expertise, and to work together in ways that would reduce reinventing the wheels. It took over a year to work through a mission statement, logo, and initial survey. For the past three years, the New Jersey Statewide Network on Cultural Competence (NJSNCC) has been holding quarterly forums with educational programs, growing a listserv that is housed at the New Jersey Department of Health and Senior Services but moderated by Bill Gaventa at The Boggs Center, and gradually adding to a website with information about the network and agencies in New Jersey:

<http://www.state.nj.us/njsncc/>

In both of these initiatives and strategies, The Boggs Center has played a central leadership role, but one clearly shaped in collaboration with others. In specific activities such as the conferences focused on employment, other partners have taken the lead because of their mission and grant funding. We still have a long ways to go. To use a favorite term of Dr. Robert Like, a medical leader in cultural diversity at UMDNJ, we have all learned something about “cultural humility.” Some of the most important outcomes from the initiatives have been the creation of new connections with leadership in several cultural and ethnic communities, as well as enhanced collaboration with the ADD network and between disability organizations. There is more to learn, but the pathways are being slowly built, top down, and grassroots up.

For more information: <http://rwjms.umdj.edu/boggscenter/>

## ADD Photo Library

As the familiar proverb goes, a picture is worth a thousand words. Complex stories can be often told with just a single still image, and that image may be more influential than a substantial amount of text.

ADD is in the process of trying to build a photo library of pictures of individuals with developmental disabilities and their families for use in posters, displays, websites, and informational materials.

We've already received many wonderful pictures, but we need more. We're looking for active, inclusive, positive photos that show individuals with disabilities participating in a wide variety of activities. Photos that tell a story are more helpful than portrait-style shots of individuals or board members.

One of our first projects will be a display poster, and we're still in particular need of pictures that depict the issue areas of transportation, housing, and inclusive child care.

Above all, ADD wants to display photos that reflect the activities of our grantees and the interests and faces of individuals with whom our grantees have interacted with and assisted. Therefore, we're asking for you to submit your pictures to ADD for consideration for publication.

A few hints about what we need:

- Photos should be digital and sent as a JPG or compatible format. Preferred dimensions are 375 x 300 pixels.
- Please include a brief caption or description, giving first names of people pictured, location, and description of activity as appropriate.
- Due to privacy concerns, please make sure that pictures don't reveal information such as school names, home addresses, license plate numbers, etc.
- We're looking for photos that show individuals with disabilities of all kinds engaged in a wide variety of activities.



The photograph above is an example of the kind of picture we're looking for. It works on several levels. It's an active shot that tells a story. It demonstrates inclusion: both individuals with and without disabilities are pictured participating together in an activity. It illustrates one of ADD's areas of emphasis: recreation. The use of natural light allows for a clean, crisp image.

- Of particular interest are photos that show community inclusion and activities engaged in by both individuals with disabilities and their non-disabled peers.
- Photos need not be limited to activities in ADD's areas of emphasis, but we do need images that tell your clients' stories in the areas of employment, education, child care, health, housing, transportation, recreation, and quality assurance.
- Photos don't necessarily need to be only of people. A great picture of an accessible playground, house, or office building would be very useful.
- Be creative. Send us pictures that tell a story.

Photos must be accompanied by a waiver signed by the individual(s) pictured, granting permission to ADD and its grantees to use the images. If the individual is a minor or has a guardian, the signature of the parent or guardian is required. You are welcome to use your own waiver forms, but ADD is happy to provide you with our standard waiver for your use. That waiver form can be obtained by contacting Rebekah Yeager at [rebekah.yeager@acf.hhs.gov](mailto:rebekah.yeager@acf.hhs.gov).

## ADD Independent Evaluation Update

### ADD Independent Evaluation Update

The purpose of this update is to provide current information about progress on the Independent Evaluation and current activities being implemented. The independent evaluation is a project being carried out by Westat to examine the impact of the State Developmental Disabilities (DD) Network programs on the lives of people with developmental disabilities and their families.

