

Arkansas
Governor's



Autism Becomes Hot National Topic

Reporters, editors, and TV news directors have discovered autism. Since the end of December a wide range of news organizations like ABC, USA Today, NBC, the Associated Press, CBS and others have presented or printed stories about autism. (See article, page 3)

Autism Services Bill Introduced

Senators Hillary Rodham Clinton (D-NY) and Wayne Allard (R-CO) recently introduced the Expanding the Promise for Individuals with Autism Act of 2007.

As proposed, the legislation calls for a \$350 million investment to strengthen state service delivery systems for individuals with autism and their families..

(See article, page 4)

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Family Leadership Spurs Mother To Seek a Better Life for Son, Self

FLP graduate Amy Jamison "heralds" DDC-sponsored program, says it helped her see "potential for change."

All she wanted to do was help her son. That's why Amy Jamison (Burris) enrolled in the DD Council's 2000 Family Leadership Project. She began the Family Leadership Project "terrified and completely alone." What she had was a son, Steven, with autism a baby daughter, Lacey, and a husband who was having difficulty dealing with his son's disability.

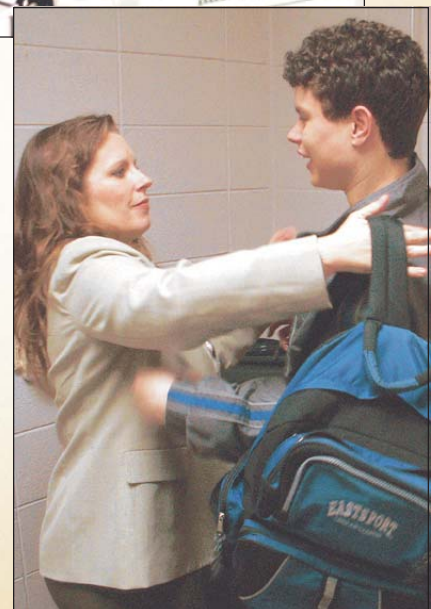
"What I didn't have was a career path or the funds needed for my son's treatment." She ended the nine-month course with more than she bargained for. Not only did she pick up the knowledge needed to better advocate for her son, Amy came away with both the desire and will to seek a better life for herself.

"I evolved from a frightened young mother to a fearless advocate." She also decided it was necessary to "thoroughly educate myself in every aspect of Autism Spectrum Disorders (ASD)."

Now, seven-years later, Amy not only has a much better understanding of ASD, she has an undergraduate degree from the University of Arkansas in Speech Language Pathology and will complete her Masters degree in Communications Disorders in May. She intends to get a PhD in Developmental Disabilities. (See *Balancing Parenting, Education, Advocacy*, page 2)



THEN AND NOW - Amy Jamison (above-right) works with other members of the class during the Family Leadership Training program in 2000. Today, she's busy getting her masters degree while she seeks to provide a better life for her teenage son Steven (right), her 11-year-old daughter Lacey and for herself.



Balancing Parenting, Education, Advocacy

Jamison plans to make helping children with autism her lifelong work

(This story continued from page 1) ral/Clinical Psychology, as well.

Why did she decide to study Speech Language Pathology and Communications Disorders? Because Steven, like many children with autism, is virtually nonverbal.

"I want to be able to provide services for as many people as possible. I want to really make a dent in our system," Amy says.

But, first she wants to help Steven. One of those with severe symptoms, Steven is making headway. But, as Amy explains, progress is painfully slow.

"It's a battle we fight daily. He does require 24-hour-a-day care." She has allies – the teachers at Southwest Junior High School in Springdale and the waiver workers who tend to Steven when she can't.

Amy knows there's no cure for autism. She also know it can be minimized. What's needed, she says, are federal and state funded programs specific to the needs of children and adults with autism.

Which is why she's become an outspoken advocate. "That's an aspect of FLP that's proved to be invaluable," Amy says.

"Could I have done all this without the Family Leadership Project's training? Yes. But, would I have? Probably not. Before FLP I would have been too intimidated."

Not like today's Amy, the single mother who successfully balances parenting, education and advocacy.

