

# adap news



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## Alabama Family Ties

Sarah Ellen Thompson is the Executive Director of Alabama Family Ties (AFT). Serving Alabama since 1998, AFT is a statewide educational, resource, referral and support organization that works with families of children with emotional, mental and behavioral disorders. ADAP invited Ms. Thompson to share her thoughts on the state of mental health services for children in Alabama.



Working at Alabama Family Ties, one of my most important responsibilities is to answer calls from parents.

These mothers and fathers, grandmothers and grandfathers, stepmoms and stepdads tearfully share with me stories of children in crisis, schools that won't accommodate their

children's disabilities and communities who want these precious gifts from God off their streets and out of their neighborhoods.

The Alabama Department of Mental Health and Mental Retardation (DMH/MR) accomplishes many good things for the youth of our state. It supports residential and day treatment programs; crisis intervention services; individual, family and group therapy; medication administration and monitoring; physician services; juvenile court mental health liaisons; case management; and in-home intervention services.

All of this is known as a continuum of care and it all sounds wonderful. But, the truth is these services are not consistently provided throughout the state. Instead, the continuum is fragmented and incomplete, leaving too many children without the care they need.

So, I answer the phone, and listen to families who are lost and without hope.

What do I tell the mother of a youth from Montgomery County who just spent the weekend sitting by a bed in a local hospital ER watching over her suicidal teenager? There was no admission to a facility, no medications given, and no referral to another hospital. No one came to offer her a break to get food or go to the bathroom. She was charged with caring for her child, not the hospital. On Monday morning, the hospital told her to take her son home.

What do I tell a Mobile grandmother, who is on a wait list for services for her six and seven year old grandchildren? Children whose behaviors are so erratic and volatile at school they repeatedly get suspended.

Is she a bad parent for taking in her grandchildren from a drug abusing mother who has left the state? Is she a bad parent for not knowing how to handle children with hyperactivity? Are these two young children bad for not knowing how to handle a brain disorder?

What do I tell the Bullock county grandmother who worked for three years to get a male therapist to come weekly to school for her twelve year old grandchild with depression and ADHD who calls to tell me that the therapist left and there is no one to take his place? He was moved to another region in the mental health



center's service area and no one, not the therapist, or his supervisor, thought to take a moment to stop by the school, call his grandmother, or write a note goodbye. Now, this young man is getting in trouble again at school and is on the verge of failing or being kicked out.

What do I tell a Morgan County mother who tells me that she has a depressed and suicidal child and was referred to the local mental health center only to be told she had to wait two months before she could get an appointment?

This situation is not the fault of the community mental health center, its employees, or central office personnel. On the whole, these people are hard working, dedicated, and caring.

But the tireless dedication of the few who work for the youth of Alabama and the small percentage of DMH/MR's budget that goes toward mental health services for Alabama's youth just aren't enough.

### These youth need:

- readily available and consistent case managers and therapists
- psychiatrists in all areas of the state, especially rural areas
- increased access to emergency care
- school staff trained to be responsive to youth with emotional disorders
- improved substance abuse treatment
- transition services to the adult continuum of care

### Their families need:

- access to up-to-date information on public mental health agencies and services
- a responsive one-stop-shop system so they only have to call one place to get their child help
- increased access to coordinators to help them find and coordinate services and care
- better understanding of their child's diagnoses and treatment programs
- advocacy training and information regarding their child's rights to services

As AFT gets ready to celebrate its tenth anniversary in 2008, the best present I can hope for is that Alabama will take decisive steps forward in providing better funding for children's mental health services and in expanding its continuum of care to address these needs so that every child in crisis has a mental health "home" and so that no family has to watch their child suffer.

*Pictures from AFT's Annual Conference, July 2007. For more information about AFT, contact Ms. Thompson at 1-877-834-0615 (toll free in state).* ●



## State to Pilot Consumer-Directed Care in West Alabama

Senior citizens and people with disabilities in west Alabama have a new choice in the way they receive home and community based services. The new Personal Choices program will give them greater flexibility and control over the delivery of their personal health care services. In May, Alabama became the first state to make consumer-directed care for Medicaid home and community-based services a permanent part of its state Medicaid plan.

Those in the pilot area who are part of the Elderly and Disabled (E&D) waiver and the State of Alabama Independent Living (SAIL) waiver for home and community-based services are eligible to take part in Personal Choices. The Alabama Department of Senior Services (ADSS) developed the program in collaboration with the Alabama Medicaid Agency and Alabama Department of Rehabilitation Services. ADSS will administer Personal Choices.

