



TARC NEWSLETTER

Oklahoma's leading information source on issues impacting the lives of people with developmental disabilities and their families

October 2008

CONTENTS

Now is the Time for All Good Advocates to Vote.... 1, 2, & 3

Presidential Candidates on Key Health Care Issues 3

TARC Disabilities Month Speaker Series 3

New Disability Resource Guide Available 4

Sibshops for Siblings of People with Disabilities..... 5

Financial Hardship for Families of Children with Disabilities..... 6

Fall Autism Workshops..... 7

ADA Amendments Act..... 8

Autism News Roundup..... 9

Calendar of Events..... 10

Now is the Time for All Good Advocates to Vote!

by John F. Gajda, TARC Executive Director

“Our American heritage is threatened as much by our own indifference as it is by the most unscrupulous office seeker, or by the most sinister foreign threat. The destiny of this Republic is in the hands of its voters.”

President Dwight D. Eisenhower

It's that time of year again.

For some people as we move out of summer and into fall thoughts turn to the changing season with leaves turning colors, the approaching cooler weather and upcoming holidays. My immediate association, however, is the approach of Election Day on the first Tuesday of November. You see, I take Eisenhower's words to heart. It is the one time when the destiny of our advocacy for people with disabilities and their families is most in our control.

I devote much of my commentary throughout the year to what I think our elected officials should be doing for people with disabilities and their families. And each year when the Oklahoma Legislature adjourns in May, we look back at what the legislature did and bemoan the fact that the services people need didn't get adequate funding, that progressive bills being supported by advocates died in committee and bills supporting the old ways of thinking and doing things got passed and signed by the Governor. The Oklahoma Legislature (with the exception of a few members who have championed the cause of people with disabilities) just doesn't have a good record for addressing the concerns of people with disabilities and their families. Things don't change!

We spend far too much time reacting to events rather than trying to shape them. Our attempts to influence the legislature are just one example of this approach. Waiting until February to try and influence the members of the Legislature when they gather to begin a new legislative session is too late. Election Day is the only time when we can actually do something about the slate of officials we depend on to do the right thing for people with disabilities and with whom we will be advocating over the coming years.

We have this wonderful mechanism to influence our government. It's the election process. This November, Oklahoma voters will be electing a President and Vice-President, five U.S. Congressmen, and one U.S. Senator to represent us in

please see "Now is the Time" on pg. 2



TARC is committed to ensuring a high quality of life for Oklahomans with developmental disabilities through education, empowerment, support and advocacy. For additional information about TARC or to volunteer, contact us at:

16 East 16th Street, Suite 405, Tulsa, Oklahoma 74119-4447
www.ddadvocacy.net tarc@ddadvocacy.net 918-582-8272/800-688-8272 918-582-3628(Fax)

Now is the Time, from pg. 1

Washington. On the state level there are still races for 58 of the 101 seats in the Oklahoma House of Representatives that must be decided and 11 of the 48 seats in the Oklahoma Senate. The incumbents for some offices did not have an opponent while contests for some offices were settled in primary elections because they only drew candidates from one party.

I am sure that this is not news for anyone. What I am urging people with disabilities and their families to do, though, is deal with their frustrations with the Oklahoma Legislature's and United States Congress' response to disability issues now, at the ballot box. Take a proactive rather than a reactive approach.

Our elected officials are important because the reality is that the vast majority of people with disabilities are dependent on government benefits at some point, if not throughout their lives. While some candidates pitch pro-family values to voters, it is hard to determine what that philosophy really means for people with disabilities and their families. While on the surface it would seem to be a good deal for families supporting family members with disabilities, often as it is practiced it turns out to be less interference by government in the lives of families (that translates into less support and fewer services provided by government to families), lower taxes (and the excuse used by legislators that "we would like to help but we just don't have the money"), an unwillingness to impose or enforce standards and regulations (that feeds the long term struggle many families face to get schools to meet their responsibilities for providing education to children with special needs and a weakening of oversight of providers), and the freedom for families to take care of themselves (with no expectation that the government should help if families can't do it all). Other candidates pitch eliminating "handouts" and "waste" in government. When pressed, they are including people with disabilities among the "broad array of special interests" that received "handouts" from government. Are we really prepared to pay privately for all that government currently provides for people with disabilities? What can you do? I suggest the following:

