

ADD UPDATE

DECEMBER2007

December Message from the Commissioner

INSIDE THIS ISSUE:	
Commissioner's Message	1
Youth Center Announcement	2
A Conversation With Dr. Temple Grandin	3
P&As Help With Assistive Technology	6
Florida UCEDD Envisions Possibilities	7
Utah UCEDD Provides an Open Road	8
New York Council's Loan Program	9
West Virginia UCEDD's Assistive Technology	10
Independent Evaluation Update	11
Watch Our Words	12
NACDD Conference in	12

From a first grade class in Kansas using a web-cam to talk to their peers in China to a teenage daughter using a cell phone to keep in touch with her parents on a Saturday night, technology has changed the way we do things. It has turned into reality that which was once the stuff of science fiction. We microwave our meals, listen to podcasts, research our vacations online, and talk to our friends and colleagues via email. These new technology applications, unimaginable even fifty years ago, have changed the face of our society.

Technology has also impacted the disability community, and has the capacity to revolutionize the way individuals with disabilities carry out daily tasks, interact with their communities, and live their lives. Voice-recognition software, adaptive keyboards, devices that alert a parent with an auditory disability to her baby's cry—all of these bridge the gap between yesterday's realities and tomorrow's possibilities.

Assistive technology devices are mechanical or electronic aids which substitute for or enhance the function of some physical or mental ability that is impaired. Assistive technology can mean anything from simple, homemade devices to highly sophisticated systems. It can be adapted toys, com-

puters, powered mobility, augmentative communication devices, special switches, and thousands of commercially available or adapted tools to assist an individual with learning, working, and interacting socially.

ADD's grantees are consistently researching, tweaking, and applying new technologies in order to eliminate barriers and create new opportunities. Assistive technology can be applied in all of ADD's issue areas, impacting everything from the ways individuals learn to the ways they receive health care.

This issue of the ADD Update is intended to provide examples of assistive technology programs that are working, and of innovative ideas that are changing lives. Grantees are approaching the need for assistive technology in a variety of ways-- by conducting research, by developing new assistive technology applications, by making sure that financial limitations do not stand in the way of access to needed assistive technology, and by helping individual people get the devices they need, when they need them.

I'd also like to wish everyone a happy holiday season, and a productive and peaceful new year. It's been a pleasure to work with you this year, and I look forward to continued collaboration in 2008

www.acf.hhs.gov/programs/add

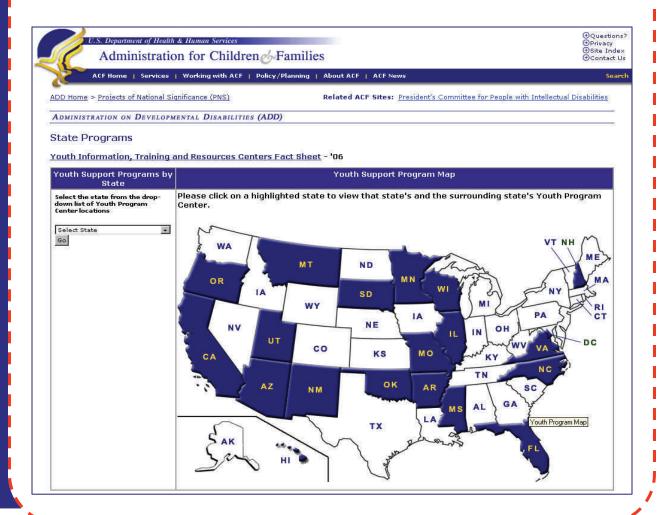
ADD Announcement:

Youth Center Program Location Map and Project Abstracts

Please visit ADD's website to see our newest feature.

The project abstracts are linked from the respective state on the National Map and/or from the drop down list of Youth Center grantees and available at ADD's Web Site at:

<u>Projects of National Significance</u> section: http://www.acf.hhs.gov/programs/add/states/youth_map.html



A Conversation With Dr. Temple Grandin

Basically, my mind works like *Google* for *Images*."