Under Personal Choices, individuals will be provided a monthly allowance from which they will determine what services they need. They may choose to hire someone to help with their care or they may wish to save money for equipment purchases. Financial

counselors will be available to guide them through the process which includes developing a budget to help manage the funds designated for their care.

Personal Choices will use the "Cash and Counseling" model for delivering services. "Cash and Counseling" has been tested over the past decade in Arkansas, Florida and New Jersey. These states have partnered with the Robert Wood Johnson Foundation and the Centers for Medicare and Medicaid Services (CMS) to study the outcomes of self-directed services in an extensive and carefully controlled research design that has been well documented. Because of the very positive results, CMS and Congress have seen fit to encourage States to make self-directed services more available as an option for people who receive home and community-based services. Development of Alabama's program was made possible by a grant ADSS received from the Robert Wood Johnson Foundation.

Personal Choices is targeted to start on August 1, 2007. It will operate as a pilot project in Bibb, Fayette, Greene, Hale, Lamar, Pickens and Tuscaloosa counties. People who receive personal care or personal assistance services under the E&D waiver or the SAIL waiver and live in one of the seven counties will be offered the choice of self-directing.

For more information on the Personal Choices program, contact the West Alabama Regional Commission's Area Agency on Aging at (205) 333-2990 or 1-800-432-5030. ●

## Social Security Administration

### What is the Ticket Program?

The Ticket to Work and Self-Sufficiency Program is an employment program for people with disabilities who are interested in going to work. The Ticket Program is part of the Ticket to Work and Work Incentives Improvement Act of 1999 - legislation designed to remove many of the barriers that previously influenced people's decisions about going to work because of the concerns over losing health care coverage. The goal of the Ticket Program is to increase opportunities and choices for Social Security disability beneficiaries to obtain employment, vocational rehabilitation (VR), and other support services from public and private providers, employers, and other organizations.

Under the Ticket Program, the Social Security Administration (also referred to as the Agency) provides disability beneficiaries with a Ticket they may use to obtain the services and jobs they need from a new universe of organizations called Employment Networks (ENs).

In October 2006, the Social Security Administration (SSA) replaced the Benefits Planning, Assistance and Outreach Program with the Work Incentives Planning and Assistance (WIPA) program. The Program was renamed because of an increased emphasis on work incentives, return to work supports and jobs for beneficiaries.

SSA, as authorized by the Ticket to Work and Work Incentives Improvement Act of 1999, awarded 99 cooperative agreements to a variety of community organizations to serve as WIPA projects. These WIPA projects provide all SSA beneficiaries with disabilities (including transition-to-work aged youth) access to benefits planning and assistance services. The goal of the Work Incentives Planning and Assistance (WIPA) Program is to better enable SSA's beneficiaries with disabilities to make informed choices about work. Each WIPA Project has Community Work Incentive Coordinators (CWICs) who will:

- Provide work incentives planning and assistance directly to SSA's beneficiaries with disabilities to assist them in their employment efforts;
- Conduct outreach efforts in collaboration with SSA's Program Manager for Recruitment and Outreach contractor to beneficiaries with disabilities (and their families), who are potentially eligible to participate in Federal or State work incentives programs;
- Work in cooperation with Federal, State, and private agencies and nonprofit organizations that serve beneficiaries with disabilities;
- Refer beneficiaries with disabilities to appropriate Employment Networks based on the beneficiary's expressed needs and types of impairments;
- Provide general information on the adequacy of health benefits coverage that may be offered by an employer of a beneficiary with a disability and the extent to which other health benefits coverage may be available to that beneficiary in coordination with Medicare and/or Medicaid; and
- Provide information on the availability of protection and advocacy services for beneficiaries with disabilities and how to access such services.

For more information on the various work incentives provided by the Social Security Administration, please contact the Alabama Disabilities Advocacy Program and request information on the Protection and Advocacy for Beneficiaries of Social Security (PABSS) program. ●

## National Disability Rights Network Urges Congress to Pass ADA Restoration Act

### 17th anniversary of landmark Americans with Disabilities Act reveals progress and much yet to be done

On July 26th - the 17th anniversary of the Americans with Disabilities Act (ADA) - leading Members of the House and Senate, including Majority Leader Steny Hoyer (MD), Rep. Jim Sensenbrenner (R-WI), and Senator Tom Harkin (D-IA) introduced the ADA Restoration Act with strong support from the National Disability Rights Network (NDRN) and the larger disability community.