Westat continues to make progress on the Independent Evaluation project. They have spent much of this summer with the **working groups** for each of the ADD grant programs (DD Councils, P&As, and UCEDDs), as well as a collaboration working group. Below is a listing of the members of each working group:

#### P&A Working Group

Mary Faithfull, Texas  
 Sarah Wiggins-Mitchell, New Jersey  
 Robert Joondeph, Oregon  
 Timothy Shaw, Nebraska  
 Jeanne Thobro, Wyoming  
 Tom Gallagher, Indiana

#### DD Council Working Group

Jamie Wolfe, Delaware  
 Debra Dowds, Florida  
 Vendella Collins, Michigan  
 Becky Maddy Harker, Iowa

Richard Weathermon, Nevada  
Waynette Cabral, Hawaii  
Bill Lynch, Oregon

**UCEDD Working Group**

Lucille Zeph, Maine  
Tawara Goode, Washington, DC  
Fred Orelove, Virginia  
Fred Palmer, Tennessee  
David Mank, Indiana  
Carl Calkins, Missouri  
Gloria Krahn, Oregon

**Collaboration Working Group**

Fred Orlove (UCEDD), Virginia  
Jeanne Thobro (P&A), Wyoming  
Becky Maddy Harker (DD Council), Iowa  
Robert Joondeph (P&A), Oregon  
Bill Lynch (DD Council), Oregon  
Gloria Krahn (UCEDD), Oregon

Initially Westat conducted meetings and conference calls with the entire working group. These events helped to orient working group members to the Independent Evaluation and overall process for developing **DRAFT** performance standards for each program's **key functions**.

To facilitate more focused discussions about each program's **key functions**, the working groups were divided into smaller teams of two or three people. The teams have been functioning like mini focus groups. To this end, they are providing information to Westat around the **key functions** for their respective program and for collaboration. Following the discussions with the teams, Westat analyzes the information and organizes it into tables that capture and describe what the ADD grantees are doing in terms of structures, processes, outputs, outcomes. These are fondly referred to as SPOO tables (**S** = Structures, **P** = Processes, **O** = Outputs, **O** = Outcomes). The information in the SPOO tables have been used to start developing the **DRAFT** performance standards for each program and for collaboration among the DD Network grantees.

The process has been iterative, meaning Westat is continually going back to the teams to get their feedback on the SPOO tables and the standards that are being developed. This helps to ensure that the information was analyzed appropriately and reflects what programs are doing.

Since Working Group members have been working in teams during the summer, Westat would like to give the full Working Group the opportunity to see the proposed standards, indicators, and performance levels for all key functions and to provide further input as a group. Therefore, as was done in the spring, Westat is planning a full day Working Group meeting that piggybacks on the dates of each program's national meeting in October and November.

Next, Westat will make revisions to the measurement matrices based on comments received. Then,

the measurement matrices (or some understandable version of the contents of the matrices) will be made available to all programs so that they can comment on the DRAFT performance standards.

Finally, Westat will revise the measurement matrices and make them ready to deliver to the Validation Panels. With assistance from the Advisory Committee and ADD, Westat will establish four validation panels for each DD Network program (Councils, P&A Systems, and UCEDDs) and a separate panel for collaboration among the three network programs. Each panel will contain up to eight members consisting of individuals with developmental disabilities, family members, advocates, researchers, representatives from the DD Network, and policy specialists. The validation panels will review the draft standards developed for the DD Network programs and confirm whether the proposed standards accurately measure program performance and impact.

In an effort to keep grantees informed about the project, Westat made presentations in October and November at the UCEDD and DD Council national annual meetings to describe the process used with each Working Group and to describe the process that will be used for sharing a draft version of the evaluation tools with all programs. This project continues to keep us busy, and Westat is making good progress on their work. ADD will continue to keep you informed on the Independent Evaluation project through the ADD Update. In the meantime, if you have questions about the activities being carried out through this project, please contact Jennifer Johnson at 202-690-5982 or [jennifer.johnson@acf.hhs.gov](mailto:jennifer.johnson@acf.hhs.gov).