Find out where the candidates stand on issues you are concerned about. If you are on the waiting list, find out if Oklahoma legislative candidates support additional funding to provide services to people on the waiting list. If your residential service provider can't hire good staff, ask candidates if they support adequate

rates for providers. If you are having trouble getting the special education services you are entitled to, find out if they support legislation to make schools accountable. For presidential candidates you can visit the websites of the respective campaigns to view the information they have posted about issues of concern to the disability community. The Obama campaign has a nine page policy paper posted at www.barackobama.com/issues/disabilities/. The McCain campaign does not have a separate policy paper on disability concerns, but addresses issues in other topical papers at www.johnmccain.com. Both campaigns also have staff members assigned responsible for policy and outreach in the disability community.

Educate the candidates for state and federal office about your needs and your family's needs.

Elected officials are never more willing to listen than when they need something from you – your vote. The election season presents a unique time to educate people who will be making decisions that are important to you.

Make contributions to the campaign of candidates who support your issues. Now, I know that we can't all make large financial contributions, but in a small house district, you would be surprised how little can make a difference. If you can't make any cash contributions, give your time and influence. Offer to put a yard sign in front of your house. Deliver brochures. Hold a coffee for your neighbors. Offer to call your friends.

Get to know the people who will represent you. There is no better time to begin establishing a relationship with your elected representative than at election time. Make a point of introducing yourself when they are campaigning. Tell them about yourself and your family. Let them know what issues you want them to work on. Offer to provide information on the issues. Let them know you will be calling them when the legislature is in session. Later contact will be more effective if you have already established a relationship.

For those seeking re-election, look beyond the rhetoric and assess the positions and votes candidates have taken regarding disability issues before you award them your vote. Saying and doing are different independent acts that for our politicians are often not correlated. They say they support an issue and then act or vote in a way that is inconsistent with their rhetoric.

please see "Now is the Time" on pg. 3

Now is the Time, from pg. 2

You may wonder what you, a single voter, can do. I think people underestimate their impact. As Robert Kennedy said, "Each time a mans stands up for an ideal...he sends forth a tiny ripple of hope and crossing each other from a million different centers of energy and daring, these ripples build a current that can sweep down the mightiest walls...of resistance." Together we can make a difference. So this election day, become one of the ripples Robert Kennedy was speaking about and become part of the current of change by trying to get the people who will support our issues into office.

Now is the time for us all to shape policy, programs and services for people with disabilities and their families. Educate yourself about the candidates and vote on November 4th like the lives of people with disabilities depend on your vote, because THEY DO!

Presidential Candidates on Key Health Care Issues: a Side-by-Side Comparison



The Kaiser Family Foundation has added two new resources on its www.health08.org web site, detailing Sen. McCain's and Sen. Obama's stances on key health care issues, building upon the site's existing comparison of the candidates' health reform proposals.

- A new, interactive tool (http://www.health08.org/healthissues_sidebyside.cfm) allows users to compare the candidates' proposals and positions on a range of health care issues. A separate side-by-side comparison of the candidates' health reform proposals is also available on www.health08.org (<http://www.health08.org/sidebyside.cfm>).

- The site now features a new compilation of video clips (<http://www.health08.org/ontheissues/healthreform>) of the candidates speaking about various aspects of health reform including expanding coverage, employer-sponsored coverage, costs of coverage, the government's role in health care, the insurance market, preventive care and tax subsidies for health insurance. The clips are drawn from www.health08.org's extensive web-cast library.

The web site serves as a hub of information about health and the election, providing original polling and analysis produced by the foundation, news summaries, videos and podcasts from the campaign trail, and easy access to health-related resources from the campaigns, other organizations and news outlets.

