

ADD Update

Commissioner's Message

December 2006

An education is one of the most important things we can give our children. Education levels the playing field and ensures that *all* children have the ability to achieve their goals, regardless of background and financial circumstances. Education is the key to our children's future, and to the American dream.

Education, therefore, is a major component of the work that ADD's grantees do. Developmental disabilities, by definition, begin before age 22. Therefore, the vast majority of individuals with disabilities will, at some point, require assistance with education-related issues.

ADD firmly believes that every child has the right to belong to a community, and to share fundamental experiences with family, friends, and neighbors. Children with developmental disabilities have a right to a free, appropriate education in their local schools, rather than being isolated in separate special education programs. Working side by side with peers with varied skills and strengths helps all children to develop the skills to live in a diverse community in the future.

A related area of great interest to ADD is the issue of school-to-work transition. For any student, the period after graduation is difficult, as he or she learns to live alone, handle finances, and make decisions affecting the future. Students with developmental disabilities face unique challenges during this transitional period. Without appropriate support, the loss of the structure and comforts of high school can be upsetting, and the adult world can be overwhelming. ADD strongly believes that one of the best ways to help an individual with developmental disabilities build a strong foundation for independent adult living is to provide both a solid education and a strong support network as the individual transitions into the working world. Education provides a bridge between individuals and their dreams.

I continue to be impressed by the work of ADD's grantees in this area, and by the many innovative programs that are helping to ensure that individuals with disabilities have the education and tools they need to make their dreams a reality. Effective, inclusive education helps not only individuals with developmental disabilities; it impacts all Americans and improves our Nation as a whole.

As 2006 draws to a close, I want to extend a heartfelt thank-you to all of ADD's grantees. I would also like to express my appreciation to the many individuals and organizations who worked so hard, and so effectively, to improve the lives of individuals with developmental disabilities, and of all Americans.

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ADMINISTRATION ON DEVELOPMENTAL DISABILITIES

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



Spotlight on Self Advocacy

In October, Michael Long assumed the role of Executive Director of People First of California. In taking this position, Long made history. He became, as far as we know, the first self-advocate to ever become the paid director of a statewide self-advocacy organization.

On December 12, 2006, Long met with Commissioner Pat Morrissey and Sally Atwater, executive Director of the President's Committee for People with Intellectual Disabilities. He discussed his plans for his tenure as Executive Director, and his desire to meet with self-advocates across the State of California. Commissioner Morrissey congratulated Long on his achievement, and expressed her encouragement for him in his important role as a self-advocate leading self-advocates.



Michael Long (right) meets with Commissioner Pat Morrissey (left) and Sally Atwater at ADD's offices in Washington, D.C.

The goal of self-advocacy, after all, is to ensure that the voices of individuals with developmental disabilities are heard and understood. And who better to serve as a self-advocacy leader than someone who knows, first hand, what the lives of self-advocates are like.

“Self-advocacy is important because you learn how to speak for yourself,” says Long. “And that’s important because there are so many people who’ve never had the chance to speak up and speak out. This gives them a new breath of opportunity, a chance to learn new tools.”

One of Long’s goals as Executive Director is to train other self-advocates to take on similar professional leadership positions. He also wants to focus on training self-advocates in public speaking skills, and is committed to People First’s mission of self-advocates training self-advocates.

Long comes to this position well-qualified to bring his voice to the table and serve as a representative of self-advocates. He was appointed to the California Department of Developmental Services by former Governor Pete Wilson, and he served there for fourteen years as a liaison between the Department and the disability community. He made recommendations, participated in decision-making processes, used his voice to advocate for the real needs of individuals with disabilities.

Long believes that his tenure at the Department of Developmental Services was a valuable experience, and looks forward to the new challenges and experiences of his new job.

“One thing I like about this job is that I’m constantly with my peers,” says Long of his new position and his daily involvement with other self-advocates. “At the Department of Developmental Services, I was the sole consumer. I sometimes felt frustrated and lonely. I’m excited about interacting with my peers. If I stumble, I’ll have other people to rely on, so I can be more confident as their leader.”

