

ADAP

Alabama Disabilities Advocacy Program



MARCH 2005



**From the desk of
Ellen B. Gillespie, Ph.D.**

ADAP Interim Director

“Sticks and stones may break your bones, but words will never hurt you.”

All of us have heard this saying, and we may have used it without much thought. The more I live, and the longer I work with people with disabilities, the more I think this old saying was one that totally missed the mark. I can easily be hurt by words, and so can all of us.

For over 20 years, those of us who work in this field have heard from people with disabilities that words can hurt, and that we need to use the most dignifying language. Last month I attended a meeting of a national committee in which I still heard a reference or two to “retarded people” and “autistic boy.” At ADAP we continue to be amazed at the language used in stories about people with disabilities, especially in Alabama newspapers.

In 2005 most of us are careful to use People First language ourselves. It is second nature after all these years. We need to do more, however, to tactfully remind the public and the press that many of the labels commonly used are
(Continued on Page 3)

Lawyers disagree on R.C. status State, foster children's attorneys file opposing briefs

*Reprint from The Birmingham News
Saturday, February 05, 2005*

By: Kim Chandler, News Staff Writer

MONTGOMERY - Lawyers for foster children and the state of Alabama vehemently disagree whether court oversight of the state's child welfare system should end, according to Friday court filings.

U.S. District Judge Ira DeMent had asked the two sides to submit a joint report about how to resolve outstanding issues and pave the way to end the 1988 lawsuit against the Department of Human Resources. Instead, they filed separate reports Friday afternoon saying they couldn't agree.

DHR is seeking dismissal of the lawsuit. Filed in 1988 on behalf of a foster child known by his initials, R.C., the suit led to court-ordered reforms of Alabama's child welfare system.

The case, which the state settled in 1991, set practice standards and caseload maximums, including one that says a family service worker should handle no more than 18 cases at a time.

Attorney General Troy King said in

a telephone interview that DHR had made promised improvements. “The state has done what it agreed to do,” King said. “We have come into compliance with the consent decree. We are entitled to be relieved of federal court oversight of this department.”

In their report to the court, lawyers for DHR said problems discussed in a December hearing were being addressed. They said the caseload standards set in the decree lawsuit would become part of the state's administrative code this spring. The state also will publish report cards every six months on each county's performance in respect to the consent decree.

Lawyers representing foster children said the state has improved, but not enough.

“But without meaning in any way to belittle those accomplishments, the fact remains that the foster care system in its current form has not yet achieved or demonstrated a reasonable prospect of sustaining substantial compliance with the consent decree,” lawyer James Tucker wrote.

Tucker asked the court to deny the state's request for termination or hold an evidentiary hearing on the matter.

In plaintiffs' report to the court, they cited reviews of 11 counties in 2003 and 2004, and none of the counties earned a “strength” rating for child safety.

ADAP's Advisory Councils

Guiding our Mission

Denise Smith
Interim Associate Director

As required by federal law, ADAP has established Advisory Councils for its PADD, PAIMI and PAIR programs. These Councils provide a voice for individuals with disabilities to help guide ADAP's mission by advising the agency on program policies and priorities.

Council Structure

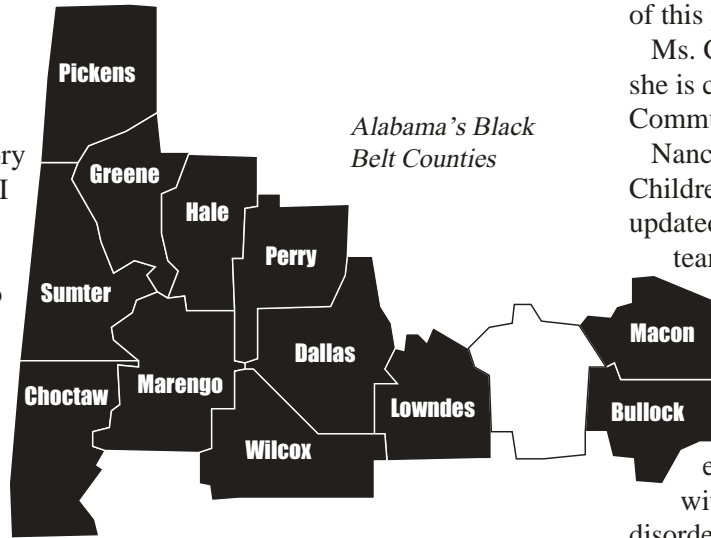
The Councils for the PADD and PAIMI program each have twelve members while the PAIR Council has six members. ADAP's Executive Director appoints members with input from stakeholders. At least 60% of each of the Council rosters must be consumers and/or family members. ADAP strongly believes that consumers and family members should be the driving force on these Councils since they are the ones who are impacted directly by our work.