Source: Monday Morning in Washington

TARC Disabilities Month Speaker Series Slated

In recognition of October as Disabilities Awareness Month, TARC will present the 6th annual Speaker Series. All lectures are presented free of charge and no reservations are required to attend. Locations, program dates and topics are as follows:

Staffing Solutions: Recruiting, Supporting, and Retaining Quality Support Staff for People with Developmental Disabilities

Tuesday, October 7

Time: 6:00-7:30 p.m.

Location: Schusterman-Benson Library, 3333 E. 32nd Pl., Tulsa

A panel discussion on ways to recruit staff, provide the supports necessary to retain staff, and tips for hiring, interviewing, and making expectations of care clear to all parties.

Panel members include Brooke Andrews, an HTS who has worked with the same individual for several years; Amanda Cothorn, OK-AIM program coordinator, TARC (and former DDSD case manager); Susan Garrett, parent of self-advocate with experience securing staffing on the Self-Directed Services pilot; and Cynthia Parson, parent of self-advocate with proven success retaining staff for long term care.

Psychiatric Medications for Children and Adolescents with Autism Spectrum Disorders

Tuesday, October 14

Time: 6:30-8:00 p.m.

Location: Hardesty Library-Pecan Room, 8316 E. 93rd St., Tulsa

A review of current psychiatric medications for treating behavioral and emotional problems related to Autism and tips for developing an effective team approach in assessing response to medication.

Presented by Dr. Marciale Ledbetter, M.D., Board Certified in General, Child, and Adolescent Psychiatry and Medical Director, Riverside Behavioral Health.

All About Guardianship

Tuesday, October 21

Time: 6:30-8:00 p.m.

Location: Hardesty Library-Redbud Auditorium, 8316 E. 93rd St., Tulsa

An expert panel will provide an overview of guardianship, including pros and cons, the capacity assessment process, and the legal process and requirements to obtain guardianship of an adult with developmental disabilities.

Panel members include Aaron Brown, assistant executive director, TARC; Maureen Knudson, P.C.; and Ray Gene Trimble, Area II guardianship coordinator, OKDHS-DDSD.

Renewed Disability Resource Guide Available



OKLAHOMA CITY, Okla. – For individuals needing disability information, the search just got easier. The Oklahoma Department of Rehabilitation Services (DRS) completed a major renovation of its popular Disability Resource Guide, which shares disability information on the local, state and national level comprised of more than 3,000 entries.

The guide is available on-line at www.okdrs.gov. It includes information on housing and legal issues as well as where to find adaptive clothing or equipment or just acquire information on specific diseases/conditions.

“Originally, we wanted disability and social information for our counselors and clients in a central location,” Linda Parker, DRS director, said.

“Through the years, the guide delivered a vast amount of hard to find or hard to understand information on the web and in a summarized format for the average person. This update brings new life to a valuable document that utilizes new technology in a more efficient and user friendly way,” Parker said.

“We know the guide is a valuable resource due to the fact that it receives anywhere from 3,000 to 4,000 hits a day.”

In the last year and a half, many new changes occurred. The guide now includes a modern search engine that allows users to find information easily. Users can choose a large print format or a standard print format depending on their needs through an adjust text feature.

The index gives users the ability to view a known organization or company’s information individually without having to search through a chapter or section.

“I love the index. You can go straight to what you are looking for,” Oklahoma City Visual Services, Rehabilitation Technician Jeannette Ridner said. “I use the guide all the time, four or five times a week. It’s an easier way to find multiple services in one place.”

There are also those outside DRS who use the guide to assist people with disabilities or their families, such as Sooner SUCCESS’ Blaine County Coordinator, Billie Roane. Roane is a resource for parents of children who have disabilities or are critically ill. She helps to connect parents or medical providers with vital information or

assistance.

“It is very easy to navigate and has a wealth of information in it,” Roane said. “The detail consideration in how a page prints off, all of it on the page just as it appears online, makes my work so much easier in passing on a completed hard copy for a family or provider.”

