

ADD Update

The American Dream Belongs to Everyone

NOVEMBER 2008



INSIDE THIS ISSUE:

UCEDD TA Conference	2
P&A/CAP National Conference	2
Councils TA Conference	3
SABE Conference	3
Autism and Faith	4
My Schedule Works Around Me	5
Dreaming Big in Kentucky	6
North Carolina Council and Direct Support Professionals	7
The South Carolina UCEDD Consumer Advisory Committee	9
Utah UCEDD Gives Children a Place to Play and Learn	10
Helping Families Thrive	11
Maryland P&A Systems Focus on Health Care	13

Message from the Commissioner

Disabilities affect families, not only individuals. Just ask the mother fighting for the services her child needs, the sibling who feels pushed aside when the family focuses on his brother, or the adult child struggling to properly care for her parent.

ADD strongly believes that when the entire family of an individual with a disability is supported, the family members are in turn better able to support that individual. By creating a net of services and supports that address the needs of *all* family members, we can help families stay together and thrive. This belief led ADD to fund Family Support 360 Projects. Family Support 360 One-Stop Centers were created because while many service programs are available in this country, human service systems often fail to meet the diverse needs of an individual with developmental disabilities and his or her family. A family may need several services and most service systems address primarily one need, such as health, education, or employment.

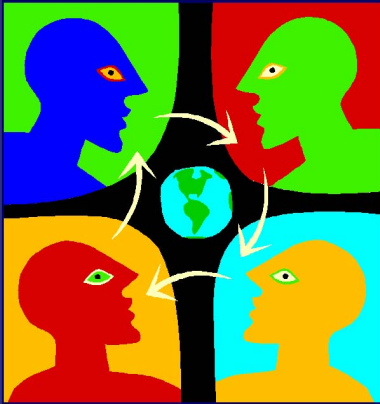
Family Support Programs are not the only ADD grantees working to work the needs of families. Programs are being implemented to offer activities for siblings, to help families enter into

the least restrictive guardianship arrangements necessary, to provide respite care, and to help parents strengthen their marriages. ADD applauds these efforts.

This issue of the ADD Update also focuses on autism spectrum disorder (ASD). ASD has for several years been a hot-button issue, a frequent news headline, and a source of controversy as its causes are debated. ADD's grantees have found a myriad of ways to meet the needs of individuals and families affected by ASD, some of which are highlighted in these pages.

On another subject, the recent box office release of the movie *Tropic Thunder* has thrust into the spotlight the issue of language used in reference to people with disabilities. While certain topics raised in the movie are a painful reminder that some attitudes in this country are in need of serious adjustment, it also provides the disability community a powerful opportunity to enter into a dialogue about this subject and let our voices be heard. We have the chance now to exercise *our* First Amendment rights, to speak out, to educate the American public about a subject that is all too often ignored. In the words of Jeff Ridgeway, a self-advocate in Mobile, AL, *The only "R word" we need is respect.*

UCEDD TA Conference



The UCEDD Technical Assistance conference was held on June 12-13, 2008. The first day, focus was on new Annual Report and the changes that the Directors can take back with them to discuss with their staff. There has been a committee formed so that feedback can be given and changes can be made. The UCEDDs are asked to provide input so that the report will

display their yearly reviews to ADD. In addition, a work group was held to discuss the transition of Directors, with the intention of creating a book that can be passed along to all UCEDDs when transition arises at individual programs. This booklet will be a beneficial tool that will help to keep the UCEDD running and

on task once the present director leaves. Also, attendees discussed the ADD/UCEDD Resource Center that AUCD updates as instructed by ADD program staff so that resources are available at all times. During that afternoon session, outside presenters discussed strategies to improve the financial stability of the programs. During the next day's meeting, a wrap-up session provided an overview of the forms that are needed by the grantees once the FY 2007-2008 ends on June 30, 2008. Attendees also discussed the annual reports and received information about a fellowship opportunity (information available on the AUCD website www.aucd.org). The morning finished up with break-out sessions participated in by all directors.

P&A/CAP Annual Conference

The P&A/CAP Annual Conference this year was productive and light-hearted too, being located in down-town New Orleans.

Meanwhile, there was a lot of learning and sharing going on inside the hotel at the Annual Conference. It began on Monday, June 9, with major workshops on investigative interviewing and School-to-Prison Pipeline Reform, in addition to the Legal Director's meeting and a two-day workshop by the National Institute of Trial Advocacy (NITA).