This is what Temple Grandin says when I speak to her on the phone a few weeks after I've listened to her acceptance speech in Washington at the *Secretary's Highest Recognition Awards*, given to individuals who have made significant contributions that have im-

proved the lives of individuals with disabilities. She's talking about visual thinking.

"I think in pictures," she explains. "The best way to tell you how it works is for you to give me a word or phrase, and I'll tell you what comes into my mind. Don't give me an image of something I'd be able to see in my home office."

"Tell me about animals."

"Okay, I immediately saw images from when I was little, images of horses. The scenes are like slides. Any image I hold in my mind turns into a video."

Dr. Grandin, who was diagnosed with autism when she was two years old, is a Professor of Animal Science at Colorado State University. She is a noted autism advocate and a designer of livestock handling facilities and techniques. Facilities she has designed are located worldwide. In North America, almost half of the cattle are handled in a system that she designed. She has also developed an objective scoring system to promote animal welfare, which is being used by many corporations for assessing and handling cattle and pigs at meat plants.

Dr. Grandin's love of animals came early. She rode horses when she was growing up, and showed them. She cred-

its her high school science teacher, Mr. Carlock, with helping her turn this passion into a career. Because children with autism often have vaery defined and specific areas of interest, Dr. Grandin believes that is crucial for parents and teachers to be thinking about career development early, and helping children develop their strength area.

"If kid is fixated on the metro," says Dr. Grandin, "read about rains, do math with trains, take that fixation and use it to motivate. Some kids are fixated on video game- that's okay, too. Mario (a character in the *Mario Brothers* video game) is a plumber, lets learn about plumbers and the science that goes along with that."

In addition, Mr. Carlock helped support her when she invented her "hugging machine"

The hugging machine, also called a squeezing machine, a hug box, or a squeeze box, is a deep pressure device designed to calm hypersensitive persons,

"If I could snap my fingers and become nonautistic, I would not because then I wouldn't be me. Autism is part of who I am."

-Dr. Temple Grandin usually individuals with autism spectrum disorders. Dr. Grandin invented it because she realized that the pressure helped her to calm down in times of anxiety. A hug from an actual person, she explains, can be overwhelming or overstimulating for persons with autism and sensory issues, but the pressure, and the sense of being held, is stress relieving.

The hug machine, in general terms, consists of two hinged side-boards with thick soft padding, which form a V-shape. There is a control box at one end, and heavy-duty tubes leading to an air compressor. The user lies between the side-boards, for as long or short a period as desired. Using pressure exerted by the air compressor and controlled by the user, the side-boards apply deep pressure stimulation evenly across the lateral parts of the body. Dr. Grandin's hugging machine is now widely used by individuals with autism.

But back to visual thinking. Visual thinking, Dr. Grandin explains, is part of what helps her understand animals. Animals don't think in the abstract. They're not verbal. No metaphors. They process the world through what they see.

To further explain visual thinking, Dr. Grandin asks me to picture two things. The first, she explains, needs something I see every day. I'm at home, so she asks me to describe my office at work. I give her a descriptive tour of my government cubicle. Photographs, files, computer.

"Okay," she says, "good."

Then she asks me to tell her what I see when I think of church steeples.

I'm pretty vague. They're pointy. They're on top of churches.

"Yeah, you're not a visual thinker," she says. If I were a visual thinker, she tells me, the word steeple would conjure images of individual steeples. I'd see a specific steeple in my mind, not offer a sketchy conglomerate of all the steeples I've ever seen.

Visual thinking is part of who Dr. Grandin is, part of what's allowed her to be successful in her work. And it's a common trait of individuals with autism. Teachers sometimes come to her, she says, and ask, "How do I get these pictures out of this kids head?"

The answer, of course, is that you don't. The goal in working with people with autism, Dr. Grandin says, should not be to make them like everyone else, but to understand how their minds work, and to help them find ways to use that unique perspective to be successful in a world that doesn't always understand them.