(Editor's Note – Anyone who wants to receive the new e-newsletter must, by state law, subscribe. A subscription form is available by email, mail or on DDC's website (www.ddcouncil.org). Subscribers must provide their name, address, phone number and email address. Monthly issues will be emailed during the first week of each month.)



ADVOCACY AND EDUCATION – When not pursuing her masters degree, Amy Jamison is either talking with Marilyn Edwards, her state representative (top), encouraging her son Steven at school (above right) or joining other parents like Felicia Jefferson as they meet with State Rep. Fred Allen during DDC's recent Legislative Luncheon.

Autism from a Sibling's Perspective

Having a brother with autism is, in Lacey's words, "cool" and "weird." Cool because he makes her laugh "It's funny living with Steven sometimes. We laugh at life a lot."

Weird when he tries to touch the face of complete strangers or makes odd noises. Or, when he takes stuff off the shelves "when we go to the store."

She also gets "angry" and loses her temper when he tears up her collectors cards. "I know he doesn't understand, but I can't help but yell at him sometimes." But I still love him – even when he tears up one of my best or favorite collecting cards."

She does wonder what other people think. "I want them to know he helps me understand what other brothers and sisters of children with autism go through." More than that, Lacey wants them to know that "it's not always bad."

"So, why do I love my brother? First, because he's my brother. Second, because he's funny. Sometimes he does a funny duck dance. Third, because he's silly. Especially when he runs and makes his funny noises."

The point, Lacey says, is that "he's a brat, like all brothers, but I love him."

Nation Turns Attention to Autism

Signing of Combating Autism Act, the release of a CDC study on increasing rates generates flurry of media activity on autism and associated disabilities

Reporters, editors, television news directors and TV personalities have discovered autism. Since the end of December, such news organizations as Reuters, ABC, USA Today, NBC, The Washington Times, MSNBC, the Associated Press, CBS 60 Minutes, and the Arkansas Democrat/Gazette, have provided, presented or printed stories about autism and associated disabilities. Even CNN's Larry King, with guest Bill Cosby, devoted an entire show to autism and its impact on children and their parents.

The flurry of interest in autism began when the U.S. House passed an amended version of Combating Autism Act (S.843) on Dec. 7 of last year. The day after, ABC reported "Congress Declares War on Autism." Not long after President Bush signed the bill on Dec. 19, the Washington Times published a Brookings Institute piece entitled "Combating Autism Act: A key Achievement of 109th Congress."

Then on Feb. 9 the Centers for Disease Control and Prevention (CDC) released the results of study which said the reported number of children with autism had risen from 22,664 in 1994 to 193,637 in 2005. Headlines like "Autism: the Hidden Epidemic" and "Autism Disorders Affecting 1 in 150" quickly followed. None of the reports said anything families of children with autism didn't suspect or already know.

- ◆ Autism involves delays in the development of many basic skills, including forming relationships, the ability to communicate and the use of imagination;

- ◆ It is a pervasive disorder not usually diagnosed in children until after age 3, and

- ◆ The earlier the intervention the better the outcome.

Activists have said for years that autism is more common than many believe. And, while they're happy that the disorder is getting attention, they believe the nation needs to turn its attention to how to help those already affected (see related story on page 4).



Children and adults with autism face a wide range of challenges. Their tendency toward rigidity and inflexible thinking make it difficult for them to participate in such mainstream activities as schooling, marriage and holding a job.

Authored by Senators Rick Santorum (R-PA) and Christopher Dodd (D-CN), S.843 passed unanimously in the Senate on Aug. 3 of last year. The House passed its amended version on Dec. 6. At a cost of nearly \$1 billion over five years, the Act's key provisions include:

- ◆ Developing and implementing a strategic plan for research related to autism spectrum disorders;

- ◆ Reauthorizing Autism Centers of Excellence and providing funds to the centers for coordination of services and information for patients;

- ◆ Supporting basic and clinical research into the fields of development.

(Article continued on page 4)

UAMS Study Finds Arkansas Autism Rate Among Highest

Report says early diagnosis and treatment lacking

A University of Arkansas for Medical Sciences (UAMS) study has found that 1 in 145 Arkansas children has autism, the fourth highest rate among 14 states participating in a national study.

