



ADD Update

The American Dream Belongs to Everyone

MARCH 2009

Message from ADD

As Acting Commissioner of ADD, I am pleased to write to you in the first ADD Update of 2009. On January 2, 2009, Dr. Patricia Morrissey stepped down as Commissioner, and it is my honor to serve as Acting Commissioner until the new Commissioner is appointed by President Obama.

President Obama has been vocal regarding his intention to make disability issues a priority. In his words, *"We must build a world free of unnecessary barriers, stereotypes, and discrimination.... to ensure that everyone has a chance to get the education they need and live independently as full citizens in their communities."* The Obama administration's agenda on disability can be viewed at <http://www.whitehouse.gov/agenda/disabilities/>.

As we at ADD watch the changes in Washington and the transition of administrations, I am reminded of the consistency of ADD's goal: to ensure that the American Dream belongs to everyone.

ADD believes that self-advocacy is our mission at its most pure. Our goal is not just to improve the lives of individuals with developmental disabilities, but to empower these individuals to change their own lives. Historically, people with de-

velopmental disabilities have often been on the receiving end of change. Thanks in part to the work of grantees, people with developmental disabilities are currently *creating* change by advocating for their rights and shaping the world around them. ADD encourages programs that promote and support that change.

This edition of the ADD Update focuses on the changes that are happening in this country as a result of the work, determination, and creativity of self-advocates across the Nation. We are pleased to share the personal stories and original writing of several self-advocates, and to serve as a platform for an exchange of ideas about self-advocacy.

It is also my pleasure to announce a new feature of the ADD Update: the Self-Advocate's Forum. We intend to include in each future issue of the ADD Update an original article by a self-advocate. Articles can be the story of a personal experience, an individual's opinion on a current issue, or focus on anything of interest to the writer. Articles should be between 300 and 600 words, should include a photo, and can be submitted to Rebekah Yeager at Rebekah.Yeager@acf.hhs.gov.

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Many residential services staff use the site to increase consumers' choice-making and self-determination in terms of what types of activities they select and pursue. "It empowers them to make decisions and choices."

The Minnesota UCEDD is working to connect people to their communities. In 2002, an ADD grant for innovative projects to promote recreation and leisure for persons with developmental disabilities was awarded to a Minnesota organization, Partners in Community Supports (PICS). At that time, this agency was a coalition of six agencies which provided residential support (group homes, supported apartments, and family support) to persons with developmental disabilities in the Twin Cities area of Minneapolis-St. Paul. The grant was for "an interactive web-based database and multi-agency initiative to increase opportunities, access, choice and support in community recreation and leisure activities for people with developmental disabilities." This project resulted in the www.lifepages.org website which continues to be an extraordinary resource for the recreation and leisure opportunities for Twin Cities residents.

The six agencies which comprised PICS (Lutheran Social Services, Dakota Communities Inc., Hammer Residences, Mount Olivet Rolling Acres, Fraser and Opportunity Partners) and their group-home residents assisted in the development and piloting of the site. PICS was the or-

ganizing entity, and the Institute on Community Integration at the University of Minnesota managed the website development work and evaluation. While several of these agencies are no longer PICS members, and the formal project is completed, the site continues. Today, over 1,500 activities and other resources are listed on the site, and between 5,000 and 6,000 people visit the site every month.

The project evaluation showed that staff, consumers, and family members who use the site appreciate the wide variety of experiences it provides, and that people with disabilities have had many opportunities to have life experiences they would never have had without the site. More than 80% of the people who used the site during the project period were satisfied with it and found it useful, with 90% satisfied with the recreation and leisure information the site provides. Family members whose children live at home were particularly enthusiastic about the relationship opportunities the site has provided.

In each and every one of the evaluation focus groups, some participants responded that they "loved the site" and "it's very easy to use." The site features "free resources," Mapquest Links, and a monthly calendar. Personal profiles are also available,

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which allow for such individualized features as email alerts when a particular activity that fits a person's interests is listed. Besides recreation and leisure activities, many other community resources are also listed, such as self-advocacy groups and human services resources.

