

Commissioner's Message

Our staff began work on this issue of the ADD Update with the intention of focusing on youth with developmental disabilities and addressing back-to-school issues important to the DD community. Then, as the school year began in many States, two major hurricanes struck, changing the landscape and the outlook across the Gulf Coast.

My focus, and the focus of the ADD staff, is now on meeting the needs of Americans with disabilities whose lives were affected by Hurricane Katrina and Hurricane Rita. Our thoughts and prayers are with the residents of the devastated areas, and we are committed to helping them rebuild their lives. While most of the hurricanes' impact will be felt in Louisiana, Mississippi, Texas, and Alabama, evacuees will be housed across the country, and their needs must be met on a national scale.

Along with Faith McCormick, Margaret Schaefer, and Jennifer Johnson, I spent several days in Louisiana, Texas, and Mississippi in order to see the effects of Katrina and develop a plan for helping individuals with disabilities to deal with the aftermath of the hurricane.

After Hurricane Rita hit, Margaret and Jennifer returned to Louisiana, and are working in shelters and with grantees to ensure that the needs of individuals with disabilities are met. While both hurricanes have received extensive media coverage, there has been almost no reporting of the unique challenges faced by individuals with developmental disabilities who inhabited the region impacted by the storms. It is ADD's goal and responsibility to make their voices heard, and to ensure that they receive the help and support that they need in order to begin to rebuild their lives.

Among the challenges facing us after the storms are issues related to finding accessible housing, helping people with disabilities find or maintain access to needed services and supports, addressing medical and health concerns, and educating thousands of displaced students with disabilities.

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ADMINISTRATION ON DEVELOPMENTAL DISABILITIES

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



ADD has established a web page devoted to individuals and families affected by Katrina and Rita. This page can be viewed at <http://www.acf.hhs.gov/programs/add/resources/hurricanekatrina.html>. Over the next few weeks we will continue to populate it with new information that will assist individuals and families who have relocated. ADD will provide information to all grantees about portability of eligibility for federal programs. Working with its University Centers, ADD will reach out to the U.S. Department of Education to suggest that we develop family-friendly transition guidelines for children with disabilities entering a new school. ADD will join SAMHSA in supporting Protection and Advocacy Agencies which have begun and intend to expand efforts to assist individuals and families secure benefits and find housing.

This issue of the ADD Update contains information and resources regarding the hurricanes as well as the original content on youth with developmental disabilities. Over the next few weeks, we will be putting together a special issue of the Update focusing on the DD Network's efforts to help the victims of the hurricanes. If you have any information, resources, or stories related to Hurricanes Katrina and Rita, please send them to ryeager@acf.hhs.gov.

ADD remains dedicated to the belief that the American dream belongs to everyone, and committed to the goal of helping all of the victims of the recent hurricanes to regain what they have lost and move forward with their lives.

Network Collaboration

An Historic Meeting – Developing a Truly Integrated Kentucky DD Network!



On August 18, 2005 the three DD Network agencies for Kentucky – held *the first ever* joint meeting of its respective agency Advisory Councils, in Lexington. The purpose of the meeting was to develop a common target in a major life area of emphasis that each of the agencies would commit time and resources to achieve.

In order to prepare the respective Boards and agencies for this meeting, the agencies completed several initial steps to build “strategic collaboration.” First, they developed a joint Kentucky DD Network Brochure and website (www.KYDDNetwork.org), created to organize their efforts and give information to the community about each agency and what they are doing collectively. Secondly, they produced the first edition of their joint newsletter, the *Kentucky Developmental Disabilities Network*, published earlier this spring. Thirdly, they developed a *joint needs assessment*, designed to collect information from individuals with disabilities, family members, professionals and policymakers, about the key needs in the State. Finally, at individual board meetings earlier this spring, information was presented about each of the other agencies, so that each of the Boards would understand the complementary roles of all three agencies.

At the joint meeting on August 18th, the IHDI Consumer Advisory Council, the Protection and Advocacy Developmental Disabilities Advisory Board, and the Kentucky Council on Developmental Disabilities reviewed the results of the needs assessment, and broke into collaborative small groups under the facilitation of Jo Allard Krippenstapel, to develop a common target in a major life area of emphasis.