Although this is the next generation of the guide, it still provides information on important topics such as:

- Accessibility and Assistive Technology
- Education
- Employment
- Financial Assistance
- Health and Mental Health
- Housing
- Information Sources
- Legal Rights and Legal Assistance Resources
- Programs for Minorities & Underserved Groups
- Personal Assistance and In-Home Services
- Rehabilitation and Independent Living
- Sports, Recreation, Leisure and Travel
- Support Groups
- Disability Tax Provisions and Special Benefits
- Transportation

For more information about the Disability Resource Guide or Oklahoma Department of Rehabilitation Services, call 405-951-3400, or 800-845-8476. Also, visit DRS Online at www.okdrs.gov for comprehensive information about DRS, including employment-related, education and self-sufficiency services provided to Oklahomans with all types of disabilities.

Source: DRS



Help TARC by becoming a member today.

Benefits of membership include:

- Monthly and quarterly newsletters;
- Participation in TARC governance;
- Voting rights in the annual TARC Advocacy Awards; and
- Membership in The Arc of the United States.

TARC
helps families

Call 1-800-688-TARC or visit www.ddadvocacy.net to become a member of TARC.

Online Directory for Finding Community Services for Children and Families



The Maternal and Child Health (MCH) Library has released a new edition of the Community Services Locator, an online directory that can be used by service providers and families to find health, mental health, family support, parenting, child care, and other services in their communities. Topics include education and special needs, health and wellness, mental health and well-being, family support, parenting, child care and early childhood education, and financial support. It is available online at http://www.mchlibrary.info/KnowledgePaths/kp_community.html.

Source: Monday Morning in Washington

Support Workshops for Siblings of People with Disabilities



Several workshops, called Sibshops, will be offered in the Tulsa area for children with siblings who have special health care needs or disabilities.

Sibshops are organized by the Sibling Support Project, a national effort dedicated to the life-long concerns of brothers and sisters of people who have special health, developmental, or mental health concerns.

Sibshops are designed to increase the peer support and information opportunities for brothers and sisters of people with special needs and to increase parents' and providers' understanding of sibling issues through workshops, websites, and written materials.

A series of four Sibshops will take place between October 2008 and May 2009 and are available to siblings ages 6-13. The cost to attend a single Sibshop is \$6, which includes lunch, or \$20 for all four sessions. Sibshops will be held on the campus of Saint Francis Hospital in Tulsa. For more information, contact Lora Roberts at 918-227-1797 or email lora-roberts@oklahomafamilynetwork.org.

TARC Newsletter

How Medicaid Helps Oklahoma



As the economy deteriorates, states find themselves under increasing fiscal pressure. Some may be tempted to trim their Medicaid programs to help balance their budgets but this is exactly the wrong thing to do.

You can show your state officials that cutting Medicaid is a big mistake if you visit the revised and updated Medicaid calculator developed by Families USA. It can be found at <http://www.familiesusa.org/issues/medicaid/other/medicaid-calculator/medicaid-calculator-states-map.html>. Simply click on Oklahoma on the map and use the worksheet to find out how much Oklahoma stands to lose in jobs, wages, and business activity.

In tough economic times, the Medicaid program is more essential than ever. Hopefully you will find the Medicaid calculator a useful tool in your efforts to help preserve it.

Source: Monday Morning in Washington

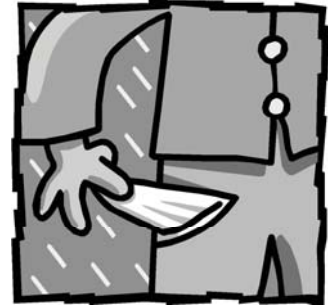
Resources for Helping Children Deal with Disasters

The National TA Center at United Advocates for Children and Families (UACF) recently released a set of resources offering help for individuals who are physically, psychologically, or emotionally impacted from the effects of natural disasters. The resources offer advice and tips for communities to prepare for and deal with the repercussions of hurricanes and other disasters. The following resources can be found on the Association of University Centers on Disabilities' (AUCD) website, http://www.aucd.org/template/news.cfm?news_id=3003&id=26&parent=26:

- *After the Storm: A Guide to Help Children Cope With the Psychological Effects of a Hurricane*
- *Disaster Preparedness for Families of Children With Special Needs*
- *After the Disaster: A Children's Mental Health Checklist*
- *Emergencies, Mental Health, and Traumatic Stress*
- *Disaster Preparedness for Children*
- *Mental Health Services in Disasters/Major Traumas*

Source: Association of University Centers on Disabilities

University Study Finds ‘Chilling’ Hardship Rates Among Families Raising Children with Disabilities



Families of children with disabilities are struggling to keep food on the table, a roof over their heads, and to pay for needed health and dental care. But according to a new study from the University of North Carolina at Chapel Hill, these challenges are now falling on middle-income households and not just on poor families as previous research has found.

These latest findings show that long-held federal standards for identifying the nation’s poor are not capturing everyone in need and should be re-evaluated, especially for the financial effects on children with disabilities, said Susan L. Parish, Ph.D., the study’s lead investigator and an assistant professor in the UNC School of Social Work.

“The bottom line is that U.S. families raising children with disabilities are reporting severe hardships at rates that are chilling, including families that are solidly middle-class,” she said. “We were shocked to find such high rates of hardship among upper-income families.”

The study, which is based on 2002 data from the National Survey of American Families, is being published in the journal *Exceptional Children*. The survey analyzed 28,141 households.

The UNC study found that overall, families across all income levels who have children with disabilities are significantly more challenged by food, housing and health issues compared to families of children without disabilities. Many also struggled to pay their phone bills.

Most surprising, Parish said, was data indicating that a significant percentage of those struggling are higher-income households. Yet based on federal poverty guidelines – which have remained unchanged since the 1960s and are used to determine eligibility for many income, food, health and disability-related programs – those same households would not be classified as “poor,” she said. They also would not qualify for assistance, despite the higher costs of raising children with disabilities, Parish noted. In 2002, the federal poverty level for a family of four was \$18,100.

According to the study, 40 percent of the surveyed families of children with disabilities who earned between two to three times the federal poverty level (between \$36,200 and \$54,300 for a family of four, for example) experienced at least one food hardship, including worrying that food would run out or skipping meals because of a lack of money. Fifteen percent of families with incomes at three or more times the federal poverty level (\$54,300 and up for a family of four) experienced housing instability, meaning they were unable to pay their rent or had to move in with others.

“These results suggest that state and federal policies that are in place to help families of children with disabilities are not going nearly far enough,” Parish said. “They are not eliminating deprivation. And these findings are particularly troubling now when the nation’s economy is struggling. Families raising children with disabilities are likely to be hardest hit during this economic downturn.”

Though the study found that children with disabilities were more likely to have health insurance and a usual source of care, they were 61 percent more likely than children without disabilities to have postponed necessary medical care and 83 percent more likely to have postponed needed dental care. The study didn’t examine the causes for those results, but Parish said they likely are related to the expenses of obtaining care – even with health insurance – and other issues, such as limited transportation.

The research results offer a compelling reason to expand eligibility standards for federal programs designed to assist families of children with disabilities, Parish said. Though more study is needed to determine how best to assist these families, UNC researchers suggest that increasing the income limits for food stamps, housing assistance and federal Supplemental Security Income (SSI), which assists low-income people with disabilities, would probably be a good start. Raising the asset limit for SSI and Medicaid, the federal insurance program for the poor and people with disabilities, so that families are not penalized for saving money in case of a hardship would also help, Parish said. “These families struggle to provide adequate care for their children with disabilities,” Parish said, “and stronger supports are vital.”

Source: University of North Carolina

Oklahoma Autism Network to Present Fall Workshops



The Oklahoma Autism Network, an organization committed to improving the outcomes and quality of life for individuals with autism and their families, will host two workshops in Tulsa this fall.

The first, *Understanding Asperger Syndrome*, will be held October 15, from 9:00 a.m.-2:30 p.m. The training will include information on diagnostic criteria, core challenges (social skills and communication), areas of strength, behavior challenges, and effective strategies for supporting children with Asperger Syndrome in school and home settings.