There are several specific areas of benefits which were reported:

- Consumers' activities and life experiences broadened. In the words of one staff: "There's activities they went on, they wouldn't have known about, because of the web-site."
- The site has made it far easier for program coordinators in residential services agencies to plan activities, especially for the weekend or for a month at a time. "No one has an excuse to sit around anymore!"
- Many residential services staff use the site to increase consumers' choice-making and self-

determination in terms of what types of activities they select and pursue. "It empowers them to make decisions and choices."

- For people who prefer to not attend activities with others with disabilities, the site has provided the opportunity to find classes and activities with ordinary community members.
- The web-site and the project served to bring many people with disabilities and their staff into the computer age. Because of the project, many consumers are now using the computer and email to connect with family and friends, and have grown in their self-confidence in learning computer skills.
- The project itself has provided many recreation and group home coordinators the opportunity to emphasize the importance of recreation and leisure in the lives of consumers.

New Hampshire Young Adult Self-Advocacy Conference Organized & Hosted by the Generation Y Not Committee

About two years ago, five to six young adults, ages 18 – 35 came together to begin to talk about what young adults want. Sponsored by People First of New Hampshire, the discussion centered on issues of relationships, education, careers, living on your own, future plans and self-advocacy. The group decided to name themselves the Generation Y Not Committee and began to organize a statewide conference in New Hampshire to help other young adults learn about these life issues together. From there, many details for the conference began to unfold. Nationally known self-advocate leader, Julie Petty, was chosen as the keynote speaker. Several young adults from New Hampshire were selected to pre-

sent about their stories and accomplishments, such as their marriages, careers, and their individual challenges that each succeed in overcoming.

With over 140 participants, the conference took place in Concord, New Hampshire on November 7th, 2008. Participants attended four different workshops throughout the day to help with planning their own futures and as a result, report that it was an exciting and inspiring day. The Generation Y Not Committee is already considering plans for next year's conference.

www.peoplefirstofnh.org



Generation Y Not Committee Members Include:

- Courtney Belanger
- Justine Gayhardt
- Charlie Helfrich
- Chester Hill
- Jillian Libby
- Tracy Moltisanti

Small Beginnings, High Expectations

By Sylvia and Eleanor Wolfe, Tennessee Council

All eyes of the attractive group of high school students seated around the classroom conference tables were fixed on her face and small frame as she spoke in her slow, gentle voice. "So why am I telling you about my face-blindness? Because it's an example of the barriers that students with disabilities experience. At our school are many students who have disabilities that are both visible and invisible. But we have something in common; we miss out on real life with students who don't have disabilities."

With that, 17-year-old Eleanor Wolfe, who has autism, began a short presentation to the Leadership Initiative class at Farragut High School in Knox County, in hopes that she would find both support and recruits for her Senior Project, an innovative approach to the Volunteer Tennessee Aspire program. Aspire is a Tennessee Department of Education service-learning program for high schools addressing safe schools issues such as drugs, alcohol and violence. Eleanor proposed to use the Aspire model to address an altogether different issue: the social isolation she and other students with disabilities experience. Unlike all other school programs at Farragut High, Eleanor envisioned a program intentionally diverse with regard to ability.

What made sense to Eleanor and to her mother, Sylvia Wolfe (a 1999 Tennessee Partners in Policymaking™ graduate), was the way Aspire goes about working to change a school's "climate" through student-led projects and activities. This seemed like a good match for the highly success-oriented student body at Farragut High. But Eleanor needed to convince the school administration that such a program was needed. Before meeting

with the Leadership Initiative class, she made her pitch to the school principal. His response was favorable but reserved. Her concept would work best as an approved school club, he explained, and must follow the

prescribed approval process for new clubs.