A member's term begins on January 1 and runs for two years. Members serve staggered terms to ensure consistency and experience from year to year. A member may serve two successive terms if reappointed for a second term by the Executive Director. After his second term, a member must sit out for two years before being reappointed again.

Each Council meets at least three times per year. To facilitate long-range planning, ADAP often holds joint meetings with all the Councils.

February's Meetings

At the recent February meetings for the PADD and PAIMI Councils, Executive Director Ellen Gillespie reported on the extensive outreach work that the agency is doing in Alabama's Black Belt and discussed



Alabama's Black Belt Counties

our year-end outcomes. She also introduced some new publications that the agency has developed including materials for our traumatic brain injury and mental health work.

ADAP staff attorney Lauren Carr gave an overview of her well-researched presentation on the history of disability. While it is a sobering look at how persons with disabilities have been discriminated against and treated through the ages, it also showcases how far the disability rights movement has come and the power of self-advocacy. If your organization would be interested in hosting a presentation

2005 Council Meeting Dates

(Unless otherwise indicated, all meetings will be held in Tuscaloosa. All meetings are open to the public.)

PADD	February 4, May 6
PAIMI	February 11, May 13
PAIR	February 18, May 20

A joint Council meeting for PADD, PAIMI and PAIR Councils will be held on September 16. This meeting will be held at the Independent Living Center in Birmingham, AL.

of this program, please contact ADAP.

Ms. Carr also outlined the work that she is coordinating within ADAP's Community Access Team.

Nancy Anderson, staff attorney and Children's Advocacy Team chair, updated the Councils on the work the team is doing to support children with disabilities. Most notably, the Team is working on a joint project with the Children First Foundation and Alabama Family Ties to enhance services to children with mental illness and behavioral disorders.

ADAP Litigation Director James Tucker updated the Council members on ADAP's legal advocacy, highlighting the agency's work on waiting list issues and its foster care lawsuit, *R.C. v. Walley*.

Upcoming Meetings and Projects

Later in the summer, as we prepare for the coming fiscal year, ADAP staff will seek input from stakeholders to determine what issues and problems are most important to individuals with disabilities in Alabama. Guided by this information, ADAP staff will develop goals for the 2005-06 fiscal year. At a joint meeting on September 16, these draft goals will be presented to the Councils for their review, comment and approval.

New Members for 2005

We are still accepting nominations for a couple of open Council member positions so if you or someone you know might be interested in serving, please contact our office with the name and contact information. Before you submit a name, please discuss it with that individual so we will know they are interested in participating on this important part of our team.

ADAP's Programs

Protection and Advocacy for Persons with Developmental Disabilities (PADD)

The PADD program was created by the Developmental Disabilities Assistance and Bill of Rights (DD) Act of 1975. PADD was established to protect the legal and civil rights of individuals with developmental disabilities.

Advisory Council for 2004 :

Brenda Doss, Chair
Willadean Ash
Diane Roberts
Rebecca Roberts
Jim Sears
Lisa Manley
Cathy Burke
Lillie Hicks
Julie Oetting Miller
Andrew Carr
Myra Jones
Hugh Nichols

Protection and Advocacy for Individuals with Mental Illness (PAIMI)

The PAIMI program was established by Congress in 1986 and receives funding from the National Center for Mental Health Services. The purpose of the PAIMI program is to protect and advocate for the rights of persons with mental illness and investigate reports of abuse and neglect.

Advisory Council for 2004 :

Jill Russell, Chair
Mary Watkins

James Hickman
Don Baker
Patricia Powell
Todd Cannon
Rebecca Poole
Jeffrey McDaniel
Madeline Hollingsworth
Susan Spencer
Jessie Bailey
vacant

Protection and Advocacy for Individual Rights (PAIR)

The PAIR program was established by Congress as a national program under the Rehabilitation Act as amended in 1993. PAIR programs were established to protect and advocate for the legal and human rights of persons with disabilities who are not eligible to be served in the CAP, PAIMI, or PADD programs.