The five small groups were based on the five areas of emphasis rated as the greatest needs in Kentucky: Education, Employment, Health, Transportation, and Quality Assurance. Each small group developed a proposed project based on their respective needs data, presented that project to the larger group, and through a series of votes, everyone selected one project to initially target joint resources. Kentucky's first joint initiative will center on a mentoring project in self-advocacy for youths ages 11 to 17.

Faith McCormick, Director of the Office of Programs for ADD, provided opening remarks. Joe Caldwell, AUCD Policy Fellow, and Sharon Hauss, Co-Chair of the AUCD Council on Consumer Affairs, were present as observers for the day. The next steps will be to begin to formulate action steps for addressing the common priority in self-advocacy. Each of the respective Boards will provide guidance in shaping the role that individual agencies will play in addressing this target.

Announcements and Recent Events

UCEDD Annual Report Format

On August 8, 2005, the Office of Management and Budget (OMB) approved the UCEDD Annual Report template. The Annual Report template establishes a uniform system for UCEDDs to provide information to ADD regarding progress on their activities. Beginning July 30, 2006, UCEDDs will follow this format when submitting their Annual Report to ADD. If you have questions about the UCEDD Annual Report template, please contact Jennifer Johnson at 202-690-5982 or jjohnson1@acf.hhs.gov.

2005 Fiscal Management Conference

On July 26 -- July 29, 2005, ADD, working with the Center for Mental Health Services (CMHS) and the Rehabilitation Services Administration (RSA), sponsored the 2005 Fiscal Management Conference in Portland, Oregon. This effort is supported by a training and technical assistance contract funded by the three federal agencies. The contractor is the National Disabilities Right Network (NDRN), formerly known as the National Association of P&A Systems (NAPAS). This conference was one of the four major training and technical assistance conferences supported this year.

The first day of the conference was set aside for new fiscal managers to focus on issues that all P&A fiscal managers should understand. This session was led by two experienced P&A fiscal managers: Kelli Kaufman from Montana and Shelia Mullis from Tennessee. That day included some lively discussions on topics such as cost principles, indirect cost rates, budgeting, and fiscal reporting,

During the next three days, issues vital to all P&A fiscal managers were explored. A highly charged session reviewed fiscal issues that were identified during fiscal site-visits to P&As, and featured the new fiscal expert from ADD, Cheryl Torbert, and the CMHS fiscal expert, Roy Friday.

Other issues that were visited at the conference regarded various topics of interest to fiscal managers, including:

- Report submission issues;
- Human Resource management, including EEO issues;
- Audit issues; and
- Board Orientation.

In exploring these topics, the managers were sharing with each other their experiences regarding how to deal with specific challenges. Additionally, policy opportunities were identified, and this was viewed as a valuable aspect of the conference by the federal staff attending from ADD and CMHS. Some of the trainers were outside experts who had expertise that is needed by P&A fiscal managers. Other trainers were seasoned P&A fiscal managers with experience in specific areas.

As a consequence of these conferences, fiscal management at P&As is improving, and challenges are being addressed.

The 2005 Technical Assistance Institute and its impact on the youth grantees.



The two-and-a-half day 2005 TA Institute convened on Monday, July 25, 2005 at the Ritz-Carlton, Pentagon City. The youth grantees gathered to listen to Commissioner Morrissey's welcome and a variety of other presentations which included a session on Cultural Competency. Their comments on the Cultural Competency session included "I never thought of disability as a culture," and "we just have to listen to each other to understand each other." The young people got lessons on Leadership Development in the areas of outreach and dissemination.

There was an opportunity to build advocacy skills in a youth-led Advocacy session, where the young people led teams in responding to a variety of questions that affect them on a daily basis. A wide range of disabilities was represented and everyone was enlightened as to the different needs of persons with developmental disabilities, as well as being sensitive to the terms used when communicating with persons with cognitive disabilities.

Other sessions provided continuous learning opportunities as well as opportunities to share with other grantees on topics such as transition, employment and collaboration. The TA Institute gave the attendees tools to use when they returned to their respective projects. Those tools included relationships that could serve as bridges to their future efforts. Materials in various forms were included, which gave the readers instructions that they could use when faced with the same challenges as the presenters did. This TA Institute gave the attendees an opportunity to provide and receive technical assistance. They returned to their centers with a wealth of information, to aid in their journey of impacting the lives of youth and emerging leaders with developmental disabilities.