Eleanor and her mother teamed up to tackle the real world bureaucracy on a fast-track: recruiting at least 15 club members and two adult sponsors, gaining the approval of Student Government and the principal, and securing financial support to send all of the new members to the required Aspire leadership training. Eleanor assumed she could recruit students with disabilities and peer tutors, but approaching the Leadership Initiative

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"Now Eleanor had to move forward to recruit Aspire team members and secure funding on a dauntingly compressed time schedule. Significant red tape lined the path. But Eleanor's inspiration was contagious and she did not give up."



class was an attempt to bridge the divide and find students who don't have disabilities and have no experience with ability diversity. To their credit, those students were instantly energized to assist Eleanor in real world matters they were more familiar with than she, including publicity and fundraising.

How had this student with autism—who didn't want to "miss out on real life"—learned about Aspire in the first place? Eleanor was fortunate that her recent experience in Tennessee's Youth Leadership Forum (YLF), a program of the Council on Developmental Disabilities, had increased her self-confidence, helped her better articulate her ideas on advocacy and provided a new set of networking connections. Inspired to address the social climate at Farragut High with regard to ability, Eleanor turned to YLF director Ned Andrew Solomon for ideas or leads.

Ned already was aware that Aspire program director, Melia Arnold, was considering ways to enhance student diversity in Aspire teams and was par-

ticularly interested in bringing students with disabilities into the teams, so he forwarded some Aspire information to Eleanor. About to rule out Aspire because its targets are drugs, alcohol and violence, Eleanor, in a creative dialogue, posed her passion for another core value. Melia explained the generic character of the Aspire leadership training and its potential flexibility and encouraged Eleanor to proceed.

Now Eleanor had to move forward to recruit Aspire team members and secure funding on a dauntingly compressed time schedule. Significant red tape lined the path. But Eleanor's inspiration was contagious and she did not give up. Financial support was received from the Council on Developmental Disabilities and the Tennessee Department of Education, Division of Special Education. As a result, the eight charter members of Farragut High School Aspire Club attended the intense, productive and fun Leadership Training weekend held at Nashville's Joe C. Davis YMCA Camp and Outdoor Center.

Eleanor's unique concept is born.

<http://www.state.tn.us/cdd/>



Get the **help**
you need

BRAIN INJURY
Awareness Month

www.health.mil

The Military Health System (MHS) recognizes March as Brain Injury Awareness Month, a time to raise awareness about traumatic brain injury (TBI), the most common brain injury among Service Members. TBI is complex and affects people in unique ways. Cases range from mild to severe and can occur from a blow, jolt, or blast wave to the head. Many players in the NFL have suffered a TBI from action on the gridiron. [March is Brain Injury Awareness Month](#)

Grassroots Coalitions Take Hold in Florida

During the past decade in Florida, disability advocacy groups have grown increasingly influential - thanks to the collaborative efforts of disparate groups who share the same policy goals, and who have been influential in bringing the faces and voices of individuals with disabilities to the attention of Florida's policymakers.

The Florida Council (FDDC) has been instrumental in this movement, and this past summer, the FDDC took another step toward promoting full inclusion in community life for persons with disabilities by establishing seven grassroots coalitions around the state, led by seven "Inclusion Ambassadors". These individuals, including Partners in Policymaking graduates, family members of individuals with disabilities, and other advocates, met in Tallahassee, Florida, in July 2008 for a one-day training session on how to spread the message of inclusion to lawmakers, the media and the general public.

The Inclusion Ambassadors are now working on building membership in their individual coalitions, educating and influencing lawmakers on the need for increased funding for programs and services for persons with

disabilities, and getting increased media coverage for the issues affecting persons with disabilities. Each ambassador has a deep commitment to inclusion of persons with disabilities and to seeing services and programs for these individuals fully funded by Florida's lawmakers.

The seven leaders are receiving on-going training, support and technical assistance from FDDC staff on how to expand their membership base, talk with lawmakers, and educate the media on disability-related issues. Each local coalition reflects the strengths and needs of that region.



Ambassadors are required to make periodic reports on the success of their inclusion efforts. They report on the number of face-to-face meetings with lawmakers, the success of those meetings, their interactions with the media, and the steps they have taken to expand their coalitions. The FDDC will be using incentive monies to ensure the continued growth and success of these grassroots coalitions.