Tuesday began with a plenary on emergency planning after Katrina, which included a presentation by Dr. Morrissey

as well as a presentation by Mitch Landrieu, the Lt. Governor of Louisiana. This was followed on Thursday with a plenary entitled "The Disability Industrial Complex."

The rest of the week included numerous workshops covering such subjects as abuse and violence against persons with disabilities, ADA issues, jail issues, school issues, closing sheltered workshops, and issues in vocational rehabilitation. There were self-advocacy workshops that featured influential speakers with developmental disabilities.

Councils TA Conference

This year’s Technical Assistance Institute for State Councils was held June 9 & 10 at the Westin Arlington Gateway in Arlington, VA. The Institute entitled “Dialogue and Directions – The Culture of Council Accountability” featured keynote addresses and workshops focused on the concept of Council accountability in the age of the Government Performance and Results Act (GPRA).

Michael Collins, Executive Director, and Marylyn Howe, member, from the National Council on Disability (NCD), and Nancy Thaler, Executive Director of the National Association of State Directors of Developmental Disabilities Services were the keynote speakers. Mr. Collins and Ms. Howe provided an overview of the responsibilities and work of the NCD including its review of federal disability legislation; and Ms. Thaler addressed the relationship of State Councils to state services systems and how they can better address the needs of individuals with developmental dis-

abilities.

Commissioner Patricia Morrissey led the workshop “Accounting for Actions: Guidance for Council members in their roles as advocates with public policymakers,” and also provided a luncheon presentation summarizing her experiences from her years of legislative advocacy and leadership of programs for individuals with disabilities. The National Association of Councils on Developmental Disabilities presented Dr. Morrissey with a token of appreciation for her leadership over the past seven years.

Other workshops focused on evaluation of designated state agencies, new approaches to grants and contracts, self-advocacy, performance measurement and data analysis, and council member responsibilities.

SABE Conference

Self Advocates Becoming Empowered (SABE) held its ninth national self advocacy conference in Indianapolis, Indiana on September 4-7, 2008. With over 1,500 attendees this conference, SABE 2008 was unique in many ways, not the least of which is that every one of the over 100 presenters was an individual with a disability; focusing on the most critical areas they have identified. Topics included:

- Making Your Voice Heard During Your IEP Meetings

- Having the Career of Your Dreams
- Partners with a Twist

- Co-Executive Directors: Take a Walk in our shoes
- The Story of my Brother and the Institution
- Changing Lives: Life Outside the Institution



The dreary weather outside was no match for the enthusiasm in the downtown Marriot as conference attendees socialized, made new friends, and shared their stories, concerns, and goals with one another. <http://www.sabeusa.org/>

Autism and Faith

Autism and Faith: A Journey into Community



The New Jersey UCEDD, the Boggs Center, has developed a new resource entitled *Autism and Faith: A Journey into Community*. The guide provides an introductory, empowering resource for use by clergy, religious educators, and families to develop inclusive spiritual supports for children and adults with autism and their families and recognize the unique

gifts that congregations and people with autism can offer to one another.

The fifty-two page guide for including individuals with autism in faith communities was developed by The Autism and Faith Task Force of The Boggs Center and The Center for Outreach and Services to the Autism Community (COSAC) with funding from The Daniel Jordan Fiddle Foundation. The Task Force worked for more than two years collecting stories and experiences from families, best practices and strategies from clergy and human service professionals, and resources from around the country.

The guide features more than fifteen short articles written by clergy, parents, professional experts on autism, religious educators and people with autism, illustrated by numerous sidebar stories and examples from families who shared their experiences, both positive and negative, with their own faith communities in New Jersey. It is interfaith, including examples from Christian, Jewish, Hindu,

and Muslim communities.

Sample articles include:

- Autism Life Cycles and Faith Communities
- Autism and the Family
- Creating Sanctuary: A Clergy's Guide
-

Linda Fiddle, the executive director of The Daniel Jordan Fiddle Foundation, which provided the funding for the printing of this booklet notes, "This new resource will create a better understanding by faith communities of autism and the challenges and joys families and individuals find as they seek to participate. It also is our hope that those with autism will use this as a vehicle to open the doors to their faith communities as a means of support and spiritual growth that The Daniel Jordan Fiddle Foundation believes is an important component to lifetime wellness."