By any definition, Dr. Grandin is extremely successful and at the head of her



Dr. Temple Grandin

field. She views her autism as part of who she is, and as a contributing factor to her success, not an obstacle she had to overcome in order to achieve it.

I ask Dr. Grandin what the knowledge and treatment of autism was like when she was diagnosed. "They didn't have *any* knowledge in 1949," she says.

Nonetheless, her parents were able to cobble together a support program that was in many ways similar to the Applied Behavior Analysis (ABA) approach frequently used today. She was in early intervention by the time she was two-and-a-half, and in a speech therapy program. She also worked with a nanny who gave her individualized attention and practiced turntaking games and social skills.

During our conversation, Dr. Grandin stressed two things above all others: the importance of early intervention, and the need for additional research and attention regarding sensory issues.

"If you think you have a two-year-old with symptoms, don't wait," says Dr. Grandin. "Get him in a program, he needs to be with a teacher one-on-one twenty hours a week."

Early intervention, Dr. Grandin believes, is one of the most important factors in determining the future of a child with autism. Early identification and intervention are crucial.

In addition, Dr. Grandin stresses the importance of addressing the sensory issues that often come hand-in-hand with autism. These sensory issues, says Dr. Grandin, are among the most debilitating obstacles faced by people with autism and their families.

Dr. Grandin rates her own sensory issues as

about a four on a scale of one to ten. For her, they can be a problem. For individuals with more severe sensory issues, the problem can be crippling.

"I'm so glad there were no smoke alarms when I was a child," she says. "Smoke alarms would have been my death. I hate noisy restaurants. I can't screen out the background noise. I can get through an evening in a noisy restaurant, but I'm not going to enjoy myself. People with more severe sensory issues can't get through the evening. You can be a brilliant, high-functioning person with autism, but if you can't go to a grocery store or a ball game, you can't live a normal life. We've got to put more money and research into sensory issues. It's hard to find funding, because other aspects of autism get more attention, but sensory issues can be totally debilitating."

In addition, she says children with autism need to be taught social skills at a young age.

"Autistic children need to learn social skills like learning a role in a play," says Dr. Grandin. "In the fifties, all children were taught social skills. They learned table manners and how to act in social situations, in a formal way. That's not done anymore, and it hurts aspergers kids." Children with autism can't always pick up social cues and learn social norms on their own, says Dr. Grandin, and therefore need specific instruction in social skills, which will help level the playing field and allow them to handle social situations with greater ease, and to succeed in careers.

Dr. Grandin has written several books and produced several DVDs that add her voice to the discussion on autism. For more information on her books and her perspective, please visit her website at http://templegrandin.com/

P&As Help Individuals with Assistive Technology

District of Columbia

Pursuant to a federal court order for compensatory education for the public school's failure to provide a required triennial evaluation, the DC P&A ensured that a 13-year-old girl with Cerebral Palsy and other developmental disabilities

received one hour of assistive technology services per week at school and was provided with a communication device for use at home, school and in the community.

Maryland

"Carl" is 12 years old and has severe developmental delay and an articulation disorder which makes it very difficult for him to communicate verbally. Children are eligible to receive assistive technology through the Medicaid program when it is medically necessary.

Carl's pediatrician and school speech therapist both made a referral to his MCO. The service was denied and the MCO representative refused to send a written denial of the request to Carl's mother. The representative suggested that Carl should carry around a pad and pen to communicate.

The Maryland P&A helped Carl's mother file a complaint with the *Health Enrollee's Action Line*, complaining about the MCO's refusal to cover the service or issue a denial letter. That same day, the MCO called Carl's mother and told her the device would be covered.

Carl is now successfully using his assistive technology device to communicate his needs and feelings, and has recorded the family's outgoing answering machine message using the device.