Advisory Council for 2004 :

Dan Kessler, Chair
Gayle Benson
Toni Franklin
Jimmy Osmore
Mike Hamilton
Mike Smith

Protection and Advocacy for Beneficiaries of Social Security (PABSS)

The PABSS Program is a federally funded program authorized by the Ticket to Work and Work Incentive Improvement Act of 1999. The Act authorizes the Social Security

Administration (SSA) to fund ADAP to provide work incentive assistance to SSDI and SSI beneficiaries seeking vocational rehabilitation, employment and other support services or seeking to secure or regain employment.

Traumatic Brain Injury Protection and Advocacy (PATBI)

PATBI is a federally funded program authorized by the Traumatic Brain Injury Act of 1996 and its reauthorization as part of the Children's Health Act of 2000. The PATBI program ensures that individuals with TBI and their families have access to: information, referrals and advice; individual and family advocacy; legal representation; and specific assistance in self-advocacy.

Protection and Advocacy for Assistive Technology (PAAT)

The PAAT program provides legal and non-legal advocacy services for individuals with disabilities who are denied access to assistive technology devices and/or assistive technology services.

Protection and Advocacy for Voter Accessibility (PAVA)

The PAVA program ensures that every qualified person with a disability has the opportunity to vote.

Ellen Gillespie

(Continued from Page 1)
derogatory.

The words we allow to be used are not just words, but are indicative of the attitudes we really have about people. People with disabilities are already dealing with challenges, and using stigmatizing labels is just an additional problem. In a society where most adults with disabilities are not

employed, or are underemployed, it is apparent that we have a long way to go to change perceptions of the public.

For those of us who choose to do this work, we have an extra responsibility to push this issue. Our language needs to indicate that all people are not just "okay", but are valued and gifted. Our language must be inclusive and nonjudgemental. Our language should push people to think about the fact that we are all different,

we have varying abilities and disabilities, and that we must find ways to live in full community with one another. Once we "talk the talk," we begin to really communicate about how to support one another in our journeys.

**For Your Copy of
ADAP Publications
contact ADAP at:
1-800-348-4928**



IDEA 2004 Reauthorization

Regulatory process under way...Your input is needed

Nancy Anderson
Senior Staff Attorney

On December 3, 2004, President Bush signed into law Public Law 108-446, the Individuals with Disabilities Education Improvement Act of 2004 (IDEA 2004).

In the coming months, the Office of Special Education and Rehabilitative Services (OSERS), U.S. Department of Education will be developing the regulations that it will use to administer IDEA 2004. During this regulatory process, the Department, with public input, will draft regulations that clarify and interpret the language of the statute.

During January and February, OSERS hosted eight meetings around the country to allow the public to share and suggestions for developing regulations based on IDEA 2004.

ADAP attended the February 15th public meeting in Atlanta, Georgia where approximately thirty people - service providers, teachers, parents and advocates - testified before a three-person panel of OSERS representatives, including John H. Hager, Assistant Secretary, and an audience of about 120 people. We also submitted written comments to OSERS in time for its February 28 deadline.

Opportunities for your input

Before the regulations are finally approved there will be other opportunities for advocates and parents to comment upon them, so look for information from our office on how you can share your concerns about this important development in special education law.

In the meantime, below is a sum-

mary of just a few of the IDEA 2004 issues that families and advocates are addressing in the regulatory process. Check ADAP's website (www.adap.net) for more information and advocacy recommendations or call our office at 1-800-826-1675.

Regulatory issues for IDEA 2004

Benchmarks and Annual Goals

Background: In an attempt to reduce paperwork and to streamline the IEP process, IDEA 2004 no longer requires that benchmarks or short-term objectives be written into an IEP to track a child's progress toward meeting his annual goals. Benchmarks will only be required for children who take the state's alternate assessment testing - in other words, only children with the most significant disabilities.

However, IDEA 2004 does require that the IEP include a statement of both how the child's progress will be measured and when "periodic reports" of this progress will be provided to parents. This requirement was intended to reduce paperwork, but not to reduce a school's obligation to define and measure a student's progress towards annual goals and to report that information to families in a comprehensive, regular, and understandable manner. To ensure full compliance with this language, the periodic reports must explain, in reasonable detail and with specific measures, the extent to which the student is making progress in each of the annual goals on the IEP. In addition, the regulations should clarify that annual progress reports are insufficient and instead urge the use of quarterly reporting (or reporting at the time that report cards are normally

issued).