For more information, please contact Rev. Bill Gaventa, director of Community and Congregational Supports at The Boggs Center, 732-235-9304 or email bill.gaventa@umdnj.edu. To place an order, please visit The Boggs Center website at <http://rwjms.umdnj.edu/boggscenter> or call 732-235-9317.

"It also is our hope that those with autism will use this as a vehicle to open the doors to their faith communities as a means of support and spiritual growth..."

My Schedule Works Around Me

By Steve Fleisher

I began my new life in September 2004. That was the month that I left group homes and agency-run day services forever and became part of the Self-Determination Pilot Project. I lived in three group homes and one two-person apartment. It was hard and definitely not for me. There were many rules and restrictions, like frequent fire drills, that I did not like or agree with. I already knew how to get out in case of a fire because I did many fire drills in my lifetime!

Steve Fleisher is a 28 year old man who also happens to have a developmental disability that falls on the Autism Spectrum. His story was submitted by the New York State Developmental Disabilities Planning Council.

In one of the group homes, they always cooked fried food. That can make you really fat! In the other group homes, they had menus that came from the main office of the agency, without asking the guys what they wanted to eat. Guys should have choices in their home. I started Weight Watchers, but the staff did not know how to help me. The manager bought me Weight Watcher's frozen dinners, but said it was too hard for the staff to learn about counting points, so my parents helped me bring my own food, and taught me how to write down my points. I called my mom a lot for help! I had to bring "lock bags" for the refrigerator and freezer so that no one took my food or threw it out.

It was ridiculous. I did not have freedom to come and go to the activities of my choice. I did not like doing activities with some of the guys because they sometimes got out of control and it embarrassed me. Some-

times I got nervous, and so I refused to go to the outings the house planned. Then no one could go, and they got angry at me. When there were things I wanted to do, other guys always had to come with me. I couldn't play on my baseball team unless someone was able to take me, there was a car available, and other guys were willing to come along for a ride. I worried about it all week. Finally, my parents took me to my practices and games.

When I went to my personal appointments, I had to lock the passenger car doors, or one of the other guys would get into the car. When there was not enough staff, you were stuck in the house. In one of the group homes, two of the guys needed one-on-one support,, leaving one staff for the remaining four guys. Once,



all day long they promised to take me to 7-11, but they kept needing to help the other guys. Finally I said, this is ridiculous and went by myself. Next thing I knew, they had called the cops because I was out alone. I just wanted to buy a newspaper and soda! Sometimes some guys would get out of control, and damage the walls, scream or yell. Sometimes I yelled back at them, but it only made things worse. I know they couldn't help it, but it drove me nuts.

My day services were called "Opportunities Without Walls". It was just me, with one worker, and we were supposed to do stuff in the community. That was the good part. Here is the bad part...it was only from 10am to 3pm. That made it very hard to get anything

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done. I love to travel into Manhattan by train, but by the time I would get there, I would have to turn right around. I wanted a job, but nobody hires someone for just those hours.

Group homes and agency programs might work for some people, but I was determined to live on my own and have my own life. Then my parents heard about Self-determination using Consolidated Supports and Services (CSS). At that time, there were no Start-up Brokers. Now you can pay someone to help you get started. But I was very lucky because I had a great Circle of Support who helped me get everything going.

There are many reasons CSS works for me. I live alone in my own apartment, with support staff always there to help me. I hire and supervise my own staff, with the help of my parents. In a group home, my activities had to work around the staff's schedule, but with CSS, the staff's schedule works around my activities. I can go on my personal appointments alone, make my own schedule, organize how to get to my baseball games, get my own job and work the hours I want to work. I can go to

Manhattan – or anywhere else --whenever I want without having to get permission from an agency. Last Labor Day, I got to do something I always wanted to do: I volunteered and answered phones at the Labor Day Telethon. I can choose to do activities with other people who have disabilities, or people without disabilities.

I am now part of the New York State Self-Determination Speakers Bureau, where I speak to agencies, classrooms and colleges about self-determination. This is a paid position, and I don't have set hours, which is great.

I am really interested in law enforcement. I really wish I could be an undercover cop in the street crime unit in a law enforcement agency. Maybe some day I could get involved in something like that. I would also like to increase my time spent advocating for people with disabilities, and advance my career doing that. With CSS, it is possible. Now I have a real life! I live alone in my own apartment and, with the help of my parents, hire staff to assist me.

www.ddpc.state.ny.us

Dreaming Big in Kentucky

Kentucky's "Project Dream" collaborative came about as a result of an annual meeting in which the Council, P&A, and the UCEDD members all worked together to create. For this the network approached Big Brothers Big Sisters of Kentucky. They learned that only 5% of children served within BBBS had developmental disabilities. They negotiated with the agency and agreed upon a project in which 50 children with disabilities were included in the program.