Wyoming

"Maria," an 11-year-old elementary school child with cerebral palsy and visual disabilities, needed modification of the restroom closest to the student's regular education classroom. She also had assistive technology needs. As a result of the Wyoming P&As intervention, the necessary

modifications to the restroom occurred. The client received a Dell laptop that included the Paper Point scanning program, Kurzweil screen reader, and Math Pad. The parents will also receive training on the assistive technology.



DC



Florida UCEDD Envisions Possibilities

The Mailman Center for Child Development, Florida's UCEDD, increases assistive technology awareness through community outreach

Assistive Technology is used to help individuals compensate for sensory, motor, cognitive and social limitations. Assistive technology is important because it provides solutions to help improve a person's ability to learn, work, and play. One of the barriers to technology use is the lack of awareness of assistive technology among educators, other allied health professionals, and individuals with disabilities and their families. The UCEDD is reaching out to the community to increase the awareness of assistive technology to support persons with disabilities.

Envision the Possibilities: Assistive Technology Awareness 2007 was a collaborative project with the UCEDD, Miami-Dade County Public Schools, the Florida Alliance for Assistive Services and Technology, and other community agencies. Over 300 educators, allied health professionals, individuals with disabilities and their families attended this two-day event which took place on February 9th and 10th, 2007. The purpose of the event was to raise awareness of the capability of assistive technology to empower, educate and include persons with disabilities

in all aspects of life. The event which was open and free to the public included a variety of presentations, exhibits, and demonstrations by vendors and community agencies as well as recreational activities and art displays. Planning for the second annual Assistive Technology Awareness 2008 event is underway.

In addition, the *Deb-Tech* project, funded this year by the Miami-Dade County's Children's Trust is outreaching to underserved communities in Miami-Dade County. The purpose of the project is to provide training and support to parents, teachers, and caregivers on how to facilitate early social, emotional, cognitive, language, literacy, and motor development in infants and young children through developmentally appropriate uses of low-tech and high-tech technology. To date over 300 parents and 100 professionals have attended hands-on workshops and professional development trainings. This highly regarded project is providing training to parents and professionals so that infants and toddlers with special needs can be included in every day activities at home and in childcare centers.

To learn more about additional assistive technology services provided at the Mailman Center for Child Development please visit, http://peds2.med.miami.edu/mailman/assist-tech.htm .

Announcing Coglink!!

Coglink is an electronic mail program designed for use by individuals with brain injury or cognitive disabilities. This program helps the user build a community of email partners. The email software is personalized to include only the people the user wants to exchange email with.

Those who send spam and viruses excluded from the community. With Coglink, email messages are sent in a few steps, with no hidden windows or distracting pop-up screens. Coglink includes a free training program that helps users learn the basic skills for using the mouse, keyboarding, and emailing. A subscription includes a personalized notebook containing the email and training software programs, manuals, getting started posters, and email and phone access to the HelpDesk for adding email partners, customizing the Email program, or troubleshooting technical problems. COMPATIBILITY: For use on IBM and compatible computers. SYSTEM REQUIREMENTS: Windows XP (any edition); a CD-ROM drive; connection to the Internet through a dial-up modem, DSL, Cable, or wireless broadband; speakers in order to hear the audio input from the training program.

Note: This program was developed under a research grant from the National Institute on Disability and Rehabilitation Research.

Utah UCEDD Provides an Open Road

When Matt Maw fell on his neck doing a triple back tuck at tumbling practice, he instantly became paralyzed from the shoulders down, with only partial movement in his arms. Although this accident in 2000 changed his life in some ways, Maw graduated from Utah State University with his bachelor's degree in statistics. He

will finish his Masters degree in the spring of 2007. Maw also married the love of his life, Alia, in November of 2005.