Network Collaboration

Collaboration to Impact Public Policy in the District of Columbia

On Friday, December 15, representatives from the District of Columbia DD Network arrived at ADD's office to meet with ADD staff and hammer out a strategy for a new collaborative project.

The DC DD Network, which consists of the Council on Developmental Disabilities (Council), the Protection and Advocacy System (P&A), and the University Center for Excellence in Developmental Disabilities (UCEDD) is known collaboratively as "The Triad." The Triad has successfully worked as a unit on several past endeavors, including:



ADD staff and DC DD Network members meet to discuss collaboration

- Conducting focus groups in different wards of the city to elicit input from individuals with developmental and other disabilities and their families as each entity developed its annual plan of activities; and
- Developing a strategic plan of action to undo proposed emergency legislation to amend the Home and Community based Service Waiver, to serve only individuals with mental retardation, eliminating individuals with other developmental disabilities.

The purpose of the December 15th meeting was to pick a new issue area to focus on as a team, and to outline goals and next steps. ADD staff will join the DD network as a full partner in this initiative. In attendance at the meeting were Toni Fisher (UCEDD), Tawara Goode (UCEDD), Mary Brown (Council), Jane Brown (P&A), Commissioner Pat Morrissey (ADD), Faith McCormick (Director, ADD), Jackie Ezzell (ADD), Mary Beth Green (ADD), Ophelia McLain (ADD), and Rebekah Yeager (ADD).

After much discussion, a decision was reached regarding the focus of the DD Network's new collaborative effort. The team will work together to affect public policy around disability services in the District of Columbia.

The timing of this initiative is ideal. Adrian Fenty was recently elected as the new Mayor of Washington, and will take office on January 2nd, 2007. Central among his stated goals and objectives is a desire to reform and improve the DC Public School System, including special Education programs.

ADD looks forward to working with the DC DD Network to ensure that public policy in Washington reflects the needs of *all* District residents, including those with developmental disabilities. The DD Network will document their efforts, ensuring that the public policy work done here in our Nation's capital will be easily replicable across the country.

ADD Photo Library

Over the past several months, ADD has been asking grantees to submit photographs that illustrate the effect their programs have on the lives of individuals with developmental disabilities.

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, health care, 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.

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 and/or sample photographs can be obtained by contacting Rebekah Yeager at rebekah.yeager@acf.hhs.gov.

A reminder 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, 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, etc.
- We're looking for photos that show individuals with disabilities of all kinds engaged in a wide variety of activities. 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.
- Be creative. Send us pictures that tell a story.

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. The majority of Westat's work has focused on developing draft performance standards for each ADD grant program (DD Councils, P&As, and UCEDDs), as well as for collaboration. Much of this has been accomplished through collaboration 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

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

DD Council Working Group

Jamie Wolfe, Delaware
Debra Dowds, Florida
Vendela Collins, Michigan
Becky Maddy Harker, Iowa
Richard Weathermon, Nevada
Waynette Cabral, Hawaii
Bill Lynch, 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

Through the working groups, Westat has been able to tap into the expertise of the ADD grantees and develop draft performance standards that truly reflect the work of the ADD grantees. The working groups continue to meet and refine the language of the draft performance standards.

To keep all grantees informed about the project, Westat conducted presentations at the DD Council and UCEDD meetings this fall. The presentation provided an update on progress to date and provided an opportunity to look at future activities.

At the end of October, Westat held a meeting of the Independent Evaluation Advisory Committee.

This two-day meeting provided the Advisory Committee an opportunity to hear about progress to date as well as discuss the draft performance standards. It was a very productive meeting that provided Westat with constructive feedback on the project.

Westat hopes to complete the development of the draft performance standards by February 2007. The next step will be presenting the draft performance standards to four validation panels. There will be a validation panel 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. Westat plans to convene the validation panels in May 2007.