The Council has administered the project while P&A and the UCEDD have provided training to BBBS staff. Network

partners have also helped BBBS network within the disability community to find children and mentors.

July marked the beginning of the project's second year in which another 50 children will be included. The UCEDD is about to undertake a research initiative to determine outcomes from this project.

Once this has been completed, the Network will be attempting to work with the BBBS partner, the New Mexico Council and their partners to make this a nationwide component of all BBBS programs.

<http://www.kyddnetwork.org/>

Only 5% of children served within Big Brothers Big Sisters had developmental disabilities.

North Carolina Council and Direct Support Professionals

Beginning in 2007, the NC Council on Developmental Disabilities (NCCDD) undertook a series of initiatives to support the state in addressing the recruitment and retention of a high quality, frontline workforce to assist people with disabilities. In doing so, NCCDD introduced the state to a new term from the national community –direct support professionals (DSPs). DSPs go by many different job titles and support people with varying needs. The quality of a DSP’s work lies right at the heart of a person’s quality of life. This insight led the Council to fund a broad partnership aimed at achieving two key goals: 1) producing a plan for workforce development for the state’s DSPs through a grant to the NC Council of Community Programs and 2) introducing an internet, competency-based curriculum for DSPs through a grant to the NC Council of Community Support Providers. The Council and its grantees have realized both goals.

The NCCDD is far from alone in being concerned about workforce development. The Center for Medicare and Medicaid Studies (CMS) understands the connection between high quality service delivery and a well-trained staff. To assist, CMS has made technical assistance on workforce development available to select states. North Carolina is one of these, thanks to the Council’s advocacy. Teaming up with the state’s Division of Medical Assistance and other DHHS divisions, the NCCDD helped to bring CMS’s team to the state for a

pre-conference workshop at statewide Workforce Development Conference in October of 2007. Later, members of the CMS team worked under the leadership of one of the members Amy Hewitt, Ph.D., of the University of Minnesota to assist North Carolina stakeholders in developing a workforce plan. The Council’s funding of Dr. Hewitt secured exceptional support for the Commission on Mental Health, Developmental Disabilities and Substance, the Division of MH/DD/SAS and diverse stakeholders (including consumers, providers and DSPs themselves) to work together. The group produced the first DSP workforce development plan for North Carolina. NCCDD’s work with the state culminated in a presentation by Dr. Hewitt to the Legislative Oversight Committee (LOC) in spring of 2008.

The Direct Support Professional Workgroup Report identified the major barriers faced by provider agencies in recruiting and retaining qualified Direct Support Professionals. One of the most daunting is an increased demand for DSPs, projected at an additional 37 percent by 2020. This increase, coupled with an estimated 50 percent of Direct Support Professionals leaving their jobs every year, will cause, without concerted intervention, an enormous gap between the number of people needing services and the number of DSPs available. In addition to the increasing demand for Direct Support Professionals and a high turnover rate, low wages and lack of benefits are

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“The Center for Medicare and Medicaid Studies (CMS) understands the connection between high quality service delivery and a well-trained staff”

also common difficulties among DSP. Presently, the average wage for a Direct Support Professional within the private sector is \$8.68 an hour. This, in combination with limited opportunities for quality training experience, often leads to high stress, burnout, and a decrease in service quality, readily felt by people with disabilities and their families. In addition to low wages, many Direct Support Professionals in community settings do not receive health insurance. These basic issues combine to create perhaps the most significant overarching difficulty; a devalued occupational status. Though DSPs provide the majority of community services to individuals with intellectual and other developmental disabilities, they receive little to no professional recognition or opportunities for career growth because they are undervalued, except by those they support.

The report also addressed evidence-based strategies being employed nationally to increase the competencies of Direct Support Professionals and maximize recruitment and retention. These include tapping the networks of people already working for the organization to find other potential workers; web-based registries that match people with available positions; and community sponsored events and job fairs. Many provider organizations have also been incorporating “realistic job previewing.” This strategy cuts down on turnover and training costs by giving potential hires a deeper understanding of the job before they find themselves in it. Competency-based training, exemplified by the College of Direct Support, for both Direct Support Professionals and their supervisors, focuses training time and dollars on skills and knowledge rather than rules or regulations. These strategies, combined, can significantly reduce or even eliminate the gap between those that

need DSPs and the available pool of these professionals.

