ADD Program Update

Administration on Developmental Disabilities

Administration for Children and Families • U.S. Department of Health and Human Services

Inclusion Integration Independence Productivity Self-Determination ADD

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Commissioner's Message

Commissioner's Forum

The Administration on Developmental Disabilities (ADD) is sponsoring a Commissioner's Forum on Tuesday, February 18 through Thursday, February 20, 2003 at the Mayflower Hotel in Washington, D.C. The forum is being held in collaboration with the Developmental Disabilities Quality Coalition.   In addition to members of the DD network, ADD is inviting representatives of other public and private partners -- self-advocates, consumers, HHS sister agencies, and representatives from other Federal agencies. The Secretary of the Department of Health and Human Services is the invited keynote speaker. Principals from the U.S. Department of Labor, the Social Security Administration, and the U.S. Department of Education are also invited speakers. ADD anticipates about 350 attendees.

The theme of the 2003 ADD Commissioner's Forum is **Building a Comprehensive Quality Management Program and Supporting the Direct Support Workforce for DD Service Systems**. The forum will address two important issues: (1) the quality of services and supports provided to individuals with developmental disabilities; and (2) the shortage of qualified direct support professionals. The Forum will showcase innovative state projects on quality management and workforce development. For more information on the Commissioner's Forum go to the ADD web site at http://www.acf.hhs.gov/programs/add/index.htm or contact Gina Barbaro at (202) 401-6300.

Program Progress

State Councils on Developmental Disabilities

ADD Executive Director's Focus Group

Three years ago ADD created the Executive Directors' Focus Group to provide guidance on the implementation of the DD Act of 2000. Group members represent the broad spectrum of Councils and have a variety of expertise in reporting,

measurement, and consumer satisfaction. This expertise is crucial to ADD's objectives for the group including measuring consumer satisfaction, reporting processes and formats, and ongoing review of the Council measurement process to ensure consistency with the DD Act and with other Federal legislation. The consistency of the membership, varied expertise, focused objectives, and excellent working relationship all contribute to the successful collaboration between ADD and the group.

At the ADD Technical Institute this summer, Council Executives requested regular opportunities for dialogue with Commissioner Morrissey. In response, ADD initiated conference calls utilizing the Focus Group on a trial basis. Commissioner Morrissey conducted conference calls in September and October and a third will be planned in January. ADD is evaluating the conference call process to see how it can better meet the needs of Councils, for instance, focusing calls on specific issues or regions, and conducting on a meet-me-call basis. Commissioner Morrissey welcomes the opportunity to correspond with Councils and appreciates your continued interest in dialogue around issues. For more information contact Mary Beth Greene at 202/690-6028 or email mgreene@acf.hhs.gov.

Protection and Advocacy Agencies

TASC/NAPAS Program Management Conference 2003

The P&As are starting the New Year with the TASC/NAPAS Program Management Conference 2003: Skills-Building for Individuals and Organizations. It is being held in San Diego, California January 8-11, 2003. There will be Federal officials represented along with P&A Executive Directors and staff, governing board/advisory council members and other interested parties. ADD is excited about the opportunity to give Passport to Advocacy Learning (PAL) a boost with the workshops based on skills-building areas. ADD expects that this conference will be well-attended, provide an opportunity for new P&A staff, governing board and advisory council members to learn about the system, enrolling in PAL and provide mentoring and networking opportunities.

Face-to-Face Committee Meetings

ADD extended its thanks for the successful committee meetings held recently in Washington, DC. ADD understands that the committees worked diligently towards providing input to the Project Advisory Committee (PAC) on training and technical assistance needs, making updates on projects available, reviewing mission statements, and proposing plans and ideas for future work under the T/TA contract. ADD staff recognize that it takes commitment and time to work on these committees. The information/referral committee and the PAC will meet at the January conference.

Policy Guidance

ADD stresses the need for each of you to recognize that authority for interpreting the statute and regulations rests with ADD as the agency charged with administering the program. ADD is vested with the authority for our programs, including making policies and interpreting the applicable statutes and regulations. Please make contact with Jackie Ezzell at (202) 690-5905 or e-mail her at jezzell@acf.hhs.gov if you have a question about this issue.

Notice to P&A's attending the Commissioner's Forum

The Commissioner's Forum is taking place February 16-18, 2003 in Washington, DC. We are asking the P&As to come prepared to discuss your role in the quality assurance emphasis area. P&As play a critical role, especially in the DD Network. We want to ensure that you are in attendance and ready to participate in and initiate some of the discussion.

University Centers for Excellence in Developmental Disabilities Education, Research and Services

ADD recently requested descriptions of innovative UCEDD projects. Many Centers provided examples of projects that emphasize efforts to further a specific goal or priority, though many projects will have a lasting effect across more than one area.

Media/Technology- Media and technology can be important tools for disseminating information and educating consumers, professionals and the general public. In the paragraphs that follow are some examples of work being done in media and technology.