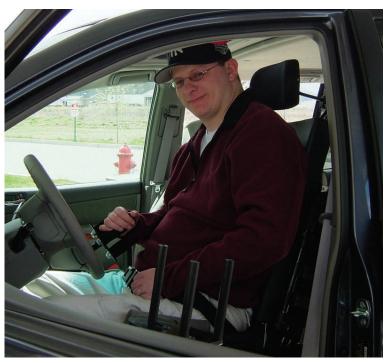
With the help from the Utah Assistive Technology Foundation (UATF), funded by the Utah UCEDD, Maw is now purchasing a van with modifications that will allow him to drive himself.

"Now I will be able to drive myself places, something I

have not done in seven years," said Maw. "I can be more independent and not have to rely on someone else to drive me."

Maw's minivan has been ordered with all of the modifications he needs to drive, including reduced-effort steering, a lever for the brake and gas, a scrolling button for secondary controls like blinkers and wipers, a water moisture detection feature that will automatically turn on the windshield wipers when water is detected, electronic tie-downs for Maw's wheelchair and a lowered floor and ramp.

"I am really glad UATF is an option," Maw said. "There is no way I would spend this much money on a vehicle if I didn't have a disability. UATF is essential to be able to afford something like this."



Maw could qualify for a traditional loan, but the interest rate would be much higher. The lower monthly payment is saving him a great deal of money, said Maw.

"The loan process through UATF is very simple," Maw said. "I filled out the loan application and someone called and told me I was approved for the loan."

The UATF offers Utahns of all ages with disabilities the opportunity to borrow money at an affordable cost, no fees and very low interest, so that they can purchase much-needed devices, including accessible vans, Braille Notetakers, scooters, print enlargers, adaptive computers, home modifications, hearing aids and more. The UATF has funded more than 900 loans across the state, worth approximately 4.4 million.

More information is available by calling 800-524-5152 or visiting www.uatf.org.

New York Council Assistive Technology Short Term Loan Program

From 2004-2006, the New York State Developmental Disabilities Planning Council (DDPC) provided funding to establish two Assistive Technology (AT) short term loan programs in New York State. Two agencies received \$100,000 per year, for three years, to implement the pilot projects. Funded grantees included Albany Schoharie Schenectady, Saratoga Board

of Cooperative Education (BOCES) and a collaboration between Enable Inc. and Upstate Cerebral Palsy of Utica. Established loan programs were specifically geared toward children ages 3-21.

The two programs served over 25 counties of the state. The goal of the project was to create opportunities for children and families to try out assistive technology equipment before purchase and to reduce waiting periods for equipment and devices. Projects used a train-the-trainer approach to establish core exper-

tise within the school districts to implement assistive technology assessments and loans for children. Grant activities also focused on expanding existing AT equipment lending libraries.

DDPC funds were used to purchase seating and positioning devices, communication devices, computer hardware and software, mobility devices, sensory and visual equipment, switches, and adaptive toys. Projects provided short-term

loans of equipment, developed AT training for families and school personnel, and implemented a train-the-trainer approach for teaching AT assessment and evaluation to staff within partnering school districts. Projects offered a variety of services to participating school districts and families including information and referral, equipment loans and demon-

strations, individualized training to families and school personnel, and exhibits and AT workshops.

Outcomes over the course of the three year grant included over 1,660 children who received AT equipment loans and direct support from the two projects. 3,234 families, children, and school personnel received training in assistive technology and 2,160 providers received training and support from the two programs. Both

projects developed marketing and pilot replication guides. Each agency also developed a sustainability plan that has supported continuation of the projects beyond DDPC funding. Each agency continues to provide AT services and equipment loans. For additional information about the DDPC or this grant initiative, please contact Robin Worobey, Program Planner by phone: 518-486-7505 or via email-rworobey@ddpc.state.ny.us .



West Virginia UCEDD's Assistive Technology

The Center for Excellence in Disabilities (CED) offers comprehensive assistive technology (AT) assessments. Assessments are available for children and adults through the Assistive Technology Assessment Clinic (AT Clinic) and the AT-TV video conferencing at the Center for Excellence in Disabilities (CED).

