

Alabama Disabilities Advocacy Program

November 2009



A New Social Security Project for ADAP: A Look at Representative Payees in Alabama

By Brenda McComb, Senior Case Advocate



Beginning in November 2009, ADAP staff will receive extensive training for reviews of several agencies in Alabama who serve as representative payees for people with disabilities. All of these agencies are also employers and contract service providers for the Department of Mental Health. Across the country, over 6,000,000 people have another person (or entity) who receives their Social Security money and assists them in managing that money. To understand how this program came about, it is important to know about this shocking true story about how people with disabilities in Iowa were exploited until recently:

Henry's Turkey Farm in Atalissa, Iowa was a major employer of men with intellectual disabilities since the 1970's. Henry's often "recruited" men from Texas to come to work in their West Liberty turkey processing plant. Henry's served as the representative payee for these individuals, acted as their employer, and served as landlord and caregiver. Employees were paid a reduced wage for their work. The cost of their room, board, and care were deducted from their pay, leaving them little discretionary income.

In a major investigation, FBI agents and other federal and state investigators interviewed witnesses and reviewed over thousands of pages of records to determine whether Henry's broke any laws, including underpaying workers or violating their civil rights. The U.S. Social Security Administration examined the company's handling of federal assistance payments to the workers with disabilities.

Workers with disabilities were working and living in abysmal conditions in bunkhouses. They were paying Henry's Turkey Farm dearly for this miserable lifestyle. Finally, authorities shut down the bunkhouses in February 2009. Now the business could face \$900,000 in fines for improper payroll deductions and other alleged violations. There is no evidence that any such scandalous conditions exist in Alabama.

The Social Security Administration has decided, however, that it will contract

with the National Disability Rights Network (NDRN), our national organization, to review representative payee situations in every state and territory. ADAP will be a sub-contractor for NDRN, just as in the Katrina follow-up advocacy project we completed several years ago.



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Beginning mid-November, ADAP staff will monitor a small group of representative payees to be determined by Social Security and furnished to us in a Task Order. In the first year, ADAP will review five agencies. The review protocol has been developed by NDRN. The protocol will identify potential indicators of fraud and determine if there are indications that beneficiaries have been abused, neglected, or financially exploited by the employer representative payee. The review process will include a letter from the Social Security Administration to the agency, and a request for information prior to the on-site review. ADAP staff will have access to certain information, records, staff, beneficiaries, and locations as part of the review. Staff will complete a report to be submitted to NDRN, and ultimately to Social Security.

We are pleased to have this new area of work at ADAP. While we hope to find no problems in our reviews around the state, this is another way we can safeguard the rights of Alabamians with disabilities.

WHAT THE SUSAN J. SETTLEMENT MEANS TO YOU

By Patrick Hackney, Senior Staff Attorney

In July 2009, the plaintiffs and the State of Alabama reached an agreement to settle *Susan J. v. Riley*. Known as the “Alabama waiting list” case, the settlement ended nine years of litigation. The settlement agreement provides important protections for persons applying for waiver services, persons who have been denied waiver services, and persons on the waiting list.

Under the terms of the settlement agreement, individuals have the opportunity to object to a denial of waiver services. Persons who are determined ineligible to receive waiver services can request a fair hearing through the Alabama Medicaid Agency. At the hearing, the applicant presents evidence of eligibility, including witnesses, and is permitted to cross examine any witnesses presented by the State of Alabama. This fair hearing is very similar to a trial in that each side presents arguments and witnesses. Persons who are currently on, or in the future, placed on the waiting list for services, can dispute their placement on the waiting list (in effect, denying the requested services) through their Regional Community Services Offices and ultimately the Department of Mental Health’s (DMH) Associate Commissioner of Intellectual Disabilities.

In addition to the opportunities for applicants to object to being denied waiver services, the settlement agreement provides additional protections in the application process. When an applicant first applies for waiver services, DMH must notify the applicant of: 1) what is required to submit a complete application; 2) the fair hearing procedures; and 3) that a decision on the completed application must be made within 90 days. If an applicant is denied or placed on the waiting list, DMH must notify the applicant of any and all appeal procedures.

