

ADD Program Update

Administration on Developmental Disabilities

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

Commissioner's Message

Dear Colleagues:

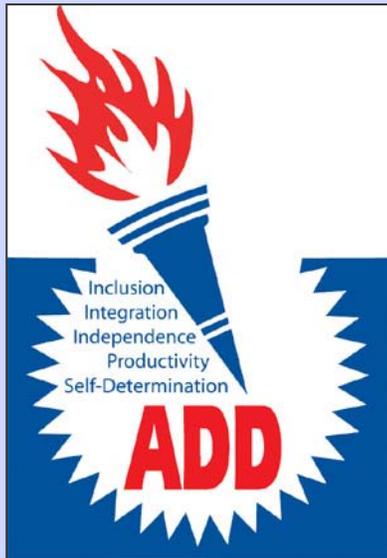
It is with great pleasure that I announce a new recognition initiative sponsored by the Commissioner's Office at the Administration on Developmental Disabilities. The New Freedom "Spotlight Initiative" is intended to acknowledge the innovation shown and outstanding services provided to consumers, by you, an ADD grantee.

Every month, beginning in January 2004, we will select two topics in which we want you to provide to us information about the programs and initiatives that your group is currently undertaking or has recently completed. At the end of each sequence an outstanding program/initiative will be selected as Outstanding Performer among our grantees. All of the Outstanding Performers will be recognized at the Upcoming Commissioner's Forum.

To help us determine which of you will be an Outstanding Performer for the New Freedom Spotlight Initiative we have provided a short questionnaire, which follows. Please answer as many questions as you can while being as thorough as possible in your answers. If there is a single source of information which we can use to locate the answers to our questions, please provide us with the location of that source.

For the month of January we have selected the topics of "**Housing**" and "**Recreation.**" You will have until March 1 to send information on those areas of emphasis. All submissions should be sent via e-mail to acfaddcomm@acf.hhs.gov

Before you begin to complete our questionnaire you may want to review the questions below to stimulate your thought processes:



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Housing

- What are you planning to do to help persons with developmental disabilities transition from institutions to community living arrangements?
- Do all people with developmental disabilities in your area have access to independent housing?
- How many more persons with developmental disabilities have received housing than the previous year?
- How have you affected legislation for housing for individuals with developmental disabilities within the past year?
- What programs are in place to assist, specifically people with developmental disabilities or families with children who have developmental disabilities, in acquiring information about the purchase of a house/condo?
- List any materials or examples that make this area of emphasis unique at your organization
- To what extent are support services available?
- Is there public or private partnership in the area of housing?

Recreation

- Are there planned activities for persons with developmental disabilities that are serviced by your organization that occur on an annual, semi-annual, monthly etc basis?
- How are the means of recreation promoted?
- What is the monthly average number of persons assisted in this area?
- Is there a system in place to show the benefits of recreation to those with developmental disabilities?

Be sure to include personal impact statements (or anecdotes) in your answers, as well as quotes from consumers, where applicable.

Thank you in advance for your participation in this endeavor. Good luck to all, and continue the great work that you do!

Sincerely,

Patricia Morrissey, Ph.D.
Commissioner
Administration on Developmental Disabilities
Administration for Children and Families
U.S. Department of Health and Human Services

New Freedom Spotlight Initiative Questionnaire

January 2004

Grant Identifying Information

- Area of Emphasis:
- Grantee Name:
- Grant Type (*choose from Council, P&A, UCEED, PNS, FS*):
- Project Name:

Contact Information

- Name:
- Phone Number:
- Fax Number:
- E-mail:
- Website:

General Project Information

- Purpose:
- Geographic Focus (*e.g., rural, regional, statewide*):
- Population Focus (*e.g., children, youth, elderly*):
- Collaborating Partners:
- Financial Support:
- Project Start Date/Stop Date:
- Project Status/Plans (*e.g., in developmental stage, service delivery stage, reapplying for funding*):

Project Description

- (*Discussion can include, but is not limited to, case selection, use of consumers, outreach, planning process, curriculum, use of technology, services provided, number of people served, monitoring, project management, unexpected outcomes and impact on legislation.*)

Project Outcomes

- Achievement:
- Products Developed:
- Information Dissemination:
- Replication: (*e.g., donor state, recipient state, suggestions to interested states*)

All submissions should be sent via e-mail to acfaddcomm@acf.hhs.gov

FY04 Final Appropriations Announced

Budget Account	FY 2004 Conference	L/HHS/ED Rescission	Conference less L/HHS/ED Rescission	0.59% Rescission	Subtotal, Rescissions	FY 2004 Enacted
Discretionary Programs						
State Councils on Developmental Disabilities	\$73,515,000		\$73,515,000	\$433,738	\$433,738	\$73,081,262
Protection and Advocacy Agencies	\$38,644,000		\$38,644,000	\$228,000	\$228,000	\$38,416,000
Projects of National Significance	\$11,642,000	\$12,000	\$11,630,000	\$68,617	\$80,617	\$11,561,383
University Centers for Excellence in DD	\$26,962,000		\$26,962,000	\$159,076	\$159,076	\$26,802,924
Subtotal Developmental Disabilities	\$150,763,000	\$12,000	\$150,751,000	\$889,431	\$901,431	\$149,861,569
Voting Access for Individuals with Disabilities	\$15,000,000		\$15,000,000	\$88,500	\$88,500	\$14,911,500
						\$164,773,069