Over the past 17 years, the courts have narrowed the definition of disability so much that people with conditions like epilepsy, diabetes, HIV, cancer, and hearing loss who manage their disabilities with medication, prosthetics, or hearing aids are viewed as "too functional" to have a disability. While these same people may be denied a job or fired because an employer mistakenly believes they cannot perform the

job, they are denied the ADA's protection from employment discrimination. This creates a Catch-22 in which employers say a person is "too disabled" to do the job but not "disabled enough" to be protected by the law.

The ADA Restoration Act introduced today ensures the right of individuals to be judged based on performance. It restores the original intent of Congress, harmonizing the ADA with other civil rights laws and requiring the courts to interpret the law fairly.

"While great progress has been made since passage of the ADA, bad court decisions over the years have eroded many of its essential protections," said NDRN Executive Director Curt Decker. "We urge Congress to quickly pass this bill to restore the rights of all Americans to be free from unfair discrimination."

Passed with overwhelming bipartisan support and signed into law by the first President Bush July 26, 1990, the ADA was passed to ensure equal rights for individuals with disabilities in workplaces, transportation, and other aspects of daily life. ●

## Disability Resources

Check out the 2005 American Community Survey at <http://factfinder.census.gov> for up-to-date statistics by state or county for people with disabilities.

[DisabilityInfo.gov](http://DisabilityInfo.gov) is the federal government's one-stop Web site for people with disabilities, their families, employers, veterans and service members, workforce professionals and many others. A collaborative effort among twenty-two federal agencies, DisabilityInfo.gov connects people with disabilities to the information and resources they need to actively participate in the workforce and in their communities. Broken down by state, the topics covered on the website are: employment; education; housing; transportation; health; benefits; technology; community life and civil rights.

### Disability Census Facts

- Six and one half percent (6.5%) of individuals between 5 - 15 years old have a disability.
- The percentage of individuals with a disability rises to 12.1% for the 16 - 64 year old population. For individuals who are 65 years of age and over, the rate of disability is at 40.5%.
- The most reported disability for individuals who are 16 - 64 years old are mental disabilities; 5.2% of the individuals with a disability in this age group report a mental disability. In contrast, the most commonly reported disability for senior citizens (65 years and older) is a physical disability (30.8%).
- Only 37.5% of individuals 16 - 64 years old who have a disability are employed.
- The poverty rate for persons with disabilities (5 years of age and older) is twice the rate for persons without disabilities (21.1% versus 11.3%). ●



## Calendar

### August 20-22, 2007

#### Full Life Ahead Foundation

#### "Helping Other People Envision"

The Full Life Ahead Foundation will be hosting a Family Summit on August 20-22, 2007 at the Riverview Plaza Hotel in Mobile, Alabama.

Topics will include:

- How to Plan and Implement a FLAPP (Full Life Ahead Planning Process)
- David Cox will present "Climbing your own personal Mount Everest"
- Bill Taylor and Family will present "How to make it happen in Alabama"
- Wanda Berry from ALAWIN will present "It pays to work"
- John Roberts, (retired ADRS and Full Life Ahead Board Member), will present "How to make Social Security work for you!"

For more information contact:

Lisa Manly, Executive Director

email: lisamanly@fulllifeahead.org

Phone: (205)261-1235 OR (866)700-2026

Web:www.fulllifeahead.org

### October 3-5, 2007

#### 2007 National Respite Conference

Alabama Respite and United Cerebral Palsy of Huntsville and Tennessee Valley, Inc., will be hosting the 2007 National Respite Conference. The conference will be held in Huntsville at the Embassy Suites Hotel and Von Braun Civic Center. Respite professionals and caregivers from around the United States will gather to receive information on best practices for respite delivery, how to develop new respite programs and information on training respite providers. If you would like more information, please contact:

Linda Lamberth, Project Manager

Alabama Lifespan Respite Resource Network

521 E 9th Street, Anniston, AL 36207

Phone: 256-237-3683

email: alabamarespite@aol.com

### August 27-28, 2007

#### Preparedness for All: Addressing the Needs of People with Disabilities and the Elderly in Emergencies & Disasters

The Alabama Department of Public Health and the

South Central Center for Public Health Preparedness (SCCPHP) are partnering to plan and host a conference that focuses on the needs of people with disabilities and the elderly before, during, and after emergencies. The purpose of the conference is to provide emergency preparedness training specifically related to people with disabilities and the elderly. In addition to raising awareness to the special needs of these specific populations during and after emergencies, the conference will focus on emergency and disaster planning at the individual, family, and agency levels.

