

Alabama Disabilities Advocacy Program

September 2010

Against Their Will

by Ellen B. Gillespie, Ph.D.
ADAP Executive Director



“Our problems stem from holding individuals against their will.”

Greg Carlson
August 13, 2010

Once in a blue moon, someone says something that perfectly sums up everyone’s thoughts. That was the case recently in an ADAP Advisory Council meeting, as participants discussed priorities and goals for advocacy in the upcoming year. As usual, everyone felt frustrated because so much work remains to be done. That’s when Greg Carlson, President of NAMI-Alabama and Vice-President for Planning and Development for Glenwood, added a very wise observation: “Our problems stem from holding individuals against their will.”

Greg is absolutely right. We all try very hard to do some good things, and we often do. There are still too many individuals, though, who are being “held” by the system even though they would like some alternatives.

Imagine the frustration of being 21 and living in a nursing home, with no chance of moving out. Imagine how an older man feels going day after day to the same “classroom” in the same program he has attended for 25 years, and doing a repetitive task he has always been assigned. What about the person who no longer has any rights as a citizen because another person is her guardian, even though she could make some decisions on her own? How about people who live in the last developmental center/institution in Alabama, languishing because we cannot do the right thing and risk public outcry about some people losing state jobs?

If we would just stop holding individuals against their will in institutions, segregated group homes, boring day programs, and other “services” we have engineered in the past, there might be some money to spend on helping people have a life. Maybe people could choose where they live and with whom. Maybe people could pursue a hobby or volunteer service instead of playing a child’s board game all day.

Maybe some people might choose to just be left alone by well-meaning case managers, or remind us that people are not cases. Maybe we could focus on just treating everyone as we want to be treated. It could even be that people with disabilities might choose services that are a lot less expensive than the ones we provide in our current system!

There is no question that Alabama does not devote enough resources to support people with disabilities. I think, however, that we cannot continue to delude ourselves by thinking we can just continue the outmoded services we have now and wait until we get some additional money to do something different.

It really is time to start over. It really is time to stop holding individuals against their will.

Another Exciting Season

by Christy Johnson, Senior Case Advocate

The countdown is on for yet another exciting season of Southeastern Conference football. One year ago the Alabama Crimson Tide brought home its 13th National Championship. Let's face it, sports are a favorite pastime in the great state of Alabama regardless of the color of your team's jersey. Competitive sports afford players the opportunity to learn important life lessons while gaining physical ability. Yet playing contact sports also carries great risks. On Saturday, September 26, 2009, football fans watched in shock as Tim Tebow, Heisman quarterback for the Florida Gators was slammed to the ground and lay unconscious during the Kentucky game. Tim eventually made his way off the field with the help of medical professionals, but he suffered a concussion and was not allowed to return to play. Tim's injury prompted a nationwide discussion about concussion and return to play.

The American Academy of Family Physicians states that, "participation in contact sports, including football, ice hockey, soccer, boxing, lacrosse, wrestling and basketball, carries a risk of mild traumatic brain injury, or concussion. The risk of concussion is also increased in other sports and activities, such as gymnastics, skiing, sledding, ice skating, roller blading and horseback riding." A report issued by the American Academy of Pediatrics estimates that 300,000 sport-related traumatic brain injuries result in a loss of consciousness each year. The

majority of these injuries are concussions. The report goes on to say that 26% of closed head injuries in children occur during athletics, but this number is likely higher as children do not typically seek medical attention. Younger athletes are more likely to suffer a concussion during contact sports and require a longer recovery time than adults. Many states have passed legislation to adopt management principles that guide return-to-play decisions.

Alabama is one of the many states that do not have legislation in place to require the adoption of policies for the management of concussion and head injury in youth sports. Four years ago, Zackary Lystedt was injured during a middle-school football game and suffered a concussion. Zack sat out for a while but returned to play in the fourth quarter. After the game, Zack collapsed and had to have emergency brain surgery. The Zackary Lystedt Law was passed in Washington State and requires that an athlete suspected of sustaining a concussion or brain injury be removed from play. "When in doubt, sit them out." It also requires written medical clearance prior to returning to play by a licensed health care provider.

Through the efforts of the Alabama Statewide Traumatic Brain Injury Task Force a subcommittee was formed to address risk factors for Traumatic Brain Injury among youth. This group is dedicated to reducing the incidence and morbidity of sports related concussions in Alabama. A goal for the group is to pass legislation in Alabama similar to the Zackary Lystedt Law in Washington State. ADAP participates on this Task Force and is actively involved in the development of proposed legislation.



The American Diabetes Association has some new online resources to help children with diabetes participate in school, daycare, camp, and recreational programs.