<http://www.fddc.org>

Utah UCEDD Program Trains Self-Advocates on Transition

When children with disabilities enter the public school system, the law guarantees them the right to an education. When those children become adults, the rules change completely. It becomes their responsibility to prove eligibility for services, and to coordinate services from unrelated agencies.



Justin Olsen, BLT
Advisory Committee

The Becoming Leaders for Tomorrow project exists to make this transition easier. Advised by a nine-member committee that includes young adults with disabilities, the project is aimed at training both young adults in transition and the professionals who serve them. More than half of the committee members are people with disabilities from the Logan and Salt Lake City, Utah areas. The project is staffed by representatives from the Center for Persons with Disabilities on the Utah State University campus, Utah Family Voices and the Bureau of Children with Special Health Care Needs in the Utah Department of Health. Funded by the Administration on Developmental Disabilities, it began in October 2007 and will run until 2010. Information generated from the project is being posted on two websites: www.blc.cpd.usu.edu and www.medhomeportal.org.



Brandi Dodda BLT
Advisory Committee

The young adults who lead the advisory committee set the agendas and run the meetings. After the program trains young adults on effective leadership and self-advocacy skills, it will encourage its young advocates to train their peers on how to navigate agencies and services including Medicaid, Social Security, higher education and vocational rehabilitation.

The group will target people on the Utah Division of Services for People with Disabilities' waiting list and teach them leadership and self-advocacy skills. From there, they can learn to coordinate their own services. The idea is to help young people with disabilities reach their goals, said Brandi Dodda, a member of the advisory committee. "I'm really excited about what we're doing. ... I think the training is going to be cool."

Justin Olson, another member of the BLT advisory committee, said mentoring could have helped him better understand issues surrounding work, Medicaid and Social Security.

Like many members of the BLT project, Dodda and Olsen started out as a member of the Center for Persons with Disabilities' Youth Advisory Committee, which advised

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Community medical professionals statewide. That group produced a DVD presentation: an eight-minute educational clip on making the transition from pediatric to adult care.

In *Respecting the Young Adult Patient*, Dodds said young adults can be encouraged to make their own appointments, call in their prescriptions, keep track of taking them and be responsible for refilling them. “That would be just one category that these people can be independent and learn to take care of themselves.” Justin Olson, another presenter, said it is important for health care professionals to talk directly to the young adults they are treating. He spoke of his own frustration when he visited an emergency room, and the doctor and nurse spoke not to him, but to his friends who brought him.

“They made their point so succinctly and so powerfully,” said Jeff Sheen, the panel’s moderator and a BLT project coordinator. The panel discussion was edited down to eight minutes, made into a DVD and posted on You-

Tube, where it got few hits until it was presented at the Association of University Centers on Disabilities conference in November 2007. In the months following the conference the number of hits rose to 1200, and calls and emails started coming in from people and pediatricians around the country.

A common theme that runs through the work of the BLT project is: Plan ahead. Whether the young adult is dealing with education, employment, medical or social issues, the project is targeting the 14 to 22 age bracket, urging youth with disabilities and their families to start preparing for the adult world before being thrust into it.

For a look at *Respecting the Young Adult Patient*, visit:

www.youtube.com/watch?v=RJVgU7aGUZw

or for a fully captioned version visit www.cpd.usu.edu/media

News from PAVE 360– For Military Families

Military families are joining the Kitsap and Jefferson County Parent to Parent Support Group Program and many others to celebrate the beginning of Autism Awareness Month on April 3rd. Liberty Bay Bookstore in Poulsbo will host a special book reading event for the whole family, including special guest readers who will read family-friendly books about Autism Spectrum Disorders. Official proclamations declaring April as Autism Awareness Month is the city of Poulsbo and in Kitsap County will be read.