Prior to the settlement, the Court ruled that the State of Alabama could impose limits on the number of persons served under Alabama’s Mental Retardation and Living At Home waivers. In other words, the Court declined to expand the cap on the number of persons receiving waiver services. Because of the Court’s ruling on the cap issue, the settlement agreement does not require the State to set aside resources to serve everyone on the waiting list.

ADAP remains dedicated to assisting persons in exercising their rights with respect to applying for and receiving waiver services. ADAP currently represents several persons in Medicaid fair hearings. ADAP is committed to advocate for individuals who want waiver services, but have been denied due to eligibility or other issues. If you need assistance with an application for waiver services or any effort related to getting waiver services, please contact ADAP toll free, 1-800-826-1675.



Alabama Foster and Adoptive Parent Association (AFAPA)

By Barbara Lawrence, Senior Staff Attorney



Foster and adoptive parents in Alabama are fortunate to have the Alabama Foster and Adoptive Parent Association (AFAPA). AFAPA's mission is to provide education and support to foster and adoptive parents all across the state. AFAPA acts as a unified

voice in serving, advocating, promoting, and encouraging foster and adoptive families as they serve Alabama's children and their families. Membership in AFAPA is free to all state-licensed and private agency foster parents and adoptive parents residing in the State of Alabama.

Training hours are required for foster parents to remain licensed by the state. Educational opportunities to foster and adoptive parents are offered throughout the year including annual regional trainings and an annual con-

ference. Trainings are open to foster, adoptive parents, social workers, and other interested stakeholders for very nominal fees. Upcoming regional trainings are being held on November 14, 2009 (Drury Inn in Montgomery) and on January 16, 2010 (Birmingham, exact location to be determined.) The annual statewide conference is planned for May 13 - 15, 2010 at Shocco Springs.

In addition to training, AFAPA provides trained advocates to assist foster and adoptive parents. AFAPA advocates are trained in the Foster Parent Bill of Rights and Alabama Department of Human Resources (DHR) policies. The Alabama Foster Parent Bill of Rights (Code of Ala. §38-12A-2) enumerates the rights of foster parents as these rights relate to DHR. These rights include the right to request that a person or persons serve as volunteer advocate and to be present at all meetings with DHR, including, but not limited to, individualized service planning, administrative hearings, the grievance mediation process, the adoption process, and the allegation process where the foster parent is present. All communications received by the volunteer advocate must be held in strict confidence under Alabama law.

For more information about AFAPA trainings or the AFAPA volunteer advocates program, see www.afapa.org

Why are there so many Protection and Advocacy agencies?

By Ellen B. Gillespie, Ph.D

When we give a presentation about ADAP, we always say that there is a Protection and Advocacy (P&A) agency in every state. Actually, there are more! There are 57 P&As across the country, all members of our trade association, the National Disability Rights Network. If there are only 50 states, how can this be true?

In addition to a P&A in each state, there is a P&A in each territory. The territories, for those who may have forgotten their geography, include Guam, Puerto Rico, the Virgin Islands, American Samoa, the Northern Mariana Islands, and the District of Columbia. That accounts for only 56.

The 57th Protection and Advocacy agency is the Native American Disability Law Center, located in New Mexico. This agency works with the tribal governments in four states – Arizona, New Mexico, Utah, and Colorado, an area of over 25,000 miles.

Most P&A agencies operate independently as private, non-profit organizations with governing boards. There are 10 state-affiliated P&As, including ADAP. ADAP is the only one of the P&As affiliated with a university, however. For questions about Protection and Advocacy services in any other parts of the country, just refer to the NDRN website, www.ndrn.org. You can find out about upcoming training events and conferences, as well as contact information for all 57 of the P&As.

Amy Roloff

By Robin Lunceford, Marketing Coordinator

My goal is to encourage people with the “why not” instead of the “I can’t,” especially those who have a disability and are facing challenges. – Amy Roloff

When you’re only four feet tall, you can do pretty much anything average height people can do; you just do it in a different way. That’s the message TLC television personality Amy Roloff recently shared with human resources managers at a conference held at the University of Alabama. Amy is a 47 year old college graduate, wife, mother, farmer, soccer coach, actress and motivational speaker. She has a type of dwarfism called achondroplasia.