There is a state legislation page that describes state laws that impact diabetes care in schools, available at <http://www.diabetes.org/living-with-diabetes/parents-and-kids/diabetes-care-at-school/legal-protections/state-laws-and-policies.html>

Also, there is a page explaining each state's laws on diabetes care in child care and other programs, available at <http://www.diabetes.org/living-with-diabetes/know-your-rights/discrimination/public-accommodations/daycare-camps-and-recreational-programs/daycare-camps-state-laws-regs.html>

If you are a family of a child with diabetes and need advocacy assistance with a school or child care issue, please contact ADAP at 1-800-826-1675. Or, contact the American Diabetes Association at 1-800-DIABETES.

Community Access Team: Social Work Interns Change is Good

by J. Patrick Hackney, Senior Staff Attorney

The “Summer of Change” adequately describes the summer of 2010 for ADAP’s Community Access Team. In the midst of preparing our annual goals and priorities and considering areas of need for Alabamians with disabilities, the Community Access Team experienced some changes amongst its staff including a retirement, promotion, and the return of a familiar face.

On July 31, 2010, Brenda McComb retired from ADAP. Brenda spent over 30 years working as an advocate for persons with disabilities and tirelessly served as an ADAP Senior Case Advocate for the past 3 years. Brenda’s wealth of knowledge, especially in the area of developmental disabilities, will be missed. While at ADAP, Brenda advocated for and improved the lives of countless clients. Brenda also never shied away from a challenge. During the most recent primary elections, Brenda completed 13 polling surveys in one day. While we are happy for Brenda in that she can now enjoy her retirement, we will miss her dedication and strong advocacy for ADAP’s clients.

Delshonda Thomas has now been promoted to the position of Senior Case Advocate. Delshonda has served ADAP for a number of years as a case advocate maintaining primary responsibility for advocating for persons with mental illness, both at Bryce Hospital and community programs, and performing intakes. Due to her promotion, Delshonda’s responsibilities will change and expand. Delshonda will now assume primary responsibility for advocating for persons with developmental disabilities, including persons residing at Partlow and those receiving services in their communities. In addition, Delshonda will take a lead role in representing clients under ADAP’s PABSS program, which assists individuals who want to return to work and are receiving social security benefits. Because of her experience in the Mental Illness System Reconfiguration, Delshonda will continue to be involved in that effort.



In August 2010, David Gamble returned to ADAP to serve as a Senior Case Advocate. Prior to returning to ADAP, David worked as a counselor in the Tuscaloosa City School System. David will have numerous responsibilities including, but not limited to, advocating for persons with mental illness, both at Bryce Hospital and community programs; maintaining and expanding ADAP’s efforts to ensure the voting process is fully accessible to persons with disabilities; and advocating for persons with assistive technology needs.



Stephanie Broughton

I am grateful for the opportunity to gain knowledge and experience through my field placement at ADAP as a Senior BSW student from the University of Alabama School of Social Work. My areas of interest include social work practice with children, adolescents, and families as it relates to mental illness, education, and health. My career aspirations lie in advocating for children and families affected by serious illness within a hospital setting. I plan to graduate in December of 2010 and begin an MSW Program. Prior work experiences include positions with the YMCA after-school program, the Boys and Girls Club, Wheeler Mission Ministries (Indianapolis), and Spring-Hill Camps (Seymour, Indiana). I am excited to be a part of the ADAP team and hope to learn from others as well as contribute to the overall mission of ADAP.



Polly Shepard

I am happy to have the opportunity to intern at ADAP for my social work field placement this fall. My interest includes working with the elderly and mental health in the hospital. I hope to gain as much knowledge as possible while at ADAP to better educate myself. In previous years I have worked at a summer camp through the YMCA called Time to Rise, volunteered at Matthews Elementary in Tuscaloosa, and did work with the elderly at Robertson Towers through the Tuscaloosa Housing Authority. After this year I will be graduating with my BSW and I hope to continue my education by pursuing my MSW degree.



Christy Adamson

I am excited to be completing my field placement this semester at ADAP. Human rights have been an interest of mine and I hope to discover new avenues for advocacy during my time here. Last spring a friend and I founded the UA campus chapter of International Justice Mission (IJM), a faith based human rights organization that seeks to end human trafficking in all forms and heal broken justice systems. My goal to work as an Aftercare Training and Research Specialist with IJM has led me to pursue a MSW at Asbury University upon graduation from UA in December 2010.