Guest readers will include:

- Mayor Quade of Poulsbo
- County Commissioner Steve Bauer, District 1 Kitsap County Commissioner
- Patti Gee, President of the Autism Society of Washington
- Dr. Victoria Crescenzi, Developmental and Behavioral pediatrician from the Bremerton Naval Hospital
- Donald Meyer, Director for the Sibling Support Project
- Congressman Jay Inslee

Iowa Council Empowers Voters



Iowa's Developmental Disabilities Council and their ID Action (Iowans with Disabilities in Action) project hit the road in Sep-

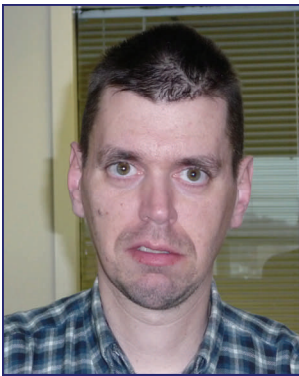
tember and October, talking to more than 1,200 Iowans with disabilities about their rights and responsibilities as voters.

Iowans with disabilities, providers and advocates hosted Vote 2008 Workshops that were held in 20 communities around Iowa.

More than just "talk," these workshops gave Iowans with disabilities the opportunity to register to vote, request an absentee ballot, practice with new election equipment, meet candidates on the ballot this year, and discuss election questions and concerns with their county auditors.

The Council worked with several organizations and individuals to help make the trainings a success: the Iowa Secretary of State, county auditors and staff and especially the local hosts who stepped up as organizers and promoters.

Spotlight on Self-Advocates



Dave Tag is a self-advocate in Trenton, New Jersey. A member of the New Jersey Council, he believes that his most important duty is to keep people informed of what's going on regarding disability issues, both within the State and Nationally. He says that two of the issues that are the most important to him are transportation and voting.

"Transportation is one of the biggest issues I have personally," he says. "We have to make sure that there's enough public transportation to help people get where they need to go. To get to our main offices (at the Council), there's only one bus, and it only comes twice a day, at certain times. I think we need to work with city and State governments to make sure that more transportation is available."

Tag also believes that voting and political advocacy are key for self advocates. "Voting is important," he says. "It's one way people with disabilities can make their voices heard. Here in New Jersey we have a great Partners in Policymaking program. I'm a Partners grad. It was a great experience- I learned how to testify before the legislature, and how to basically deal with preparing testimony. Last year there was an amendment to get the words idiot and insane out of the State constitution. That's a huge deal. In the movie the Elephant Man, there's a line, *I am not an animal, I'm a human being*. That's something I know is important."

Georgia P&A's Parent Leadership Support Project

Georgia is ranked 53rd in the nation in providing inclusive education to students with disabilities. In addition, Georgia is one of a few States that has a separate school system for children with significant disabilities and is one of the states most likely to institutionalize children with disabilities. The Georgia Advocacy Office (GAO), Georgia's P&A, in collaboration with our federal partners, utilizes a range of strategies for addressing the need for children with disabilities to receive a free and appropriate education. One of these strategies is the Parent Leadership Support Project (PLSP).

PLSP was created to increase the capacity of the community to respond to students with disabilities being excluded from the neighborhood classroom, denied high quality instruction, and excluded from the experience of being a student in the school community. PLSP seeks to address this issue on a local level, one student at a time, by recruiting and training volunteer advocates to attend school-based meetings for students with disabilities who have been denied an appropriate education. The project, now in its fourth year, has graduated 172 trained advocates who are assisting students with developmental disabilities throughout the State.

The Parent Leadership Support Project objectives are as follows:

- To assist and enable Georgia parents of children with disabilities and other concerned citizens to master information and negotiate systems in order to help secure the educational opportunity that is a civil right and legal mandate for children with disabili-

ties.

- To provide trainees with the best information on the complex issues surrounding Georgia's educational system to raise competency levels of people advocating on behalf of students with disabilities.
- To present professional speakers who educate trainees and give the project a hands-on, in-depth view.



- To develop long-standing relationships between concerned parents and citizens.