The UAMS data was used as part of the largest-ever U.S. study of autism. Published Feb. 9 by the national Centers for Disease Control and Prevention (CDC), the study found that about 1 in 150 American children have autism, making the disorder an "urgent public health

issue," said Marshalyn Yeargin-Allsopp, chief of CDC's developmental disabilities branch. Prior to the study, the national prevalence of autism was thought to be about 1 in 166.

The Arkansas study was conducted by the University Center for Excellence in Developmental Disabilities (UCEDD). A Department of Pediatrics in the UAMS College of Medicine program, UCEDD is better known as Partners for Inclusive *(Article continued on page 4)*

(Article continued from page 3)
mental neurobiology, genetics, epigenetics, pharmacology, nutrition, immunology, endocrinology, gastroenterology, psychopharmacology, and toxicology;

- ◆ Improving coordination of the various federal, state, and local supports and services available to persons with autism and their families;

- ◆ Increasing the number of providers that can screen, diagnosis and provide interventions to persons with autism; and,

- ◆ Promoting research to determine evidence-based best practices for diagnosis, early detection, prevention, intervention and the possible cure for autism spectrum disorders.

"This is only the beginning," Autism Society of America (ASA) President and CEO Lee Grossman commented. "Now, we hope Congress will get to work on a compre-



hensive services bill for individuals with autism, including reforming Medicaid waivers, employment incentives, housing improvements, job training and so much more." Grossman promised that ASA will work actively on the Hill in the 110th Congress to ensure such legislation (see related article below).

Anyone seeking more information about autism and related disabilities should contact:

Centers for Disease Control and Prevention – www.cdc.gov/actearly;

Autism Society of America – www.autism-society.org;

Center for the Study of Autism – www.autism.org;

Autism Speaks – www.autismspeaks.org;

Autism Research Institute – www.autismwebsite.com;

Cure Autism Now – www.cureautismnow.org, and

Autism Education Network – www.autismeducation.net

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Communities by people in the developmental disabilities community,

The study establishes a baseline so that autism trends can be tracked, said UCEDD Director David Deere, "While the rates reflected in the Arkansas data are very concerning, we cannot yet say whether the increase is due to changes in diagnosis or to a true increase in cases." The UCEDD findings include:

- ◆ More Arkansas children are diagnosed with autism than ever before.

- ◆ Boys are more than 3.5 times more likely to be diagnosed with autism (1 in 93 boys as compared with 1 in 345 girls).

- ◆ The disorder occurs most often in Caucasian children and least often in Hispanic children.

- ◆ The median age of diagnosis in Arkansas was 4 years 11 months.

Eldon G. Schulz, M.D., a developmental pediatrician and professor of pediatrics and rehabilitation at UAMS/Arkansas Children's Hospital, said it is unfortunate that autistic children are almost 5 years old before they're diagnosed in Arkansas.

Noting that autism can be identified as early as 18 months of age, Schulz said "we simply must identify children at an early age so they may benefit from early intervention. When intensive services for a child begin early, the effects of autism are greatly reduced."

Karan Burnette, clinical reviewer for the Arkansas Autism Study at UAMS, said it is clear that more children are being identified with Autism Spectrum Disorders (ASD). "The impact on families is tremendous – physically, emotionally and financially," Burnette said.

"The health care, educational, and human service systems in the state are strained to provide appropriate identification, intervention and support for individuals with ASD and their families. Additional support for research and intensive early intervention is critical to the outcomes for these children," she declared.

Autism Services Bill Introduced

Senators Hillary Rodham Clinton (D-NY) and Wayne Allard (R-CO) recently introduced the Expanding the Promise for Individuals with Autism Act of 2007. As proposed, the bill would invest more than \$350 million to strengthen the service delivery system for individuals with autism and their families.

The legislation would provide state demonstration grants designed to expand access to post-diagnosis care, interventions and treatments, and services for children and adults with autism. The bill also specifically calls for states to consult their councils on developmental disabilities in the planning and implementation of the grants.

These provisions would ensure that planning efforts are coordinated with larger developmental disability policies, that efforts are not duplicated, and that the resources are directed toward the special needs of each state.