Final FY 04 appropriation amounts. Detailed tables will be disseminated to grantees shortly and will be posted on the ADD web site at <http://www.acf.dhhs.gov/programs/add/index.htm>

Program Progress

Protection and Advocacy Agencies

P&A Skills Building Conference

The P&As kicked off the new year with their P&A Skills Building Conference. It was held January 13-16, 2004 in San Diego, California. The conference hosted the Legal Directors' meeting and the Project Advisory Committee met for their face-to-face meeting on Monday, the 12th. For the first time, a member of ADD's senior management team, Faith McCormick attended. She gave presentations to the attendees on the activities that are taking place at ADD and oriented new P&A staff and Board/Advisory Council members on ADD and the Federal perspective. She was also

available to talk with anyone one-on-one. Commissioner Morrissey's goal is to open the lines of communication and provide opportunities for dialogue with grantees on any topic.

Citizen Advocacy in Nebraska

Nebraska Advocacy Services (NAS – Nebraska's P&A) has developed a citizen advocacy program that is designed to build lasting relationships between people with and without disabilities who share a community. Citizen advocates commit to supporting the needs and rights of their partner with a disability, as though they were their own needs.

NAS describes their citizen advocacy program as "an invitation to people leading full lives in our communities to get to know people who have a disability and who have been or who are at risk of being excluded from their community. Citizen advocates voluntarily enter a relationship which is independent of the citizen advocacy office and the human services system."

NAS stresses that the citizen advocacy program is not a service. By introducing people with disabilities to members of their community, they open the doors to new friendships, activities, and community participation. Citizen advocates fulfill a variety of "roles including: mentor, spokesperson, guide, protector, friend, ally, conservator, payee, guardian, or adoptive parent."

The following is representative example of one citizen advocate relationship:

Even though they are not actually related, you wouldn't know it by looking at them together. Josie compares her citizen advocacy relationship with Roxana with that of an aunt or other extended family member. Josie is very family-oriented, one of the major reasons why she became Roxana's citizen advocate. From the beginning of the relationship in 1996, Josie worked hard to gain the trust of Roxana's parents. Since neither of Roxana's parents spoke English, it was very important that the citizen advocacy office recruit a bilingual advocate. In the course of the relationship, Josie's translation abilities have been put to good use, as many of the people providing medical guidance and advice to the family do not speak Spanish. Josie worked hard to find written information about diabetes in Spanish, so Roxana's aging parents could learn about and take the necessary steps to protect their daughter's health. Knowing that complications from diabetes can damage a person's eyes, Josie also arranged an eye examination for Roxana, and ensured that Roxana and her mother learned how to control blood sugar levels with insulin and diet. Aside from medical issues, Josie also took care to see that Roxana became active in the community and with children her own age, through involvement in the Girl Scouts, programs sponsored by the parks department, and a volleyball team at her school. With the encouragement of Josie and Roxana's parents, Roxana is currently learning how to read and speak English.

State Councils on Developmental Disabilities

SCDD TA Contract

The ADD Technical Assistance Contract for State Councils on Developmental Disabilities is awarded to the National Association of Councils on Developmental Disabilities (NACDD). The goals of the contract are:

1. Coordinate information and technical assistance requests
2. Build upon Council measurement system and reporting process to include requirements of the DD Act
3. Support effectively functioning Councils

In order to accomplish the goals, NACDD will implement the following tasks:

- Develop and implement on-site technical assistance, conference calls, materials, and information packets on topical areas as determined by the Councils and ADD, such as the New Freedom Initiative, self-advocacy, Council data-collection procedures, network collaboration, informing policymakers, and Council bylaws.
Information packets will be specifically developed for new Council Executive Directors and Council Chairs.
- Develop a TA Advisory Committee to be co-chaired by ADD staff and a representative of Councils. The Advisory Committee advises the contractor on matters of general policy and procedures, and general planning, assessment and evaluation.
- Develop and jointly host with ADD a conference that includes information on topical areas, and provides training to Council staff and members.
- Utilize experts on consumer satisfaction, performance measurement, and marketing to further develop reporting systems and marketing strategies for Councils.

NACDD will utilize an electronic mailing list and a newly devised TA Plan to determine areas of TA and specific TA requests by Councils. The NACDD Project Manager is Susan Madison. The ADD Project Officer is Mary Beth Greene.

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

Montana UCEDD Celebrates 25th Anniversary

The University of Montana Rural Institute (UCEDD) is celebrating its 25th anniversary this year. Since 1978, enormous changes have occurred within the organization and in the state of Montana. People with disabilities have a stronger voice and are given a wider range of opportunities than ever before. Despite this progress, much remains to be done and the Rural Institute plays a vital role in supporting increased independence, productivity, integration, and inclusion. Especially important is the organization's focus on developing solutions to the unique challenges of living, working and recreating with a disability in rural settings. The Institute is currently under the direction of Timm Vogelsberg, Ph.D. For further information on the Rural Institute and its current activities, please access: <http://ruralinstitute.umt.edu/>.