The Parent Leadership Support Project was developed in response to a statewide call to establish community support for inclusive education. Developing and supporting community advocates has allowed the GAO

to leverage the resources of the P&A to meet the needs of many more children with developmental disabilities to be fully included in their communities. The project is funded in part by the Governor's Council on Developmental Disabilities. Classes are hosted by local communities.

Graduates come from most areas of the state. Having graduates throughout such a large area makes it possible to connect people with a trained advocate in their local community who is familiar with the local school system and local resources. PLSP targets minorities, people outside metro-Atlanta, and self-advocates with developmental disabilities as participants in the training classes. PLSP serves both rural and urban areas of the State and has provided assistance to over 1,400 families in 95 of Geor-

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gia's 159 counties. In addition to advocating for individual students, many graduates also take an active role in systemic issues such as commenting on proposed changes to Georgia Rules and Regulations resulting from the IDEA 2004 Regulations.

One graduate worked on the behalf of a young man in metro-Atlanta who was be-

ing disciplined for behaviors related to his disability and ridiculed by his peers. The advocate was able to ensure a free, appropriate public education (FAPE) for this student in his neighborhood school and also explained the school's responsibility to enforce disciplinary procedures with the other students through the county "Bullying Violations Hotline." www.thegao.org

Washington P&A Stops the Unlawful Segregation of Students with Autism from the Public School Grounds

With a challenge to its refusal to allow eight students with autism to be educated on school grounds pending in a federal court of appeals, the Bremerton School District in Washington State entered into a settlement agreement with their parents and the State of Washington that allows the students to return to public school in the fall, to be educated alongside their non-disabled peers as federal law requires.

The students all reside within the school district at the Francis Haddon Morgan Center (FHMC), a state-run institution for people with developmental disabilities. They had previously received their education in Bremerton public schools. The federal lawsuit was brought by the students in response to a plan to segregate the educational services of these students to the institution, instead of providing the services in a public school. Disability Rights Washington, Washington's P&A, filed the lawsuit on behalf of the students, saying that taking these youths out of public school violated state and federal education and anti-discrimination laws.

"Every day that the students were kept out of the public school harmed them, and harmed their non-disabled peers, by denying both of them the opportunity to learn in a diverse and natural environment. This kind of discrimination is an issue that has been coming up in-

creasingly around the State and around the country," says Regan Bailey, Director of Legal Advocacy for the P&A.

Joining DRW on appeal to represent the students was Seth Galanter, a lawyer from Morrison & Foerster who took on the case pro bono. "This agreement shows that school districts, working with parents and with state officials, can reach practical solutions that protect the rights of all students," he said.

Evidence submitted in the case showed that the students were harmed by the move to a classroom in the institution. One of the parents' lawyers, David Carlson, Associate Director of Legal Advocacy at Disability Rights Washington, said, "These students have the right to develop and flourish alongside all the other students in the public-school system and to single them out as the only students who were not allowed to attend class at the local school was blatantly discriminatory."

"Brianna needs to interact in society - not to be segregated. She starves and desires to be a part of the school community, and that would not have happened without this lawsuit," commented Janet Littlefield, aunt and guardian of one of the eight disabled students represented in the lawsuit. www.disabilityrightswa.org



The next issue of the ADD Update will focus on health access for individuals with developmental disabilities. Please Send your stories to rebekah.yeager@acf.hhs.gov.



Administration on Developmental Disabilities

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



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The Administration for Children and Families (ACF) and the U.S. Department of Health and Human Services (HHS) have received a significant level of funds from American Recovery and Reinvestment Act of 2009 (ARRA). While ADD is not the direct recipient of those funds, we are supporting the important role ACF and HHS have in the implementation of ARRA to ensure the success of the economic stimulus plan and recovery in American communities affected by the economic downturn. We will share pertinent information about ARRA as it becomes available. You can visit <http://www.recovery.gov/> to learn more about ARRA in general. For information specific to HHS, please visit <http://www.hhs.gov/recovery/index.html>.

Temple University is offering online classes to help the public health workforce and emergency managers to address the needs of special populations, including people with disabilities and older Americans. [Emergency Management with Special Populations Certificate Program](#)