Spotlight On: Emerging Leaders

Micah Fialka-Feldman was in inclusive education in the Berkley School District from elementary through his high school years. He has a cognitive impairment and was supported by the general and special education staff, including a paraprofessional, peer tutors (LINKS), a Circle of Friends and use of creative modifications and accommodations in classes to meet his needs. He excels in the use of computers and soft ware programs. Micah uses Screen Reader, Power Point, and a voice-to-text program called Dragon Point and Speak which enhance his independence to learn and communicate. He actively participates in his educational planning and IEPC's. He uses Power Point presentations and includes his friends in the planning.

His Leadership Activities include: CEC "YES I Can" Award in 2004 for Self-Advocacy; attended the 5-day Michigan Youth Leadership Forum (MYLF) in 2001; Board Member of the national youth advocacy organization, KASA (Kids as Self-Advocates); Intern for State Representative Andy Meisner; Advisor to United Synagogue Youth (USY) Teen Group; and Avodah staff member at Camp Tamarack.

His Publications include: "I wanted to go to college and my dream came true;" "Scott has a Good Mind and a Good Smile," Inclusion News 2002. (www.inclusion.com); and a chapter in a new book, *New Horizons: People with disabilities share their college experiences.* (www.ahead.org)

Micah represents the Kids as Self Advocates (KASA) project and works in Michigan. www.fvkasa.org

Edward Flores is a youth resource specialist for the South Los Angeles Youth and Young Adult Determination Center (SLAYD). As a youth resource specialist, he presents at special education classes, and participates in local and regional health fairs. His bilingual skills allow him to be SLAYD's main contact with the Hispanic community. This community is one of the major target areas of the SLAYD project. Edward also serves as a Unit Assistant on an inpatient floor at Children's Hospital of Los Angeles. The pediatric patients there are those who have undergone one or more surgical procedures. He has been enjoying this part-time job for 4 ½ years.

Edward was born with Spina Bifida. Most of his work experience has been with the Spina Bifida population. He has served as a mentor to children and teens with Spina Bifida for about eight years. In High School, Edward was part of a Magnet program which focused on legal issues. It was then that he became interested in law and the way in which the legal system works. He has the desire to continue his education, which may involve law some day. Edward says that he has earned a well deserved degree from the 'University of Hard Knocks.'

Edward represents the South Los Angeles Youth and Young Adult Determination Center (SLAYD), and works in California. www.slayd.com

Betsy Valnes actively serves as the Executive Director for the National Youth Leadership Network. She contributes to an annual conference, mentorship, public information, and research. She also serves as an Ex Officio/Mentor with the National Council on disability Youth Advisory Council. On

an international level, she contributes to the Roundtable Consortium for the National Clearinghouse for Disability and Exchange and as the sole U.S. youth ambassador for the International Duke of Edinburgh Award Scheme, advocating for Inclusion for youth with disabilities and youth at-risk world-wide. She recently participated in and presented at the following: the 8th International Congress on Including Children with Disabilities and the Rehabilitation International World Congress in Norway; the United Nations and World Bank collaboration effort entitled, “Youth, Development and Peace” in Bosnia; and the International Award Scheme in Scotland. Betsy also participates in state programs such as the State Independent Living Council, the Traumatic Brain Injury Alliance, and the Youth Leadership Forum. She strives to further her contribution to the movement through presentation, round-table solutions, and research on state, regional, national and international levels.

Betsy represents the National Youth Information Center, and works in South Dakota. www.nyln.org

Program Progress

Updates on the Youth Grantees

Fifteen organizations across the country were awarded three-year grants to undertake projects which enable them to design information, resource, and training centers for youth with developmental disabilities. Grants were awarded to organizations in California, Delaware, District of Columbia, Iowa, Illinois, Maryland, Minnesota, New Mexico, North Carolina, Oklahoma, Oregon and Washington. Centers will impact youth and individuals with developmental disabilities on national and local levels. The grantees are currently wrapping up the first of the three-year grant and have exhibited their excitement upon involving youth and emerging leaders with developmental disabilities, in these projects.