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 202-690-598

Program Progress

Minnesota P&A

In St. Cloud, Minnesota, three high school students wanted to participate in a rite of passage anticipated by teenagers across the country – learning to drive a car. The three students, who are deaf, called local driver’s education schools to sign up for classes. They requested a sign language interpreter, an accommodation that all of the schools refused to provide.

The students and their parents contacted the Minnesota Disability Law center, Minnesota’s P&A, and sued the schools, charging that they violated federal and state human rights laws by refusing to provide interpreters. The schools then agreed to settle the case and provide interpreters not only for these particular students, but for any students with hearing impairments who wish to take driver’s education in the future.

Massachusetts UCEDD

The Institute for Community Inclusion (ICI), Massachusetts’ UCEDD, continues to participate in community outreach in postsecondary education options for individuals with intellectual disabilities. Since the initial year of this ADD grant, ICI has been involved with three community colleges in the design and development of transition and postsecondary education programs for students with developmental disabilities and other intellectual impairments. This effort has led to a model program with Quinsigamon Community College and the Worcester Public Schools and the movement of 72 students over a three-year period through their high school transition to a community college setting and then into employment. The model that is used includes the use of person-centered planning, full inclusion in the community college, and the career development efforts, involving the One Stop Career Center in the Worcester area.

Students typically complete a single year in the community college in a non-matriculated status (it is not likely that these students will be able to enroll and meet the typical academic criteria of the community college) and then use the resource rooms and placement supports of the One Stop. The use of mentors and the integration of the educators in the high school with the community college has been a considerable factor in the success of this program. This program has served as a national model for a fully inclusive approach to transition for students with developmental disabilities considering postsecondary options. As a component of the technical assistance to educators in postsecondary transition planning, the ICI has developed and maintains the only national information resource on postsecondary education for students with intellectual disabilities. Our website <http://www.Thinkcollege.net> now lists well over 100 programs nationwide where high school supports are available for students with intellectual disabilities to participate in postsecondary education settings. This is a first-of-its-kind listing of these resources and as such has garnered considerable attention at the federal, state and local levels among students with intellectual disabilities, family members, educators and policy makers.

New Jersey Council

In order to encourage and promote proactive and innovative inclusive education strategies, the New Jersey Council on Developmental Disabilities sponsors a Fellowship Program in Inclusive Education. The Fellowship Program was created to encourage, acknowledge and expand promising practices in including children with disabilities in all aspects of the public education system. Any individual or group of individuals who encourage the inclusion of students with disabilities in all areas of school life including academic and non-academic activities are eligible. Fellows must embrace the concept that children with disabilities have the right to be educated in the least restrictive environment and be committed to making that concept a reality for their students.

Nominees must demonstrate a commitment to the identified practice or concept. The utilization of fellowship awards must be explicitly described. Fellows will be required to participate in an activity to publicize the selected fellowship activities in early summer. More information can be found at <http://www.njddc.org/fellowship.htm>.

Program Performance

ADD's three DD network programs work with the DD population to maximize student potential to obtain the most complete and inclusive education. Since DD programs provide distinctly different services and uses different approaches, the outcome data should not be compared. Following are examples of how DD Program helped the DD Population:

OLDC Program Performance Reports FY 2005

- 35 Councils increased the knowledge, capabilities, and self-advocacy skills of 19,803 students with developmental disabilities and their families, to ensure the schools they attend are providing inclusive, appropriate, and local educational opportunities.
- 57 P&As worked with parents, educators, school administrators, and policy makers to ensure

that 11,736 students with developmental disabilities gained or maintained access to appropriate educational opportunities in their local area.

AUCD NIRS FY 2006

- 63 UCEDDs supported projects that allowed 371,720 people to gain information and increase availability of inclusive and appropriate education for individuals with developmental disabilities.

For any questions, please contact Syed Rafiuddin at srafiuddin@acf.hhs.gov

We Want to Hear From You:

The next issue of the ADD Update will focus on accessible recreation. Please send any suggestions, information, stories, and photographs to rebekah.yeager@acf.hhs.gov.