There is NO cost to attend this conference, but registration is required. The conference will be held at the Sheraton Hotel, 2101 Richard Arrington, Jr. Blvd. North, Birmingham, AL 35203. Registration for this conference will open June 1st. For more information, please contact

Natasha Ptomey, MPH, Program Manager

Email: nptomey@uab.edu

Phone: 205-975-8963

Special Needs Accommodations: Persons with disabilities or special needs who are planning to attend this conference should send a description of any services needed to Tammy Nix at tjnix@uab.edu or call 205-975-8971.

### February 25-26, 2008

#### Alabama State of the State in TBI Annual Conference

Alabama will hold the second annual State of the State in TBI Conference in February 2008 in Birmingham. The conference will be at the Cahaba Grand Conference Center, February 25 - 26. Initial plans are for the first day of the conference to be of interest to consumers with brain injury and their families. The second day will be designed for professionals.

Possible topics include TBI and special education, guardianship, assistive technology, understanding neuropsychological assessments, substance abuse, and resources for consumers and families.

Several organizations are working cooperatively to plan the conference and develop the agenda. Some of the planning partners are the Alabama Head Injury Foundation, the Alabama Department of Rehabilitation Services, UAB, and ADAP. Staff members from ADAP will provide some of the training sessions at this important conference. More information will be available from the Alabama Head Injury Foundation at a later date.

## ADAP News



### Changes at ADAP

**James Tucker**, ADAP's Litigation Director, will now be working doubly hard. He has been promoted to the position of Associate Director. In addition to continuing to oversee all litigation at ADAP, he will be supervising more of ADAP's staff and directing the completion of grants, reports and special projects.

**Brenda McComb** has joined ADAP as a Senior Case Advocate on the Community Access team. Brenda's primary responsibilities at ADAP include: rights issues for people with cognitive disabilities in the community and in Partlow, the state institution. She is also working on voting issues and the completion of Katrina Aid Today.

**Denise Smith**, formerly ADAP's Director of Case Advocates, has joined the Office of Disability Services at The University of Alabama. Denise will now be helping UA students with disabilities to determine appropriate and reasonable academic accommodations and to ensure that students' academic performance is evaluated apart from any limiting effects of disability. Best wishes to Denise in this new challenge!

## Advisory Council News

By law, ADAP must have in place two advisory councils - one for its Developmental Disabilities Program (PADD) and one for its Mental Illness Program (PAIMI).

Each Council must be composed of a majority of individuals with developmental disabilities or mental illness or parents, family members, or guardians of such individuals.

### Annual Meeting

ADAP will hold its annual joint Advisory Council meeting on September 14, 2007 at 10:00 AM at its office on The University of Alabama campus.

Both the PADD and PAIMI Councils will meet to review and adopt ADAP's proposed priorities and objectives for 2007-08.

Like all Council gatherings, this joint meeting is open to the public. For more information about the meeting please contact Vicki Hubbard at 1-800-826-1675.

### Juvenile Justice Advocacy

**Kathy Darnell**, PAIMI Council Member, has many years of experience in the juvenile justice system, having worked as a juvenile probation officer (JPO) and JPO trainer in Jefferson County for most of her career. Recently retired and now teaching criminal justice in a junior college, Kathy has been assisting ADAP in its work on behalf of youth with disabilities in the juvenile justice system. Kathy is a great example of how important Council members are to ADAP and to its work on behalf of persons with disabilities. Thanks Kathy!

### New job!



**George Neal** is a member of ADAP's PADD Advisory Council. George was recently hired by the Department of Mental Health and Mental Retardation to act as the Director of the Office of Consumer Empowerment. In this role, he will work with all stakeholders to increase the influence of self-advocates in decision-making and policy development in Alabama.

## Disability History

The Minnesota Governor's Council on Developmental Disabilities (MNDDC) has developed an exciting and informative on-line outreach tool called **Parallels in Time**.

Divided into two parts, the on-line program provides a comprehensive history of disabilities, from ancient time all the way up to the present day. The multi-media program explores significant changes in the perceptions and perspectives about disability, the types of services and supports available to people with developmental disabilities and families, and how these services and supports are delivered.

**Parallels in Time, Part 2** was recently released. It focuses on the history of disabilities from 1950 to the present. Presented by decade, the program explores major aspects of a person's life - home, learning/education, and employment - through images, video, history and personal stories.

Some of the features included in Part 2 include:

- A Place to Call Home: The Development of Supports for Having a Home in the Community
- Definitions and Perspectives on Disability
- A Place to Learn: The Development of a Free Appropriate Public Education for All Children
- Real Work: The Development of Real Jobs in Typical Work Settings

This free on-line resource is available at [www.mnddc.org](http://www.mnddc.org)

The project is part of an on-going effort to assemble resources useful to building a more just, inclusive society. For further information on the project, contact Colleen Wieck, Ph.D., Executive Director of the MNDDC, at 651-296-4018 or via email at [colleen.wieck@state.mn.us](mailto:colleen.wieck@state.mn.us).