## Recent Events



**Attendees at the self –advocate conference use a simulated voting booth**

### **Self-Advocates of Indiana**

#### ***2006 Statewide Self-Advocacy Conference***

On September 7-8, *Self-Advocates of Indiana* held a statewide conference to provide self-advocates and their families with an opportunity to socialize, express their opinions, and participate in informative conference sessions. The keynote speaker at the conference was Faith McCormick, Director of Programs at ADD. Conference activities included a silent auction, a dance, and a health fair. Self-advocates attended sessions on subjects such as owning your own business, becoming an effective legislative advocate, and living wills.

### **NADDC Annual Meeting**

On October 8-10, the National Association of Councils on Developmental Disabilities (NADDC) held its annual conference in Pittsburgh, Pennsylvania. With 317 registrants it was the largest turnout ever for the NADDC conference. Many were self-advocates and parents demonstrating the Councils' link with, and commitment to, supporting the voices of individual self-advocates in discussion of issues. The conference was jointly sponsored by the Pennsylvania, Ohio, and West Virginia Councils. Patricia Morrissey, ADD Commissioner, made comments at a luncheon.

## Program Progress

### **Illinois P&A- Equip for Equality, Inc.**

The Illinois P&A sponsors the *Latinos with Disabilities Advocacy Project*. The purpose of the project is to provide legal services for disability-related issues to the Hispanic/Latino community in Illinois. All legal services are provided by bilingual staff.

Several goals of the Latinos with Disabilities Advocacy Project include:

- Meeting with individuals and families at community-based sites
- Specializing in special education issues
- Providing training in special education issues in Spanish
- Partnering with other Hispanic/Latino disability-related organizations to raise awareness of disability issues within the Hispanic/Latino community
- Supporting Hispanic/Latino parent disability groups
- Increasing capacity in these communities with parents and individuals with disabilities learning their rights

### **National Center for Cultural Competence- Affiliated with the Georgetown UCCED**

The mission of the National Center for Cultural Competence (NCCC) is to increase the capacity of health care and mental health programs to design, implement and evaluate culturally and linguistically competent service delivery systems. The NCCC fulfills its mission through:

- (1) Training, technical assistance and consultation;
- (2) Networking, linkages and information exchange; and
- (3) Knowledge and product development and dissemination.

Major emphasis is placed on policy development, assistance in conducting cultural competence organizational self-assessments, and strategic approaches to the systemic incorporation of culturally competent values, policy, structures and practices within organizations.

In addition to sponsoring projects that advance cultural competence, NCCC provides on its website a wealth of resources, including checklists, publications, and other materials which can be found at: <http://www11.georgetown.edu/research/gucchd/nccc/resources/index.html>

## **Michigan Developmental Disabilities Council**

The Michigan DD Council's *Multicultural Committee* is designed to develop recommendations and procedures to help the Council fulfill the policy statement: *"The special needs of minorities and culturally-diverse populations will be recognized and supported in all goal areas activities."*

The committee's recommendations help to promote service equity for multicultural populations in the disability network.

The committee, at minimum, represents these minority groups: African-American, Arab-Chaldean, Asian-American, Hispanic, and American Indian. Committee members are either persons with disabilities or have a strong working knowledge of disability issues.

The duties and goals of the committee include:

- Develop a vision and workplan for the committee;
- Identify issues unique to specific multicultural ethnic groups;
- Suggest specific methods for removing barriers to full participation for those with disabilities who are from culturally-diverse populations;
- Assist the Council to identify and develop incentives that increase minority participation;
- Target potential members from each minority group, with the objective of increasing the Council's minority "pool" from which contributors are drawn for sundry Council activities;
- Generate tools and methods to accomplish the above.