Assessment programs are overseen by a nationally certified Assistive Technology Practitioner and designed to help individuals of all ages identify and use assistive technology to support independence and enhance quality of life.

Assessments are conducted from the CED and can consist of environmental assessments in the home, school and/or worksite and interdisciplinary clinical evaluations for:

- Computer access
- Environmental controls
- Adaptations to living and work environments
- Sensory impairments
- Activities of daily living
- Recreation

For individuals who have access to local video conferencing facilities but difficulty

with transportation to the Morgantown site, a limited number of tele-assessments (AT-TV) are available using video conferencing technology on environmental assessments in the home, school or work place by clinic staff.

All assessments are conducted by licensed professionals whose disciplines include occupational therapy, physical therapy, speech therapy, recreation therapy and invited vendors as determined by the individual's AT needs. Clinic staff work with clients, families, providers, vendors and insurers to determine the type of AT that best meets the needs of the individual and to identify possible AT funding sources.

The West Virginia Assistive Technology System (WVATS) provides assistive device demonstrations and device loans to interested individuals. Demonstrations of equipment and the possibility for borrowing devices are also available for clinic attendees

For more information, about assistive technology resources in West Virginia call Jamie Hayhurst-Marshall at 304-293-4692 ext. 1141 or e-mail her at jhayhurst@hsc.wvu.edu.

ADD Still Needs Pictures!!

ADD is pleased to have received many pictures from grantees in response to our photo request. We are currently using these images in our newsletter and on posters, folders, brochures, websites, and a variety of other materials. We are always looking for new images. Sending ADD a picture is a great way to shine a national spotlight on your programs. For more information, including picture specifications and waiver forms, please contact Rebekah Yeager at Rebekah. Yeager@acf.hhs.gov.

PAGE II

Independent Evaluation Update

The past several months have been a busy time for the Developmental Disabilities Program Independent Evaluation (DDPIE) project (or ADD independent evaluation). The focus of the project during this time has been on getting feedback from the ADD grantees on the draft measurement matrices. Westat has developed draft measurement matrices for each program and for collaboration. They are comprised of key functions, benchmarks, and indicators developed with input from the Developmental Disabilities Network Program working groups.

In order to obtain input and feedback from a wider range of programs, Westat presented the draft measurement matrices to each grant program at national meetings. They also sought feedback from the project's Advisory Panel.

Feedback was obtained through multiple means, which included immediately at the presentation, on-line through an eRoom (a password protected, interactive web site), through conference calls, and in writing. While most of the feedback was general and directed towards the evaluation overall, there were valuable comments targeted at the benchmarks and indicators contained in the measurement matrices themselves. Both the UCEDDs and DD Councils submitted written comments to ADD about the independent evaluation. ADD emailed responses to the UCEDDs and DD Councils. These responses can be viewed on the ADD website at http://www.acf.hhs.gov/programs/add/pns/ independent evaluation.html.

Many of the comments expressed by P&A programs

were also similar to those expressed by the UCEDDs and DD Councils. Following the process for obtaining feedback, Westat has analyzed the comments received to determine how the comments should be incorporated into the measurement matrices. They have also moved forward, based on comments from the grantees, to conduct a crosswalk that compares data required for each draft indicator and data collected in MTARS, PPRs, State Plans, 5-year plans, NIRS, and SGPs.

Westat has also started to implement the pilot study, which will involve site visits to three States per program to further explore and test the methodology and the accuracy (reliability and validity), feasibility, and usefulness of the draft data collection questionnaires and other instruments for a full-scale independent evaluation. The pilot study for this project will consist of in-person individual and group interviews, individual and group telephone interviews, and focus groups.

Westat identified the States that will participate in the pilot study using a stratified sampling procedure based on certain criteria (e.g., allotment size, region of the country). The chart below shows that States that were identified to participate in the pilot study.

States identified for the pilot study have been notified by Commissioner Morrissey. We recognize that participation in the pilot study will require grantees to spend some time organizing and preparing for Westat's visit. However, we see this experience as an opportunity to help shape the ADD independent evaluation so it can be valuable not only to ADD but also to the grantee networks.