# Changes in Federal and State Special Education Law: Will They Affect Your Child?

The Alabama State Board of Education (SBOE) adopted new regulations governing the state’s special education program at its June 14th meeting. These regulations were drafted in response to the enactment of the federal Individual with Disabilities Education Im-

### Family involvement

provement Act in November 2004 (IDEA). In the months leading up to their adoption, ADAP and other child and family advocates closely reviewed Alabama’s proposed special education code and provided many comments and sugges-

tions to the SBOE and the State Department of Education (SDE). In fact, families embraced their role in the regulatory process in a way that appears unprecedented in the SDE’s rulemaking history, providing both written and in-person testimony to policymakers on such issues as eligibility criteria, access to records and discipline. Still, when one considers that there are over 90,000 children receiving special education services in Alabama, there is room for a lot more parental involvement in policymaking. It is crucial for both the SDE and advocacy organizations to find ways to further facilitate family involve-

ment at both the state and local levels on a continuing basis, but particularly during the regulatory process.

### Major changes

Most of the changes to Alabama’s regulations simply brought the state code in alignment with the federal regulations. These changes included such things as new disciplinary procedures, streamlined IEP meeting options and parental safeguards, and the special education planning process for children enrolled by their parents in private schools.

### Upcoming Trainings on Children’s Issues

ADAP provides dozens of workshops each year on issues important to families and service providers of children with disabilities.

Some of the topics covered are: Advocating for Your Child’s Special Education Needs; Discipline Procedures under the IDEA; Advocacy for Children in Foster Care; Medicaid for Children with Special Medical Needs; and others.

Here’s our training line-up for the coming months.

- HOPE Parent Meeting/Jefferson County Family Court – August 16 (Birmingham)
- Epilepsy Foundation of South Alabama Regional Conference – August 24 (Mobile)
- Department of Mental Health/Community Mental Health Center Child and Adolescent staff – August 30 (Montgomery)
- Early Intervention/Volunteers of America September 10 (Mobile)
- Lee County Autism Support Group September 13 (Auburn)
- Calhoun County Parent Group - September 20 (Oxford)

If you would like to schedule a workshop for your parent or provider group, please call ADAP at 1-800-826-1675.

However, some of the biggest changes to the state’s regulations involve decisions that Alabama had to make regarding what it takes to make a child eligible for special education services. New definitions and evaluation criteria that reflect up-to-date scientific research and knowledge were crafted by the SDE for the following IDEA disability categories: Autism, Mental Retardation, Emotional Disturbance and Other Health Impaired. Child advocates and clinicians provided a great deal of input in this area.

If you would like to schedule a workshop for a parent or professional group on the new changes to federal and state special education law, please contact ADAP at 1-800-826-1675 or adap@adap.ua.edu.

A copy of the new state special education regulations can be found on ADAP’s website at [www.adap.net](http://www.adap.net).

# “We’ll Take the Lead Now: Partners with a Twist” Newly restructured Partners in Policy Making Puts Self-Advocates in the Lead

Partners in Policymaking, the Alabama Council for Developmental Disabilities’ (ACDD) long-standing systems change training program has started its new training year “with a twist.”

The goals of the Partners program have always been to prepare families and individuals with disabilities for leadership roles at the local, state and national levels by providing training in best practices in self-determination, self-advocacy and an understanding of the policy and legislative process. While these goals remain the same, some important changes have been put in place for the newly restructured Partners program.

For example:

- There is more of an emphasis on participation by self-advocates. While self-advocates have always been trained through Partners, they represented a small percentage of the individuals served. Now, 70% of all Partners participants must be self-advocates.
- People First of Alabama is taking the lead in running Partners and has hired a co-director who is a self-advocate.
- Partners is using a more accessible curriculum for individuals with cognitive disabilities.
- Partners has developed measurable outcomes that will document systems change and individual impact activities of current and previous Partners graduates.

For more information on Partners with a Twist, please contact Jayne Chase, Coordinator, at 1-800-846-3735 or JChase1040@aol.com.



The Alabama Disabilities Advocacy Program (ADAP) is part of the nationwide federally mandated protection and advocacy (P&A) system.

Our mission is to provide quality, legally based advocacy services to Alabamians with disabilities in order to protect, promote and expand their rights.

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