Some projects being conducted at the Centers involve long-term goals, such as acceptance and community inclusion. These projects have a goal of educating the public. The **California** UCEDD at UCLA has stimulated public awareness aimed to reduce stigma and portray accurate images of people with disabilities through publications such as *Everybody's Different: Understanding and Changing Our Reactions to Disabilities*, a library exhibit, "Whose Life Is It Anyway?" performances by individuals with disabilities, national conferences for performers with disabilities and arts administrators, an online calendar about programs and events, and radio interviews and articles in the mainstream press.

Providing consumers and professionals with the appropriate tools increases quality of life for persons with disabilities, by increasing their independence and opportunities. "No Walls," a **New Mexico** UCEDD project funded by the Department of Education, is a community technology center, which increases the capacity of persons with disabilities, their families, service providers, teachers, and advocates in the Albuquerque metropolitan area to use computer technology to access information that supports their choices and builds the capacity of the community to provide services and supports. Through a subcontract with the Houston Academy of Medicine funded by the National Libraries of Medicine, training will be provided to library personnel and information providers in New Mexico on accessing health information on disabilities and related issues and facilitating partnerships among existing consumer health information networks in New Mexico.

Event-focussed projects have a specific purpose, with a long-term lesson. The **Minnesota** UCEDD has produced the documentary video *We Watch the City: Stories in the Shadow of 9/11*. Shown at the annual meeting of the Association of University Centers on Disabilities, the film explores how the terrorist attacks of 2002 affected individuals with developmental disabilities who live and work in New York City and the people with whom they interact. Though the film focussed the experiences of people in a specific event, through their stories we are able to see the

mechanisms that help people with disabilities in an emergency, and those areas that need to be improved, making emergency services fully accessible.

Training- Training is a critical element of UCEDD projects. Training for people with disabilities and their families helps to create self-advocates, empowering people with the knowledge to fight for themselves. Training educators, physicians, and other professionals ensures that people with disabilities can receive health care, education, and other services appropriate to their needs.

The **Connecticut** UCEDD has developed a Social Competence Curriculum, which investigates the effectiveness of a strategy to promote the development of social skills in toddlers who are at risk for school failure because of behavioral challenges. Also developed by this UCEDD is a model demonstration project, "Natural Environments in Urban Settings," which aims to increase the number of children receiving early intervention services in community activities with their peers in such settings as libraries, playgrounds, museums, farms, Ys, parks, and recreation facilities. The project builds children's assets while providing families with the resources and guidance they need to enhance the development of their child within inclusive learning environments.

The use of technology in training is expanding the ability of Centers to reach the greatest number of people effectively. **Kentucky's** UCEDD has developed Virtual Patient Models, an internet-based means of portraying the needs of children and adults with developmental disabilities and their families through interactive case studies for use in training medical school students.

Virginia UCEDD is also employing new technologies to train people. Partnership for People with Disabilities (formerly Virginia Institute for Developmental Disabilities) is developing a web-based course on understanding maltreatment and people with disabilities. Through Projects of National Significance funding both local and national councils have been formed to guide the development, field testing, revisions, and dissemination of the content that is designed for health care practitioners and students. The councils consist of primary consumers, parents, UCEDD experts in the field, and representatives of Protection and Advocacy agencies. The initial development of the modular content is nearly complete and field-testing is expected to be complete by the summer of 2003.

Research- Much of the work done by the Centers is done in disabilities research. Gathering information on people with disabilities, their families, and how they meet their needs and face their challenges helps ADD grantees identify weaknesses and establish goals for future projects.

Often, a Center will conduct research among a specific demographic, to identify special needs or unique problems in a population. The BELLS (Bilingual Early Language and Literacy Supports) project of the **Utah** UCEDD has been conducting research with families for whom English is a second language in order to learn how to promote the development of language and literacy. This UCEDD has also been involved in a pilot research medical home project including various disciplines (medicine, social work, special education, and psychology) and a private hospital corporation to investigate ways to provide wraparound services. When a family brings in a child with a disability for medical treatment, the interdisciplinary staff assess needs in a

comprehensive manner and refer the family to an array of supports such as therapy, rehabilitation, and nutrition services. The UCEDD in **Hawaii** has been researching the inequitable treatment of culturally and linguistically diverse portions of the population as they interact with the vocational rehabilitation process.

Community Services- UCEDD projects in community services help to insure that people with disabilities are able to participate in and contribute to their communities.

The ability to vote is one of the founding principals of the United States, yet people with disabilities encounter numerous barriers, both physical and social, that inhibit their ability to conduct this vital activity. The VOTE Project of the **Oregon** UCEDD at Portland aims to increase the voting knowledge, skills, and participation of individuals with developmental disabilities and to develop recommendations that address the key barriers to voting, such as policies related to guardianship.

Acknowledging the need for services and establishing plans for how to achieve goals are important steps in creating an inclusive community. CAUSE (Communities Actively United for Social Equality) is a nonprofit organization developed with the support of the **New Hampshire** UCEDD. It is devoted to community organizing of strategies to improve supports and services for people with disabilities and their families.