The measure would also provide funding to protection and advocacy systems to address the needs of individuals with autism and other emerging populations of individuals with disabilities; supplemental grants for training and technical assistance to service providers and educators, and resources to establish a national center on autism services information.

College to Present Series of 'Educate the Educators' Sessions on Autism

Increased need to prepare for growing number of students with autism cited

With one out of every 150 eight-year old children diagnosed with an Autism Spectrum Disorder it is becoming clear that educators need to be educated about this pervasive developmental disability.

According to recent CDC report, "Autism Spectrum Disorders (ASD) occur in all racial, ethnic, and socioeconomic groups and are four times more likely to occur in boys than in girls." What's more, Arkansas is ranked fourth in the number of children with Autism Spectrum Disorders (see stories, pages 3-4).

"As these children enter school we need to educate the educators and others on Autism," says Dan Bakke, president of Pulaski Technical College. "Furthermore, we in higher education need to prepare for the increased presence of students with autism spectrum disorders."

Pulaski Technical College's Political Science and Behavioral Science Departments are working in partnership with Arkansas Special Children to offer a series of sessions addressing Autism Spectrum Disorders.

Researching Autism

Tuesday, April 10, 7:00 p.m.
Rachel Bowman, Psychologist,
UAMS

U.S. Bank Room

Living with Autism

Tuesday, April 17, 7:00 p.m.
Jessica (Jazz) Summers and
Lynley Summers

Campus Center Lecture Hall

Policy-Making and Autism

Tuesday, April 24, 7:00 p.m.
Former Arkansas Speaker of the
House Bill Stovall
Representative Sandra Prater (D-
Jacksonville)

Johnny Hoyt (D-Morrilton)
Campus Center Lecture Hall
Continuing Education Hours are

available with 1½ clock hours per session for a total of 4½ hours.

Rachel Bowman is a psychologist at the University of Arkansas for Medical Sciences. She works with UAMS clients with Autism and other special needs. She has been involved in home and school based interventions, including helping families with behavioral problems sometimes associated with autism and other DD issues.

Jessica (Jazz) Summers is a senior at Mills University Studies High School in Little Rock. A member of the National Honors Society and the recipient of several academic and artistic awards, she is a person with autism.

An advocate for people with autism, Lynley Summers is Jessica's mother. She is the author of *Autism is Not a Life Sentence* and has represented Arkansas before the U.S. Congress on autism issues.

The Arkansas General Assembly has recently considered several bills concerning people with autism. Ar-

kansas Special Children is a support group for parents, grandparents, foster parents and guardians of children with special needs. They can be contacted at <http://www.groups.yahoo.com/group/arsc/>

The Behavioral Science Department at PTC offers courses in psychology, sociology, social work and anthropology. The political science courses are taught through the Social Science Department. During the academic years 2007-2008 and 2008-2009, the students enrolled in the State and Local Government courses will be involved in researching and drafting proposed policies for PTC concerning students, faculty and staff with Autism Spectrum Disorders.

For more information contact Johnny Dollar, chairman of the Social Science Department, at jdollar@pulaskitech.edu or (501) 812-2353. or Jacqueline Candelaria, Arkansas Special Children Coordinator, at arsc_owner@yahoo.com

Events to Mark Autism Recognition Month

Two events, an "Autism Awareness Walk" and a Conference on Autism have been scheduled for April 13-14 in Jonesboro. Organized in recognition of National Autism Awareness Month, the Autism Association of Northeast Arkansas is working with the Arkansas Parent Training and Information Center, Autism Speaks and the Children's Clinic to present the conference on Friday, April 13 and the walk on the following day.

Speakers for the 10 a.m. to 2 p.m. conference include S. Jill St.

James, director of the Metabolic Genomics Lab and Dr. Maya Lopez, of the Developmental Pediatrician-Behavioral Pediatrics department at Arkansas Children's Hospital and Laura Corby, the founder and CEO of Autism Solution Center in Memphis.

The walk, which begins at 10 a.m. at Joe Mack Campbell Park, is being held to raise funds for education and awareness of autism programs.

To get more information or to register go to The Children's Clinic website at www.jbrkids.com