Recommendation: The regulations should clarify that IEPs must provide for progress reports, which explain in reasonable detail and with specific, concrete measures, the extent to which the student is progressing on each of the IEP annual goals. Moreover, the regulations should provide that these periodic reports should normally be provided either quarterly or whenever report cards are issued.

What does "consent" look like?

Background: Like in the old IDEA, there are numerous sections in the reauthorized statute where parent consent is required (e.g. consent needed for evaluations).

New to IDEA 2004 are many instances where the parent and school district can agree to waive certain requirements. For instance, a parent can now agree to waive the requirement that particular members of the IEP team attend a meeting. In addition, in making changes to a child's IEP after the annual IEP meeting, a parent can agree not to meet again but develop a written document instead to amend the IEP.

These sections of the IDEA 2004 provide mechanisms for parents of children with disabilities to "agree" or "elect" to follow certain alternative procedures in the evaluation and IEP processes. The regulations must clarify how those rights can be waived and what prior notice parents must receive.

Recommendation: The regulations should clarify that when IDEA 2004 provides that a parent can waive a right through "agreement" or "consent," that consent must be in writing, signed by the parent, and that the parent must be provided prior written notice.

(Continued on Page 5)

(Continued from Page 4)

Review and Revision of IEPs

Background: IDEA 2004 provides that a school shall ensure that “periodically, but not less frequently than annually,” the child’s IEP be reviewed to determine if the child’s annual goals are being achieved. A school is required to revise the IEP to address any lack of expected progress toward the goals and to consider the results of any reevaluation, parent information about the child, or the child’s anticipated needs.

This provision requires the school pro-actively revise the child’s IEP when it is not working well and is not responsive to the child’s needs. However, in ADAP’s experience, we rarely come across a school that seeks out parents to revise the IEP at any time other than at the annual review. The regulations must clarify that responsibility that districts have to conduct such reviews.

Recommendation: The regulations must clarify the school’s obligation to review and revise an IEP whenever it is apparent that the child is not making sufficient progress towards meeting his annual goals — not just limited to its required annual review.

Early intervening services

Background: IDEA 2004 allows a school district to use up to 15% of its funds to provide “early intervening services” to children not identified as children with disabilities who are enrolled in K-12 programs (with emphasis on K-3) and who need additional academic and behavioral support to succeed in a general education environment. Such services can include professional development and educational and behavioral evaluations, services, and supports, including literacy instruction.

The Congressional goal of this section is to prevent the over-identification of students as students with disabilities by ensuring that a child with a reading or behavioral need - but not a disability - can still get help. By

focusing on children in the earliest grades, it avoids premature judgments that a child has a disability when that child only needs extra help to catch up with his peers. However, it is also important to ensure that children with actual disabilities are identified and served promptly.

When read together with IDEA 2004’s Child Find requirement, it is clear that the state retains its obligation to identify and serve all children in the state with disabilities, including all students within the early intervening program who qualify.

It is important to clarify in the regulations that nothing in the section prohibits a family from requesting an initial evaluation for services under the IDEA 2004 and having that evaluation completed within the required 60-day timeline. This regulation would be similar to the situation in Alabama where a parent referral for evaluation can exempt the child from the pre-referral interventions that state law presently requires (there are other exceptions to the mandatory pre-referral interventions, including for children with a traumatic brain injury). In cases where ADAP is working with a client on eligibility, ADAP recommends that a child receive both the pre-referral interventions AND the appropriate eligibility evaluations — with both concluding within the state’s required 60-day time frame. In this way, the parent/school team is armed with a wealth of information to make a sound judgment regarding the child’s eligibility and no unnecessary delays are created.

The regulation should also clarify that children who are receiving early intervening services because of behavioral issues are included in children entitled to IDEA 2004’s disciplinary protections. This interpretation protects children with disabilities and their families, and encourages parents to participate in early intervening programs knowing that they can at any time trigger the special education process and that they are not temporarily waiving the protections of IDEA 2004.

Recommendation: The regulations

must clarify that a child who is receiving “early intervening services” is entitled to an evaluation within mandated timelines if the family so requests. The regulations must also clarify that children who receive early intervening services because of their need for behavioral supports are entitled to be treated as children with disabilities.