Health- Appropriate health care services are essential for everyone, with or without a disability. But people with disabilities may find healthcare more difficult to obtain for many reasons.

Often health professionals are inadequately prepared to handle the specific needs of people with disabilities. Patients with developmental disabilities may have difficulty with paperwork associated with healthcare, may be inadequately informed of their rights as a patient, or not offered the opportunity to make decisions about their own care.

The Real Choice Project of the **Nebraska** UCEDD is designing and implementing effective improvements in the State's health and long-term care service system to enable children and adults of any age who have a disability or long-term illness to live in the most integrated community setting appropriate, to exercise meaningful choices about their living environment and providers of services, and to obtain quality services.

The **Wisconsin** UCEDD Health Disparities October conference formulated recommendations and action steps that will serve as a blueprint to reduce health disparities for individuals with developmental disabilities. Participants explored organization and finance, training of health care providers, information and advocacy, and rights and responsibilities.

Employment- Employment of persons with disabilities is an ADD area of emphasis because of its great importance nationwide.

Barriers to employment of people with disabilities may include misinformation, fear, or personal prejudice. Systems change in employment means educating the employer and creating a more disability-friendly world. **Alaska**'s UCEDD is involved with "Alaska Works," a statewide

systems change initiative to remove barriers to employment for people with disabilities. The initiative is funded by several Federal grants (RSA, SSA, DOL) and state grants. Dissemination of accurate information regarding people with disabilities is as critical in the employment area of emphasis as it is in all other areas. The **Wyoming** UCEDD's video on employment, *The Payback: A Commitment to Service,* is used to demonstrate how people with disabilities are an untapped employment resource, and how effective vocational training and supported employment can be.

Program Performance

Electronic Data System (EDS)

ADD's Frequently Asked Questions (FAQ) on ADD/ACF Web site.

The Frequently Asked Questions section has been online since last year. You can find the common questions on the Questions and Answers Support Page and if you do not find answer to your question, you can email the question to the ADD staff. This user-friendly resource allows you to:

➢ search for answers on a specific topic
➢ pull up answers related to the one you are viewing
➢ send a question to ADD staff, who reply by email
➢ rate the effectiveness of an answer.

The Questions and Answer section was developed based on the common questions ADD staff have received in the past. New questions and answers are added to the database frequently.

During the Jan - Dec 2002 period, almost 6,800 answers were reviewed on the FAQ section and 82 questions -related emails were sent to ADD to be answered.

The FAQ section can be accessed at *Questions*? on the page banner or at:

http://faq.acf.hhs.gov/cgi-bin/rightnow.cfg/php/enduser/std_alp.php?p_cat_lvl1=69

EDS Update

PPR and SGP forms

Councils:
As of 12/31/02, all 55 Councils' fiscal year 2002 Program Performance Report forms were created and 43 were submitted to regions.

P&A: 55 P&A's fiscal year 2002 Program Performance Report forms were created and 39 were submitted to regions.
49 P&A's fiscal year 2003 Statement of Goals and Priorities forms were created and 40 were submitted to regions.

Upcoming Events & Announcements

Now Available

Publications

Protection and Advocacy Agencies 2001 Outcomes and Highlights. Reasonable requests for additional copies will be honored while supplies last, electronic copies are also available, please contact Nichole Dulin, ADD, ndulin@acf.hhs.gov.

Coming Soon

Publications

ADD Brochure
New! University Centers for Excellence in Developmental Disabilities Highlights

ADDed Resources

National Center on Secondary Education and Transition Web Site
The National Center on Secondary Education and Transition (NCSET) announces that its new Web site, www.ncset.org, is now online. The Web site is an exciting new source of information for professionals and parents supporting transition-aged youth with disabilities.
This new site is presented in an attractive, easy-to-use graphical format, is fully searchable, and provides various audiences with the latest research-based information.

The Arc Web Site on Medicaid Services
The Arc of the United States through a cooperative agreement with the ADD has established a web site on Medicaid services. The web site is designed to be used by consumers of Medicaid services, including people who have developmental disabilities.

Advocates and their family members were surveyed regarding what they thought such a reference desk website should include. Responses emphasized the need to understand the complexities of Medicaid in plain and usable language. Since much of the Medicaid program is determined at the State level, Medicaid information can be accessed for individual states. Currently the following states can be accessed at the website: Oregon, California, Oklahoma, Iowa, South Carolina, Maryland, and New Hampshire. Four other states can be accessed after February, 2003; they are Montana, Wisconsin, New York, and Colorado

Organizations participating in the design of the Reference Desk website besides the Arc of the United States, include the AIMMM, a program of HalfthePlanet Foundation, the Center on Self-determination at the Institute on Disability and Development at Oregon Health & Science University, Oklahoma People First, Family Voices and the ArcLink, Incorporated.

Visit the Reference Desk at http://www.thedesk.info