For more information on UCEDD programs contact Jennifer Johnson at ADD, jjohnson1@acf.hhs.gov

Federal News and Events

Autism Summit

In response to growing public health concerns regarding rising rates of autism, the [U.S. Department of Health and Human Services](#) and the [U.S. Department of Education](#) organized the 2003 "Autism Summit." This conference was designed to engage in a public dialogue concerning issues such as implementation of optimal services, early screening and diagnosis, and biomedical research. A 10-year Autism Research Roadmap was announced at the Summit by Tom Insel, M.D., Director of the National Institute of Mental Health.

The conference included keynote sessions from Rod Paige, Secretary of the U.S. Department of Education and Tommy Thompson, Secretary of the U.S. Department of Health and Human Services. There were also targeted sessions to cover each specific content areas related to autism. An outline of the issues addressed at the Summit can be found by clicking on this link: [Summit Outline](#). The 2003 "Autism Summit" complements the activities of the several government organizations that have been participating in the [Interagency Autism Coordinating Committee](#) since its inception in 2001. The IACC was formed in response to a mandate of the Children's Health Act of 2000 and holds regularly scheduled semi-annual meetings.

Federal Interagency Coordinating Council

Staff from ADD participated in the December quarterly meeting of the Federal Interagency Coordinating Council (FICC). Established in 1991 under the Individuals with Disabilities Education Act, the FICC is an advising body to a number of cabinet secretaries including the departments of Education and Health and Human Services regarding early intervention services for young children (birth to age 5) with, or at risk for, disabilities and their families. A highlight of the meeting was a presentation on medical homes by a cross-disciplinary group from Arizona. They discussed mechanisms for effective collaboration across providers in the medical and early intervention fields to meet the needs of young children and their families. Rebecca Landa from the Center for Autism and Related Disorders at the Kennedy Krieger Institute and Stanley Greenspan from The George Washington University Medical Center also presented on issues related to assessment of and services for children on the autism spectrum.

Upcoming Events & Announcements

Announcements

ADD's New Office Space

ADD has completed their much-anticipated move to the fourth floor of the Hubert H. Humphrey Building, at the Department of Health and Human Services. All staff have moved into their new spaces, and the computers, phones, and faxes are up and running. Thanks to everyone for bearing with us during this transition.

ADD's address remains unchanged with the exception of the mail stop. For reference our mailing address is:

ADD/ACF/HHS
Mail Stop: **HHH 405 D**
370 L'Enfant Promenade
Washington, DC 20447

All staff members have maintained their previous phone numbers. The new ADD fax numbers are 202-205-8037 and 202-690-6904. Your intended recipient will be able to tell you which is most convenient to their space.

Upcoming Events

Advocate for Action

The Governmental Affairs Seminar, *Advocate for Action*, sponsored by Arc, AAMR, AUCD, and UCP will be held March 21-23, 2004 at the Mayflower Hotel in Washington, D.C. Preliminary materials and registration information are available now. Information on how to register is posted on the AUCD web site at <http://www.aucd.org>. View the Invitation/Call-to-Action at http://www.aucd.org/meetings/GASeminar/seminar_invitation.htm

National Women's Health Week

May 9 – 15, 2004 – In 2004, the Department wants to increase the impact of National Women's Health Week and its signature event by increasing the number of health providers who sign on and agree to offer preventive services to women on that day, as well as the number of organizations hosting events. Organizations are asked to volunteer to host an event during that week.

Last year, more than 1,000 events, proclamations, and health screenings occurred in every state and thousands of women received preventive health information and services. The Department hopes to expand the impact of this year's National Women's Health Week by inviting more organizations to become National Women's Check-Up Day providers or to host an event during the week. Providers agree to encourage women in their community to make appointments for preventive health services on May 10, 2004. Example services may be blood pressure checks, pap tests, mammograms, diabetes tests, HIV/AIDS tests, and other health screenings. Event sponsors agree to host a community event to improve understanding and awareness of women's health issues during May 9-15, 2004. All providers and event hosts will be listed on the National Women's Health Information Center Web site and may order free promotional and educational materials at <http://www.4woman.gov/whw>, while supplies last.

Provider or event hosts can sign up by completing the appropriate form and submit no later than February 15, 2004. Visit the National Women's Health Week Web site at <http://www.4woman.gov/whw> for the sign-up forms. You can also contact Sharon Ricks of the Office of Women's Health, sricks@osophs.dhhs.gov, for more information on this program.

Correction

In the November 2003 issues of ADD Update, we accidentally provided an incorrect title for a micro-enterprises project conducted by the New York State Developmental Disabilities Planning Council.

The article read:

"New York – Path Maker Recruitment and Retention Viability of self-employment as a vocational day program choice for person developmental disabilities is being tested by training providers and consumers/families on necessary step in developing enterprises."

In fact, the beginning of that statement should read:

"New York – Self-Employment & Micro-Enterprise Viability."

Thank you to NYS DDPC for bringing the error in the project name to our attention.