Consent - to - Eligibility Timeline

Background: IDEA 2004 provides that an initial evaluation of a child shall be conducted within 60 days of receiving parental consent or, if the State establishes a timeframe within which the evaluation must be conducted, then within such timeframe.

In Alabama, the “evaluation clock” runs from the date that the child was referred for evaluation, not the date on which the consent form was signed. This is a sensible way to frame the timeframe because, as P&A staff report in states where timelines are triggered by parents’ written consent, children’s evaluations are sometimes delayed when school districts do not promptly provide families with the necessary written consent forms.

Even in Alabama, where it is the referral that triggers the timeframe, ADAP has encountered many districts that do not complete the required evaluations within the 60 days that Alabama law provides, thus affecting a child’s right to a free appropriate public education (FAPE). The Congressional purpose of ensuring that children with disabilities are evaluated and served in a timely manner will be supported by a regulation that states that schools are required to present families with the consent forms promptly (for example, within 3 school days of the referral).

Recommendation: The regulations should clarify that States cannot adopt timeframes for conducting initial evaluations that are longer than 60 days. In addition, the regulations should clarify that families must be promptly provided consent forms (within 3 school days).

Children's Health Act of 2000 Seclusion and Restraint Reporting Requirements

By Lydia Akin, Senior Case Advocate

"Seclusion and restraint should no longer be recognized as a treatment option at all, but rather as treatment failure."

Substance Abuse & Mental Health Services Administration (SAMHSA) Administrator Charles G. Curie, M.A., A.C.S.W., quoted in SAMHSA News, Volume XI, Number 2 (2003)

The Children's Health Act of 2000 laid out standards for the use of seclusion and restraint in all health care facilities—for children and adults—that receive Federal funds and in non-medical, community-based facilities for youth. These facilities include psychiatric residential treatment facilities that provide inpatient psychiatric services to children under age 21 (PRTFs).

Briefly, the Act requires that PRTFs must meet the following standards for use of seclusion and restraint (S&R):

- S&R are prohibited as methods of coercion or discipline
- S&R cannot be used for any reason but to ensure safety in

emergency situations (and emphasizing that only approved methods should be used in those situations)

- Staff and consumer debriefing and reporting of any deaths during the use of S&R
- Staff education and training on S&R

In addition, the Act requires that PRTFs in each state alert that state's protection and advocacy (P&A) agency of a resident's death, serious injury, or suicide attempt linked to or as a result of the use of S&R. These facilities must report the same information to the State Medicaid agency.

During 2005, ADAP will notify each PRTF in Alabama of its obligation under the Act to report such incidents to our office. We will work with the facilities to set up a mechanism by which this data can be collected promptly and efficiently by our agency so that we can act upon these reports in a way that will protect the rights of PRTF residents.

**Attention Parents and Consumers!
Need financial help to attend
conferences or training events?**

**Check out the
Consumer Involvement Fund**

The Alabama Council for Developmental Disabilities (ACDD) administers the Consumer Involvement Fund. The purpose of the program is to provide funds for individuals with developmental disabilities, their family members, or their guardians to participate in conferences, training events, public forums, focus groups, committees, task forces, hearings and other similar activities. The fund can help a consumer pay for registration fees, childcare or respite, personal assistance, hotel/lodging, meals or transportation. Funds are limited to \$500 per year per person for in-state events and \$1200 per year per person for out-of-state events.

**For more information, call the
ACDD at 1-800-232-2158 or email
them at addpc@mh.state.al.us.**

New International Career Publication Available Online for People with Disabilities

A new online resource from Mobility International USA/National Clearinghouse on Disability and Exchange titled "Preparing for an International Career: Pathways for People with Disabilities" encourages young adults with international interests to explore careers in the international affairs, exchange and development fields. As one International Affairs graduate, who is blind, shares, "The Berlin Wall fell when I was in high school, and I had a

world history teacher who gave us global current events every single day of class. I thought, 'Wow, what an interesting time to be alive. How wonderful if I could have a career affecting it in some way.'

This downloadable booklet, available at www.miusa.org, highlights different types of international occupations, job prospects, tips to prepare for an international career, insights from role models and emerging leaders with disabilities in these fields, and the international exchange and fellowship programs they participated in to get them where they are today. Go to: www.miusa.org/publications <<http://www.miusa.org/publications>> to find information on many activities one can

participate in as stepping stones to an international career!