The Direct Support Professional Workgroup Report makes ten recommendations. These are:

- 1) the need for a permanent organizational structure devoted to workforce issues;;
- 2) a uniform method of credentialing DSPs;
- 3) increased wages for DSPs;
- 4) design and implementation of a public awareness and marketing campaign;
- 5) training, technical assistance, and incentives for effective, training and retention practices;
- 6) system-wide training to both supervisors and managers on effective oversight;
- 7) opportunities for Direct Support Professionals to be at the policymaking table and to network with each other;
- 8) creation of new service options for individuals with disabilities and their families to “self-direct” their DSPs;
- 9) access to affordable health insurance; and
- 10) the implementation of tools and strategies to aid providers in reducing rates of early turnover.

In February NCCDD voted to endorse these recommendations. Hewitt presented these recommendations to the Legislative Oversight Committee in April as essential components in strengthening North Carolina’s direct support workforce. At the same time, Governor Easley cited the need for “continued development of appropriate community services to support the full continuum of care necessary to serve our citizens.”

www.nc-ddc.org

Many provider organizations have also been incorporating “realistic job previewing.” This strategy cuts down on turnover and training costs by giving potential hires a deeper understanding of the job before they find themselves in it.

The emergence of self-advocates and family members of people with disabilities from diverse backgrounds as leaders has made a significant impact on this nation.

The South Carolina UCEDD Consumer Advisory Committee

The true measure of how well a Consumer Advisory Committee impacts the UCEDD

network is its level of involvement. The emergence of self-advocates and family members of people with disabilities from diverse backgrounds as leaders has made a significant impact on this nation. The evolution of the participatory Consumer Advisory Committee has given people with disabilities the opportunity to not only foster the development of self-advocacy leadership skills but skills that ultimately benefit the work of Centers for Excellence in Developmental Disabilities.

The South Carolina Consumer Advisory Committee, known as the Council on Consumer Affairs (COCA), is highly engaged in guiding the direction of the Center for Disability Resources (CDR) activities and projects. In a supportive environment, the COCA meets quarterly to provide valuable input into the decision making process. It consults with the Director on the Center's five-year plan and annual review to further the mission and shared vision of full inclusion of persons with disabilities in every aspect of society. The Director attends each meeting and the COCA Liaison provides administrative support. The CDR



provides honorariums to all COCA Advisors who are individuals with developmental disabilities and family members.

In addition to administering an annual consumer satisfaction survey/focus group meeting, the COCA participates in interdisciplinary pre-service training, reviews materials and participates in conference planning with CDR projects.

It has developed by-laws and elected officers, established a travel policy, developed a COCA orientation

manual and brochure, spearheaded the update of the CDR web-site, and established non-traditional partnerships to address minority representation on the COCA. Furthermore, the COCA Advisors have participated in public hearings on taxicab transportation and expanded its role to serve as the Disability Inclusion Advisory Council for the South Carolina Commission on National and Community Service.

More importantly, COCA Advisors are afforded the opportunity to continue to develop self-confidence and leadership skills.

www.cdd.sc.edu

Utah UCEDD Gives Children a Place to Play and Learn

The big blue floor at High Point Gymnastics in Logan, Utah is soft and springy enough that aspiring cheerleaders learn stunts on it. Karate kids practice their moves there, and young gymnasts stretch. It's a surface that invites play, but it poses a challenge to a child who is learning to walk.

That's why it's a great place for the children of the Up to 3 program. Up to 3 is housed at the Center for Persons with Disabilities on the Utah State University campus, and its

focus is on children with developmental disabilities, delays or conditions likely to result in delays. Most of the Up to 3 services are provided within homes, but once a week parents can bring their children to the gymnastics floor.

If children who are delayed in walking can play on a more difficult surface, they can learn more about balance and coordination than a flat floor can teach, said Curt Phillips, a physical therapist for the Up to 3 program at the Center for Persons with Disabilities. When the children take those skills home to an ordinary floor, walking becomes easier.

Up to 3 physical therapists consult with a gymnastics instructor there,

and she teaches the children basic skills, including a warm-up before the fun begins.