Amy and her husband Matt are currently featured on their own TV show on TLC called “Little People Big World” and have written a book called “Little People Big Values.”

Amy is a long-standing member of Little People of America, a national non-profit organization. She has served on its board of directors. It was through Little People of America that she met Matt. They have been married for 22 years and have four children. They live on 33 acres of land near Portland, Oregon.

“With faith and encouragement from family and friends and a sense of independence and humor my life has been, and still is, an adventure,” declared Amy.

ADAP Marketing Coordinator, Robin Lunceford had the opportunity to talk with Amy while she was at the University last week. She started off their conversation by inviting Amy to share how she approaches having a disability.

Amy: People tell me I have a disability and that I can’t do this or that. My way of thinking is, if I believe I can’t, I can’t. I have limitations and each day is a challenge to look for solutions. I have had and continue to have my challenges and obstacles in life.

Robin: Tell me about your children.

Amy: I have four children: Zach, Jeremy, Molly and Jacob. Matt, my husband, Zach and myself are little people, while Jeremy, Molly and Jacob are of average height. Teenagers Zach and Jeremy are fraternal twins.

Robin: What advice would you like to offer to parents?

Amy: Do not pave the way for your children. Teach them to think and act independently. I try and teach my children each day to advocate for themselves.

Robin: What advice do you give the soccer players that you coach before games?

Amy: I don’t care if you win or lose. You have to go out on that field and act like you want to win! If we always play safe, we never know what we can do!

Robin: What obstacles and challenges have you faced in the workplace?

Amy: People with disabilities know how to adapt and work around obstacles in the workplace. They don’t want to be the employee that always has an issue. They don’t want to be labeled as the employee who “can’t.” We have to be our own advocate. You have to communicate what you need or what your needs are.

To contact Amy: <http://www.amyroloff.com/>

A Quick Look at...

Stigmatizing Youth with Emotional and Behavioral Challenges and their Caregivers: Who's doing it and what is its effect?

By Nancy Anderson, Senior Staff Attorney

“Stigmatization is a form of prejudice. A person who stigmatizes makes negative or unfair judgments about others before really knowing enough to make a judgment.”

Youth

- Eighty-six percent (86%) of youth respondents with emotional and behavioral challenges report that people stigmatize them because of their mental health condition.
- When youth were asked who treated them most unfairly, the most common groups reported were:
 - Peers - 70% reported stigmatization from peers
 - Friends - about 65% reported stigmatization from friends
 - Teachers - about 62% reported stigmatization from teachers and other school personnel.
- When asked why other people treated them negatively or unfairly, the top response was “they assumed you were weak-willed or not trying hard enough to be ‘normal’” (endorsed by 81% of the respondents).
- The vast majority of youth respondents stated that negative treatment from others had either a significant (53%) or moderate (33%) impact on their lives.



A summary of research conducted by the Research and Training Center on Family Support and Children's Mental Health at Portland State University and reported on in Focal Point (Winter 2009).

Caregivers

- 81% of caregiver respondents stated that there were times when people treated them negatively or unfairly because of their child's emotional or mental health condition.
- When asked from whom they experienced this treatment, the most common groups reported were “teachers or school personnel,” (approx. 65% endorsed this response) “people in the community,” (approx. 62%) and “friends or people you socialize with” (approx. 52%).
- When asked to choose from a series of reasons as to why respondents believed they were being treated negatively or unfairly, the top responses endorsed revolved around parenting issues: “[other people] assumed you were weak-willed or not trying hard enough to get your child to behave or act ‘normal,’” or they “assumed your family was dysfunctional and/or that you were a bad parent,” or “that your child would be a burden or cause extra expense or work for them.”
- Three-fourths (75%) of care-givers stated that they felt bad about themselves because of their child's emotional or mental health condition or how they dealt with it.