The committee has developed a policy statement on multicultural involvement in Council activities and put together a list of recommendations and action steps. The committee's activities have resulted in an increase in the Council's awareness and understanding of special needs required by culturally-diverse minority groups and have enhanced the Council's ability to support these needs. The Council is working to address barriers to minority participation in disability-related activities and to increase minority presence in the grants process. The Council has also taken a leadership role to expand minority participation in the disability network.

The committee has also developed a multicultural brochure, which can be viewed at [http://www.michigan.gov/documents/mulcul-final\\_153887\\_7.pdf](http://www.michigan.gov/documents/mulcul-final_153887_7.pdf).

## **National Disability Employment Awareness Month**

Congress designated each October as National Disability Employment Awareness Month (NDEAM). The Office of Disability Employment Policy in the U.S. Department of Labor has the lead in planning NDEAM activities and materials to increase the public's awareness of the contributions and skills of American workers with disabilities. Various programs carried out throughout the month also highlight the specific employment barriers that still need to be addressed and removed.

This effort to educate the American public about issues related to disability and employment actually began in 1945, when Congress enacted a law declaring the first week in October each year "National Employ the Physically Handicapped Week." In 1962, the word "physically" was removed

to acknowledge the employment needs and contributions of individuals with all types of disabilities. In 1988, Congress expanded the week to a month and changed the name to "National Disability Employment Awareness Month."

On October 25th the Office on Disability (U.S. Department of Health and Human Services) held a **Celebrating Persons with Disabilities** event in honor of National Disability Employment Month. Several individuals were recognized for their contributions to disability awareness and programs.

Honorees included:

- **Julie Beckett:** For relentless advocacy leading to the establishment of the Katie Beckett Medicaid waiver that allows families to care for their children in their homes and communities rather than in hospitals or institutions.
- **Peter Galpin, M.D.:** For professional achievements, including becoming the first surgeon in the United States to have started and completed medical and surgical training from a wheelchair, community service, outreach to the medically needy in less developed parts of the world, and a physically active lifestyle.
- **Andrew Imparato:** For commanding leadership of the American Association of People with Disabilities and politically and economically empowering all people with disabilities through public policy advocacy and programs.
- **Ronan Tynan, M.D.:** For overcoming difficult challenges, undertaking new endeavors and attaining tremendous success as a gold medal winning Paralympian, a physician, an inventor, an eminent opera singer, and a celebrated speaker and motivator.

## Program Performance

ACF's Online Data Collection (OLDC) System is ready for your FY 2006 Program Performance Reports and P&A Statements of Goals and Priorities for FY 2007. The Reports are due on/by Jan 1, 2007. If you have any program content related questions, please contact your ADD regional liaison and contact Syed Rafiuddin [srafiuddin@acf.hhs.gov](mailto:srafiuddin@acf.hhs.gov) for any technical and ID/password issues.

*Please be sure to share this information with your key staff that enters the PPR/SGP data for your report(s).*

## Announcements and Updates

### ADD Staff Changes

ADD has recently said goodbye to several of our colleagues. Margaret Schaefer, India Jacobs, April Myers, and April January have moved on to new opportunities. We wish them well, and they will be missed. ADD is also pleased to welcome Antionette Bass as Staff Assistant, and Eric Lyons as Web Specialist.

**Bi-Annual Report Available Online**

ADD is pleased to have finalized its bi-annual report. The document, titled *The American Dream Belongs to Everyone: A Report to Congress, the President, and the National Council on Disability Fiscal Years 2003-2004* is available online at:

<http://www.acf.hhs.gov/programs/add/addpublications.html#update>

**We Want to Hear From You:**

The next issue of the ADD Update will focus on education. Please send any suggestions, information, stories, and photographs to [rebekah.yeager@acf.hhs.gov](mailto:rebekah.yeager@acf.hhs.gov).