Wyoming Council- Crossroads Radio Show

In August, the Wyoming Governor's Council on Developmental Disabilities announced the debut of the Crossroads Radio Show. Aired each Saturday, the show features guests who are experts and advocates in the field of developmental disabilities, and all show topics relate to disability and advocacy issues. Local broadcast times are as follows:

- 11 a.m. Casper-- KTWO-AM 1030
- 11 a.m. Sheridan--KZZS-FM 98.3
- 1 p.m. Cheyenne-- KGAB-AM 650
- 1 p.m. Gillette -- KIML-AM 1270
- 1 p.m. Cody-- KODI-AM 1400
- 1 p.m. Jackson-- KSGT-AM 1340
- 1 p.m. Worland-- KKLX-FM 96.1
- 1 p.m. Green River/Rock Springs--KFRZ-FM 92.1
- 1 p.m. Riverton--KVOW-AM 1450

North Dakota UCEDD Leadership Conference

North Dakota held its second annual Youth Leadership Conference in Minot on June 7-9, 2005 on the campus of Minot State University. The theme for the 2005 conference was “Reach for the Stars”. Leaders in business, education and the disabled community were brought together to produce this conference.

The conference had two major goals. The first was for the students to be in a safe environment where they were allowed to have fun and be educated about the disability culture. The second was to encourage them to become leaders in their own lives and in their communities.

The presenters for the conference consisted of two individuals from the Fargo ND area who have disabilities and have completed a college education and are contributing to their communities. Kathie Snow, a nationally known speaker in the disability community, and author of the newsletter *Disability is Natural*, gave a presentation on the history of people with disabilities. And finally, Bob Ash from Indiana spoke to the students about being the best you can be. Bob is the founder of his own company, *Life Lessons*, and has provided training to over 900 organizations and businesses.

Montana Council Grant Brings Additional Resources to Rural Eastern Montana

For two years (2002-2004), the Montana Council on Developmental Disabilities (MCDD) funded the Graduate to Work Project (GTW), a collaborative effort between The University of Montana’s Rural Institute and the Missoula County Public Schools. The purpose of GTW was to implement a customized model of career planning in Missoula high schools and to pilot collaborative agreements between Vocational Rehabilitation (VR); Workforce and Developmental Disabilities (DD) agencies; families and schools to promote transition from school to work.

Schools found that the model not only enhanced transition planning and employment experiences, it also resulted in improved Individualized Education Plans (IEPs) and curriculum. Feedback from Missoula-based employment vendors indicated that when the customized model was used, job development was more individualized, streamlined, and thus more cost-effective for VR.

The Council authorized a third year of funding (October 1, 2004 through September 30, 2005) and requested that the Institute share information about this model with schools, employment agencies, DD staff, case managers, Workforce personnel, VR counselors, students and families in the extremely rural and remote areas of Eastern Montana.

The focus of Eastern Montana Graduate to Work (EM-GTW) is on the provision of training and technical assistance around customized employment, Social Security Work Incentives, self-employment, and collaborative funding of transition from school to work for students with developmental disabilities. EM-GTW staff provides training at no charge to schools, agencies and families.

In addition, staff created two internet listservs (open to all interested parties) – one to share information about general transition topics and the other to address issues specific to Social Security and working beneficiaries. They also established an internet-based question/answer forum to enable people to post questions and receive responses related to Social Security and Work Incentives.

MCDD recently awarded a fourth year of funding to allow the Rural Institute to further build capacity in eastern Montana. Project staff will mentor local VR, DD, school and adult agency staff, as well as families and individuals with developmental disabilities, to implement the customized model with two adults and two students. The Rural Institute will provide both on-site and long distance technical assistance and training.

Program Performance

Examples of DD Network Activities During FY 2004 in Youth Transition to Employment Issues

Online Data Collection (OLDC) Program Performance Reports: DD Councils

Colorado

“The Council’s Education Committee worked cooperatively with the Employment Committee to oversee the Supported Employment and Transition grant. The Committee also monitored state and national policy and legislative efforts, with particular attention to the reauthorization of IDEA”

Florida

”As a result of last year's research activities, education focus this year was to extend opportunities for input regarding transition issues, and to provide opportunities to educate others about inclusive practices. A transition conference was conducted to determine the critical issues in providing transition services for students exiting high school”

North Dakota

“The statewide Pathfinder Family Training and Information Center in Minot received SCDD funds to maintain a Transition and Employment Project. Under this project, the Center employs a transition coordinator to provide focused training and transition services for parents of students with disabilities beginning at age 14, or younger, if appropriate to unique needs. This project seeks to enable both parents and students alike to become knowledgeable, active participants in developing and implementing student transition plans.”