Planning for the Future: Take Control Now

By: Glenn Baxter, Volunteer Attorney

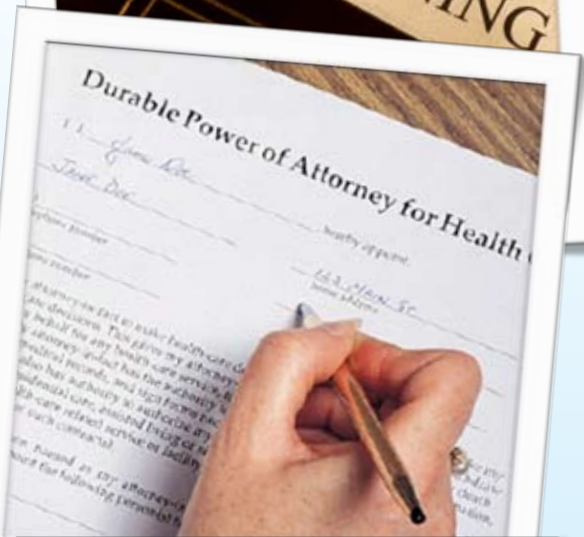
There is no substitute for advance planning for all of us. One never knows when decision-making assistance may be needed, especially due to injury, illness, aging or other cause. One should not put this off, just as one should not put off the making of a will. Several documents can assist in planning for the unexpected.

One essential tool is the Advance Directive for Health Care. This instrument allows a person to make important decisions concerning his or her own health care before the need arises. It is durable in that it survives the incapacity of the person executing it. An Advance Directive for Health Care allows the person to direct how health care providers shall treat decisions regarding such issues as artificially provided nutrition and hydration, life-sustaining treatment and permanent unconsciousness. An Advance Directive for Health Care can be very narrow. For example, the document may only grant authority to consult about surgery for only the period of time one is under anesthesia. Alternatively, an Advance Directive for Health Care can be very broad, covering a wide range of end of life decisions. Specific treatments may be included or excluded. It also allows individuals to appoint a health care proxy to make such decisions in the event that he or she is no longer able to give directions to the health care providers.

Another tool is the Durable Power of Attorney. The “durable” power survives incapacity and permits the agent, a person chosen by the individual signing the document, to exercise the granted authorities during the period of incapacity. It can be drafted as “springing”, that is going into effect upon the disability, incompetency or incapacity of the principal, or as “sprung”, that is going into effect immediately and continuing during the period of incapacity. The Durable Power of Attorney allows the agent (called the “attorney-in-fact” to manage finances, manage real property, pay bills and taxes, employ professional and health care agents, and, in general, to perform any act which the individual could absent incapacity.

A frequently overlooked vehicle to avoid the necessity of a court supervised guardianship is a Revocable Living (“Inter Vivos”) Trust. An individual, in anticipation of incapacity, may be both the trustee and the beneficiary of such a trust. In the event of incapacity, the trust typically operates according to its own terms by a successor trustee. This revocable trust offers ease, immediacy, convenience and privacy.

Using one or more of the above tools, persons can plan for the unexpected and ensure their wishes are followed.





2010 Disability Conference

Forging a New Civil Rights Movement: Declarations of Independence

October 18, 19 & 20

Perdido Beach Resort, Orange Beach Alabama

Sponsored by The Arc of Alabama, Inc. and People First of Alabama

Thanks to a grant from the Alabama Council on Developmental Disabilities, hotel costs are paid for the first 256 Self-Advocates, support staff (who accompany a Self-Advocate) and Family members (Based on double occupancy)

REGISTRATION

- Registration \$150.00 Per person (2 in a room) \$271.00 In a room by yourself
- If you don't bring a roommate we can assign one for you
- Conference begins at 1:00PM, Monday 10-18-2010
- Registration covers*:
 - Conference registration, 2 nights (18-19) at the Perdido Beach Resort*
 - All meals during the conference plus Dinner Dance

CONTACT INFORMATION

- Perdido Beach Resort
<http://www.perdidobeachresort.com/>
251-981-9811
- People First of Alabama
mmarion@pfofal.org
205-932-2240
- The Arc of Alabama
tholmes@TheArcofAlabama.com
334-262-7688 or 1-866-243-9557

Don't Forget to check us out...

adap.net

Increasing Knowledge and Understanding... Creating Solutions for Independence

ALATEC will provide an opportunity to showcase the latest in assistive technology practices and services for persons with disabilities. Our goal is to offer professional development training to consumers and professionals in the areas of: education, employment, housing, transportation, health care, and recreation.

October 7th and 8th, 2010



Alabama Department of REHABILITATION SERVICES

The Office of Public Service & CEU Certification at Auburn University has granted .65 Continuing Education Units (CEUS) for those who attend.

There will be many vendors with their products on display. Professionals, consumers, and those with special interest are encouraged to attend.