UNIVERSITY CENTERS OF EXCEL- LENCE	STATE DEVELOPMENTAL DIS- ABILITIES COUNCILS	PROTECTION AND ADVOCACY SYSTEMS
University of Georgia - Institute on Human Development and Disability UCEDD	Governor's Council on Developmental Disabilities for Georgia	Georgia Advocacy Office, Inc.
University of Iowa - Center for Disabilities and Development	Ohio Developmental Disabilities Council	Ohio Legal Rights Service
University of California, Los Angeles - Tarjan Center	Wyoming Council on Developmental Disabilities	Disability Law Center of Alaska

Watch Our Words: Colorado Council

The Colorado Council has funded a group called Watch Our Words (WOW), a group of users of facilitated communication. Last year they worked with a local video production company and developed two DVDs. The first was developed to provide an introduction to facilitated communication, and included footage of one-day trainings that the group has provided to parents, educators, support and service providers, and people who could benefit from having access to communication. The DVD

was developed to provide an introduction to facilitated communication for a broad audience. The second DVD introduces five WOW members, including the individuals' and their families' accounts of lives enriched through access to communication. The DVDs are available at no cost to anyone who is interested. Also, if anyone locally is interested in upcoming trainings or monthly WOW meetings, they can contact Brenda Granger, the coordinator for WOW, at granger@cybox.net...

NACDD Conference in San Diego

Over 300 people attended the annual conference of the National Association of Council on Developmental Disabilities in San Diego the first weekend of October. Hosted by the California Council on Developmental Disabilities, the conference speakers spoke on a wide variety of issues.

The theme of the conference, "Sailing Together Into the Future", highlighted some of the many accomplishments over the past 30 years.

ADD Commissioner Patricia Morrissey attended the conference and met with participants during meals and the many breaks. Other speakers focused on assistive technology, such as Bonnie Mintun, whose daughter Anna was able to flourish when the right technology to communicate was made available to her. Bittner and Dylan Boot, from Protection and Advocacy, Inc., as well as Dr. Olivia Raynor, co-director of the Tarjan Center at UCLA, highlighted areas where consumers in boards, council and committees can have more

meaningful and effective participation through the use of consumer-friendly materials and other tools.

Steven Eidelman, internationally recognized expert on developmental disabilities and the first Robert Edelsohn Chair in Disabilities Studies from the University of Delaware, led a discussion on the National Leadership Consortium on Developmental Disabilities for which he is faculty. Co-Founder of the M.I.N.D. Institute at UC Davis in Sacramento, Rick Rollens, spoke of the alarming rate in which autism is being diagnosed across the country.

Since emergency preparedness has become a critically important initiative in the country, there were two sessions conducted by Brian Parsons, from the Office of Civil Rights and Liberties at the U.S. Department of Homeland Security.

Rocio Smith and members of the Congreso Familiar, whose Spanish-speaking parents have become active advocates for their children, described how they develop leadership and provide education and information to the Spanish-speaking community in the San Francisco Bay area.



Administration on Developmental Disabilities

Administration on Children and Families

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The American dream belongs to everyone.

Many thanks to all of the grantees who sent us stories on assistive technology. The many program profiles we were unable to use will be reserved for future issues.

The next ADD Update will address services and supports, with a focus on direct care. Please send us your stories and program and tell us what you're doing in this area.

We're also looking for self-advocates to profile. If you know of a self-advocate with a story to tell, please nominate him or her by sending an email to Rebekah Yeager at

Rebekah.yeager@acf.hhs.gov.

http://www.acf.hhs.gov/ programs/add

Over the last few months, ADD has welcomed three new staff members. Kelli Cephas, Larissa Crossen, and Lisa Kennedy Oksala are the latest additions to our team. Their hard work has been much appreciated, and we hope that you have the opportunity to get to know them over the coming year.