South Carolina:

“South Carolina's State Transition Coordinator is housed in the state's DD Council Office. This individual works with the state's school districts to assist in improving programs for students with developmental disabilities. Some schools are looking to create occupational diplomas where students get recognized for job skills rather than a certificate for attending classes. This allows them to find jobs upon graduation”

P&As:

District of Columbia:

“D. C. P&A have educated the schools and school system about the need to ensure transition services is provided before the student exits the school system.

We represented a student who graduated without receiving appropriate transition services. We successfully advocated that the school allow her to re-enroll in the school to learn employment-related skills”

Nevada:

DALC participates on a subcommittee of the state Vocational Rehabilitation Advisory Council which specifically addresses transition issues statewide. NDALC also provided training to special education teachers in a graduate level class at the University of Nevada-Las Vegas on transition services. NDALC also participated by providing information on transition services and NDALC services at a transition forum for students in the Clark County school district, the fifth largest school district in the country.

National Information and Reporting System (NIRS)

UCEDD:

Iowa

Super Seniors Transition Project Website: <http://www.uihealthcare.com/cdd>

Project Description: The purpose of the Super Seniors project is to transition 60 students with disabilities from two rural and one urban school district into full-time, competitive employment that matches their career goals. The project will replicate proven practices reflecting state-of-the art research and proven theoretical models and curricula, including:

1. Person-Centered Planning (PCCP) facilitated by professionals, parents and people that have participated in successful PCCP, integrating the Choice-Maker self-determination vocational curriculum into the process.
2. Senior year work experiences focused on the career goals generated through the PCCP; and
3. A Super Senior, 5th year of community intensive vocational training.

The project Goals are

1. Assist high school seniors to develop specific career goals and action plans;
2. Establish a model Super Seniors, 5th year vocational preparation program resulting in full-time competitive employment matching student career goals;
3. Develop a cadre of parents/consumers to serve as PCCP facilitators and mentors;
4. Foster replication through local, state, and national dissemination and technical assistance;
5. Evaluate the program and modify procedures based on findings and Oversight Committee input; and
6. Sustain the program with local resources.

ADDED Resources

<http://www.acf.hhs.gov/programs/add/resources/hurricanekatrina.html>

Hurricane Katrina and Hurricane Rita Information for People with Disabilities, Developmental Disabilities, and their Families

Louisiana Disability Sites and Links:

- Information for people with disabilities and their families who have been affected by Hurricane Katrina: www.katrina-la.net
- Louisiana Disability Program Information: <http://www.katrina-la.net/disability-programs/index.php>
- Katrina Disaster Relief Information for People with Disabilities and people who want to help them: <http://www.katrinadisability.info/>

Government Sites and Links:

Federal Sites:

- **Department of Health and Human Services :**
<http://www.hhs.gov/katrina/index.html>
- **Administration for Children and Families :**
<http://www.acf.hhs.gov/katrina/index.htm>
- **Federal Emergency Management Agency**
<http://www.dhs.gov/interweb/assetlibrary/katrina.htm>
- **Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities:**
http://www.dhs.gov/dhspublic/interapp/editorial/editorial_0660.xml

State Sites:

- [Alabama](#)
- [Florida](#)
- [Louisiana](#)
- [Mississippi](#)
- [Texas](#)

National DD Organization Sites and Links:

- National Association For State Councils On DD: <http://www.nacdd.org>
- National Disability Rights Network (NDRN): <http://www.napas.org>
- National Association For University Centers For DD: <http://www.aucd.org>

Coping with Disaster- Links to Guides and Publications:

- [Managing Traumatic Stress: Hurricane Katrina and Children](#)
- [Managing Traumatic Stress: After Hurricane Katrina](#)
- [Managing Traumatic Stress: Dealing with Hurricane Katrina from Afar](#)

Tips For First Responders In Assisting Persons With Disability:

http://cdd.unm.edu/products/tips_web020205.pdf

We Want to Hear From You:

The next issue of the ADD Update will focus on Hurricanes Katrina and Rita. We want to know your needs, your problems, your questions, your success stories, and what you're doing to help. Please send any information related to the hurricanes, as well as any photos you may have, to ryeager@acf.hhs.gov.