For more information on stigmatization of youth with emotional and behavioral challenges, see Focal Point, Winter 2009, Vol. 23, No. 1 Regional Research Institute for Human Services, Portland State University. <http://www.rtc.edu/PDF/fpQ0901.pdf>

Bullying

By Tuwana H. McGee, Senior Case Advocate



A colleague and I were having lunch the other day and she told me about a friend's grandson, a young teen who had committed suicide. She said everyone who knew him saw no signs that he was even considering suicide. He had friends, a supportive family, was doing well in school and was involved in extracurricular activities. After his death, it was revealed that bullying may have played a big part in

the tragedy.

Almost 30% of youth in the United States (over 5.7 million) are estimated to be involved in bullying as either a bully, a target of bullying, or both. The Justice Department says that this month 1 out of every 4 kids will be abused by another youth. Seventy-seven percent of students report that they have been bullied mentally, verbally and physically. Bullying begins as early as preschool and peaks in middle school.

The most common forms of bullying are verbal or physical confrontation and intimidation, injury and destruction of personal property, and derogatory gestures or comments. Both boys and girls bully by making fun of the way that someone looks or talks. Boys more often report being hit, slapped, or pushed. Teenage girls are more often the targets of rumors and sexual comments. While teenage boys target both boys and girls, teenage girls most often bully other girls, using more subtle and indirect forms of aggression than boys. For example, instead of physically harming others, they are more likely to spread gossip or encourage others to reject or exclude.

(Bullying, Continued on Page 7)



Access and Visitation Rights of Residents of Nursing Facilities

By Lonnie Williams, Staff Attorney

Residents of long term care facilities (i.e. nursing homes) have rights and protections that must be afforded to them. In general, residents have the right to a dignified existence, self determination, and communication with and access to persons inside and outside the facility. Residents cannot be subjected to threats, coercion or discrimination in exercising their rights. Facilities must inform residents of their rights and the rules of the facility.

Residents have rights regarding access and visitation. Residents cannot be prevented from immediate access to any representative of the Department of Health and Human Services, any representative of the State, the State Long Term Care Ombudsman, their own private doctor, or any representative of the Alabama Disabilities Advocacy Program (ADAP).

Residents cannot be prevented from access to their relatives or any other visitors. Residents cannot be prevented from access to persons providing them with health, social, legal, or other services. Residents must be given regular access to a private telephone. Residents may refuse to let persons have access to them. Certain legal situations, such as the existence of a guardianship or an adult protective services order, may complicate these issues and change some of these rights.

If you have any questions about the access and visitation rights of a person residing in a long term care facility, please feel free to contact the Alabama Disabilities Advocacy Program for more information.

Children with disabilities and bullying

Children with disabilities are even more likely to be targets of bullying than children without disabilities. A review of literature indicates that children with disabilities may be at particular risk of being bullied by their peers. For example:

- A recent study of the prevalence and frequency of bullying in a sample of more than 400 children with Asperger Syndrome, whose ages were between four and 17 years, found the reported rate of bullying to be at least four times higher than for their peers.
- Children with learning disabilities are at greater risk of being teased and physically bullied.
- Children with Attention Deficit Hyperactivity Disorder (ADHD) are more likely than other children to be bullied.
- Children with medical conditions that affect their appearance (e.g., cerebral palsy, muscular dystrophy and spinal bifida) are more likely to be victimized by peers.
- Children with hemiplegia (paralysis of one side of their body) are more likely than other children their age to be victimized by peers.
- Children who have diabetes and who are dependent on insulin may be especially vulnerable to peer bullying.
- Children who stutter may be more likely than their peers to be bullied.
- Children with disabilities who have low self-esteem, look to others for cues or guidance, and lack the awareness to realize that potentially dangerous situations are developing are common targets for bullying. Children who are anxious and withdrawn, timid or shy, and have poor social skills are often bullied. Children with motor skill deficits, or physical and health-impairments can make them easier marks for bullies seeking weaker victims.