The sessions at High Point give the children a chance to catch up with their peers. There, the children can experiment with moving on a springy floor, bouncing on a trampoline or climbing a ladder leaned against a stack of mats. Once they reach the top, they can slip down another mat leaning against the other side of the stack to simulate a soft, gentle slide.



Trevor has been coming for about three months, and he likes to have new things to do and play with, said his mother, Angie Heck. Trevor uses a walker, but he lets go of it to climb the ladder and slide down the mat. "He's getting more adventurous to step out," said his mother.

Sadie has been coming for about six months. At first she was suspicious of the playtime on the blue floor because she recognized it as physical therapy, said her mother, Julie Gardner. With time, though, Sadie decided it was good to come and play.

"She doesn't recognize it as work," Gardner said. "Watching the other kids gives her incentive. ... It's cool [for Sadie] to be here because there are other kids."

www.cpd.usu.edu

"Up to 3 is housed at the Center for Persons with Disabilities on the Utah State University campus, and its focus is on children with developmental disabilities, delays or conditions likely to result in delays."

Helping Families Thrive

The realization that something was wrong was gradual.

Until he was 18 months old, Tina Dula’s son Myles was neurotypical. Then he lost all of his language. His daycare center began to report changes in his behavior, including hitting other children. Dula took Myles to the pediatrician, who assured her that everything was fine, that Myles was “just being a boy.” Myles silenced the internal voice that told her something was off, and convinced herself everything was going to be okay.

Then one day she walked into the daycare center with Myles and saw a stack of books about autism on the desk. *Oh my God*, was her immediate thought. *They think Myles has autism.*

Soon after the incident at the daycare center, Dula’s best friend invited her over. She poured her a glass of wine and said, “We need to talk about Myles.”

“I just broke down,” Dula says. I knew I’d been hiding from this.”

Myles was diagnosed with an autism spectrum disorder (ASD) shortly thereafter, and Dula and her husband immediately got him into an early intervention program.

“We struggled in every way you can imagine,” says Dula, “financially, emotionally, relationally. Because so many of the expenses associated with therapies for autism are not covered by insurance or Medicaid,

we were left to absorb many of those costs ourselves. My husband lost his job two days after we received the diagnosis, and our money dried up quickly. The frustration of not being able to provide what my son needed, coupled with the emotional turmoil we were working through with this new challenge, caused tremendous strain on our marriage. We lived in the shadow of potential bankruptcy, marital trouble, and for me, depression, for those first years.”



As things began to stabilize and Dula and her family began to find their footing, her thoughts turned outward, to other families going through the same struggles she’s endured. In December 2007, Dula established a non-profit organization called Myles-A-Part. The mission was to provide emotional and financial support for families fighting autism. The organization is still young, and its three main programs are in various stages of development. Myles-A-Part currently focuses on providing support for Georgia families. Its three anchor programs are:

The Hourglass Early Intervention Program (HEIP), which will provide financial stipends for therapies not covered by insurance or Medicaid, as well as providing guidance for effective early intervention.

Thrive, the program focused on emotional support for couples and families,

Soon after the incident at the daycare center, Dula’s best friend invited her over. She poured her a glass of wine and said, “We need to talk about Myles.”

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ADD Update Expands Reach: Myles-A-Part is not directly linked to ADD, but Tina Dula read a recent issue of the Update on a message board and sent in her story. We encourage Update readers to forward the Update to anyone who may be interested– it’s a great way to broaden knowledge of your programs!

I allowed those voices to tell me what I wanted to hear; that there wasn't a problem, even though my "mommy gut" told me that there was."

including marriage counseling, grief counseling and support for siblings of ASD children.

The Autism Initiative for Minorities (AIM), which will focus on the disparate late diagnosis and less effective intervention seen among African- American and Hispanic children with an ASD. Focus is on identifying these children, getting an accurate diagnosis, and then helping them to access appropriate services.

This summer, the Thrive program was expanded to provide a day-long workshop for single parents and grandparents raising children with autism. Myles-A-Part has also negotiated reduced-cost family counseling – marriage, sibling support, depression, addiction, parent/family – through an Atlanta counseling center. All families referred by Myles-A-Part received an 80% discount on counseling services. If they cannot afford even that, Myles-A-Part pays the remaining 20%.



make it,” Dula says. “We want to see them thrive.”