Mobility International USA (MIUSA) is an organization that empowers people with disabilities around the world through international exchange and international development. MIUSA also manages the National Clearinghouse on Disability and Exchange (NCDE), sponsored by the Bureau of Educational and Cultural Affairs of the United States Department of State. Through the NCDE, MIUSA provides information and resources for people with disabilities to learn about opportunities for international exchange, including study abroad, volunteer service, research and teaching programs.

Reprint from *The Birmingham News* / Sunday, December 05, 2004

Too many of our kids growing up in foster care



There was an old woman, she liv'd in a shoe, She had so many children she didn't know what to do.

- Old English nursery rhyme

A boy lives with his grandmother until she dies. He enters foster care soon thereafter. Less than six months later, he is placed in a locked psychiatric facility. He does not live with relatives. He does not live with a foster family. How does this happen?

When a child enters foster care in Alabama, the state Department of Human Resources becomes the legal parent to that child. As the legal parent of children in Alabama's foster care system, DHR stands in the place of the citizens of Alabama. DHR is now the parent to more than 6,000 boys and girls. The test for DHR's foster care system is how it parents its children. As such, we must ask: What kind of a parent is DHR?

Is DHR the kind of parent we want for our children?

I received a phone call this week from a lawyer who represents a child in foster care. Matthew (not his real name) entered foster care after his grandmother, with whom he lived, died. After several failed placements in residential facilities and foster homes, Matthew was placed in a locked psychiatric facility 100 miles away from his home and all he had

ever known. He has now been there for more than half a year, and has not "progressed" as he should. Instead of providing Matthew with a home where he can grow up as a part of a family, DHR is now considering placing Matthew at the far end of the state, more than 250 miles from his home.

In 1991, Alabama's DHR voluntarily made a promise (now known as the R.C. consent decree) to transform its foster care system. In promising to transform its foster care system, Alabama agreed to investigate allegations of abuse and neglect quickly, keep children at home with their parents when they did not need to enter foster care, care adequately for children who must be placed in foster care, and find permanent homes for children in foster care through reunification with their family, adoption, or other permanent alternatives.

Like Matthew, too many of the children who enter foster care in Alabama today still have the same experience of the child for whom the R.C. case was named.

Too many of Alabama's children enter foster care needlessly. In one Jefferson County region, only 12 children entered foster care over a four-month period in 2003 (just months after the region claimed compliance). Yet, over the same four-month period in 2004, 93 children entered foster care in the same region.

Too many children are not adequately cared for while in foster care. In Jefferson County, approximately one-half of all children in foster care do not live with their brothers and sisters while in foster care; only 5 percent of children in foster care live with relatives; 30 percent of children live in a restrictive residential placement rather than with a foster family or therapeutic foster family; and only two-thirds of plans for children are

completed on time.

Too many of Alabama's children still grow up in foster care. The most recent report available from the U.S. Department of Health and Human Services (2001) regarding foster care conditions in Alabama found that, "60 percent of the children exiting foster care through emancipation were age 12 or younger at the time of entry to foster care, which was the highest percentage for this measure of all states." In jarringly similar language, Gov. Guy Hunt's Special Commission on Child Welfare Services concluded 13 years earlier that "foster children too often languished in foster care with no permanent plan for their future ..."

The R.C. court monitor's most recent report states that DHR has failed to comply with direct orders from the federal court. The monitor declares that statewide "current child welfare staffing levels are not consistently meeting" the requirements of the 1998 court order on caseloads and staffing. The monitor also reports that DHR has not developed and implemented a "report card" for publicly rating the quality of each county's child welfare practice, as ordered in November 2003.

DHR has made progress since the days when the R.C. case was filed in 1988. But, the question remains: what kind of a parent is DHR? Dietrich Bonhoeffer, the great Protestant theologian who died opposing Hitler's Holocaust said, "the test of the morality of a society is what it does for its children." Is DHR the kind of parent we want for our children?

James A. Tucker is litigation director of the Alabama Disabilities Advocacy Program. He has represented the plaintiffs in the R.C. case since 1992.

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The University of Alabama
Alabama Disabilities Advocacy Program
Box 870395
Tuscaloosa, AL 35487-0395

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