Adult reactions

Bullying is frequently misunderstood by adults as an unavoidable part of growing up. As a result, if it occurs in the presence of adults, they often fail to do anything about it. Unfortunately, 25% of teachers see nothing wrong with bullying or putdowns and consequently intervene in only 4% of bullying incidents. In the classroom, more often than not, bullying is never witnessed by teachers. However, if a child responds to the bullying inappropriately such as retaliating with anger, the bully appears as the innocent victim and the child being bullied is punished.

Bullying in the 21st Century

Bullying doesn't have to occur face to face to be affective. It can also show up in the form of cyber bullying or text bullying. Children use the internet to act as cyber bullies and use cell phones to act as text bullies. Children can sit in the comfort of their own home and bully. They can say things that are harsh and hurtful or send undesirable pictures and not even have to see the person's reaction. Text bullying is more direct than cyber bullying. It's easier to delete an e-mail or set up privacy protection options on social networking sites, but it's hard to ignore a text message, which instantly pops up on your phone. It's difficult to block texts, which can be sent to the masses. (There is some evidence that cyber and text bullying were affecting the teen who I mentioned at the start of this article.) *(Bullying, Continued on Page 8)*

Schools must play a big part in the intervention of bullying behavior. Schools should take educational and prevention measures when it comes to bullying - both with the victims and bullies. While bullying should not be tolerated, bullies need help in acquiring the skills they need to feel better about themselves and eventually become productive adults.

What can parents do?

- **Look for Symptoms**

Symptoms might include: unexplained reluctance to go to school; fearfulness or unusual anxiety; sleep disturbances and nightmares; vague physical complaints (headaches, stomachaches), often on school days; and belongings that are missing altogether or come home ripped.

- **Ask the Right Questions**

If you do suspect your child is being bullied, don't ask them about it outright. Instead, ask your child questions about how he is spending lunch hour or what it's like walking to school, walking home, or riding the school bus. Ask if there are any children at school who are bullies, without asking whether your child is being bullied. In the case of text bullying, check your child's phone to make sure they're not sending or receiving mean messages. Use parental controls to help prevent cyber-bullying.

- **Listen and Understand**

If you learn your child is being bullied, stay calm and give your child plenty of time to tell you how he feels. Be a good listener. Make it clear it's not your child's fault.

- **Don't Say**

Do not tell a child who is being bullied to just ignore it. If that were possible, the child would not be asking you for help. Don't suggest that your child simply fight back either. That may increase your child's chances of further victimization.

- **Encourage Speaking Out**

Encourage your child to tell you, a teacher, or another adult when they are having a problem. It's important for them to let someone know early, before the situation escalates. Explain the difference between tattling and telling. Tattling is when you report something just to get someone in trouble. Telling is when you report that you or someone else is in danger.

- **Advocate for Your Child**

Ask the school district to convene a meeting of the Individualized Education Program (IEP) team or the Section 504 team. Explain at the meeting what has been happening and make sure that the school is taking steps to stop the harassment. If your child needs counseling or other supportive services because of the harassment, add this to the IEP.

- **Let the School Know What is Happening**

Talk with your child's teacher immediately to see whether he can help to resolve the problem quickly. If you are not happy with a teacher's response, do not give up. Speak to someone else - perhaps the assistant principal, principal or Director of Special Education. If necessary, go to the Superintendent and Board of Education. Explain what happened in detail and ask for a prompt response. Keep a written record of all conversations and communications with the school. (*Bullying, Continued on Page 9*)

- **Increase School Safety**

Suggest closer supervision in hallways, bathrooms, lunchrooms, under stairways, and on the playground. Your child has the right to feel safe at school.

- **Work with the School**

Work with the school to stop bullying. As the U.S. Department of Education (2000) recognizes, “creating a supportive school climate is the most important step in preventing harassment.” If the school system does not have a policy in place, work with the school to help establish a system-wide bullying prevention policy and program.

For more information, see: <http://stopbullyingnow.hrsa.gov/kids/> and <http://www.education.com/partner/articles/stopbullying/>.



ADAP wants your feedback on our services and future plans.

Beginning October 1, 2009, our website, www.adap.net, will include an on-going survey for your ideas.

Check it out, tell us what you think!