When asked what advice she’d give to a parent who notices possible signs of autism in her child, or who has a child with a new diagnosis, Dula says, “Do not delay. Do not deny. Do not accept excuses from pediatricians or well-meaning family and friends. Move right away to get to the bottom of any delays you notice in your child. I was so scared that for a few weeks I allowed those voices to tell me what I wanted to hear; that there wasn't a problem, even though my "mommy gut" told me that there was.”

Dula now listens to her “mommy gut,” and works to help other parents listen to their instincts and find their voices.

Today, Myles is doing well. “His progress is incredible,” says Dula. “We fight for every little step. We celebrate every step.”

www.mylesapart.org

“We don’t want to see families just

Maryland Protection and Advocacy Systems Focus on Health Care

Since 2004, Maryland Disability Law Center's (MDLC) HOMES (Helping Obtain Medicaid Essential Services) Project has focused on the rights of Medicaid recipients with developmental disabilities to access the health care services they are entitled to receive. This work -- begun as a project to represent children and expanded a year ago to serve adults too -- has enabled many families to stay together and avoid institutionalization or out-of-home placement for a child or adult with a disability. The project includes individual case work in which MDLC provides advice or technical assistance to Medicaid recipients and their families, providers, and professionals when problems arise in access to Medicaid services, and legal representation in appealing service denials or delays when necessary. In addition to handling individual cases themselves, MDLC has partnered with the private bar to recruit and train attorneys interested in taking pro bono referrals and to provide technical assistance to attorneys who accept case referrals. MDLC has prepared a number of publications on covered health care services, how to access them, rights of Medicaid recipients, and appeal options. They also offer training on these subjects for families, professionals, providers, advocacy organizations, service coordinators, and social workers or case workers for children in state custody.

Many provider organizations have also been incorporating "realistic job previewing." This strategy cuts down on turnover and training costs by giving potential hires a deeper understanding of the job before they find themselves in it.



For example, MDLC assisted the family of a 17 year old with cerebral palsy who lived with her single parent to obtain the in-home nursing assistance needed for her mother to continue to manage her daughter's care at home. The child's mother was on the verge of pursuing a residential placement after the State cut her daughter's in-home nursing hours in response to the mother's request for additional hours to enable her to manage her job and her own health care needs related to a chronic medical condition. MDLC amicably resolved the matter and secured all the nursing hours the family had sought by obtaining adequate documentation from the mother's doctor and employer and from the child's doctor.

This project has been funded with a combination of funds MDLC receives from ADD as the P&A system for Maryland, as well as grants from the Harry & Jeanette Weinberg Foundation which requires MDLC to raise matching funds for the project from other sources.

In 2008, through funding from MDLC's DD Network Partner, the Maryland Developmental Disabilities Council, MDLC expanded this project to develop a booklet and training curriculum on access to health care under Medicaid for self-advocates with developmental disabilities, and has begun training self-advocate groups throughout the state.

For further information on this project, contact Cathy Surace at cathys@mdlclaw.org or (410) 727-6352, ext. 2499.

The next issue of the ADD Update will focus on self-advocacy. Please Send your stories to rebekah.yeager@acf.hhs.gov.



Administration on Developmental Disabilities

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



On October 27, 2008, the U.S. Department of Health and Human Services held a Ceremony to Celebrating Persons with Disabilities, in honor of the President's National Disability Employment awareness month. ADD congratulates **Dr. Phyllis Magrab**, Executive Director of the DC UCEDD, who won the Advocate for Person with Disabilities Award.

Other honorees included:

- **International Award: Dr. Alim -Louis Benabid**, world renowned pioneering scientist and mentor in the area of deep brain stimulation that changes the lives of persons with movement disorders.
- **Health/Service Provider for Persons with Disabilities Award: Dr. Joseph Rosen**, noted plastic surgeon who performs facial and body reconstructions at Walter Reed Medical Center for Wounded Warriors, free of charge.
- **Persons with Disabilities Across the Lifespan Award: Mr. Kyle Maynard**, born with congenital amputation of all four limbs, is a champion wrestler, author, motivational speaker, advocate, and role model.
- **Entertainment Industry Award: Ms. Emily Kingsley**, staff writer for Sesame Workshop, credited with introducing the topic of disability on Sesame Street through the program appearances of children and Muppets with disabilities.
- **The 2008 Certificate of Appreciation: Ms. Dora Ricks**, HHS employee who instructed, mentored and motivated young persons with disabilities to become productive and employable citizens.