The second training, *Creating a Master Plan for Your Child and Family*, will be held November 5, from 9:00 a.m.-2:00 p.m. The training will help parents make the best decisions about priorities for their child and family in order to better focus time, money, and energy in ways that will be the most effective. Parents will also learn information to help them cope with the daily challenges of parenting a child with autism.

Confirmation of locations for each training will be provided upon registration. Register by contacting Kacey Denton at kacey-denton@ouhsc.edu or calling 405-271-2131, extension 47126.

Runners Can Help TARC!

The Route 66 Marathon, to be held November 16, 2008 in Tulsa, is offering a new fundraising opportunity for TARC. This year, a new event has been added to the marathon, "The Mayor's 5K Fitness Run and Walk."

Registrants in the Mayor's 5K are required to choose a Tulsa Area United Way agency to receive \$5 of their registration fee when they register for the race.

To register for the Mayor's 5K, visit www.route66marathon.com and click on the "register today" button and don't forget to choose TARC as the agency to receive part of your registration fee!



DRS Reopens Employment Services for 918 Oklahomans with Severe Disabilities

Thanks to more administrative belt-tightening by the Oklahoma Department of Rehabilitation Services (DRS), an additional 918 Oklahomans with the most significant barriers to employment began receiving critical services on Sept. 16.

DRS' vocational rehabilitation and visual services divisions must continue to defer services to another 2,148 applicants whose disabilities are less significant in terms of reaching employment goals. These individuals will remain on waiting lists, established on Jan. 19, 2007, until the agency, which is required by state law to maintain a balanced budget, has funds available to pay for their services.

"In order to help more Oklahomans go to work we have reduced staff, left critical positions unfilled and cut back or cancelled lower priority programs that, frankly, are still needed by other clients," DRS Director Linda Parker said.

"We provide specialized services that help Oklahomans with disabilities go to work and become taxpayers," Parker said. "Their success saves other state and federal agencies money previously spent on disability benefits, medical services and social assistance."

The federal Rehabilitation Act requires vocational rehabilitation and visual services programs to categorize clients in groups based on the impact of their disabilities on employment. If funds are not available to serve everyone, those applicants with the most significant disabilities continue to be served because they need help most to become employed. Others with less significant barriers to employment are the first to be placed on waiting lists due to funding limitations.

The legislation does not permit programs to cap or limit services needed by current clients in order to go to work. Instead, agencies must control costs, including inflationary increases in client goods and services, by delaying services to new applicants.

For more information about the Oklahoma Department of Rehabilitation Services, visit DRS Online at www.okdrs.gov or phone 1-800-845-8476. The number is accessible by telecommunications equipment for the deaf.

Source: DRS

President Signs ADA Amendments Act

On September 25, the President signed the Americans with Disabilities Act Amendments Act of 2008, an assertive effort to restore the original congressional intent of the 1990 Act. Former President George H. W. Bush, who signed the original ADA into law, was in attendance—the first signing ceremony he’s attended since his son became President.

The Act makes important changes to the definition of the term “disability” by rejecting the holdings in several Supreme Court decisions and portions of EEOC’s ADA regulations. The amendments signal marked departures from recent Supreme Court decisions that effectively limited the scope of protection offered by the Act. This Act changes the standards courts will use to determine whether an individual has a disability and therefore falls under the protection of the Act by precluding courts from considering “mitigating measures” an individual might use, such as medication, hearing aids, or prosthetics. The amendments also state that impairments that are “episodic or in remission [are] a disability” if they limit a major life activity when active.

It is important to note, however, that the Act changes the way that these statutory terms should be interpreted in several ways. Most significantly, the Act:

- directs EEOC to revise that portion of its regulations defining the term “substantially limits;”
- expands the definition of “major life activities” by including two non-exhaustive lists:
 - the first list includes many activities that the EEOC has recognized (e.g., walking) as well as activities that EEOC has not specifically recognized (e.g., reading, bending, and communicating);
 - the second list includes major bodily functions (e.g., “functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions);
- states that mitigating measures other than “ordinary eyeglasses or contact lenses” shall not be considered in assessing whether an individual has a disability;”
- clarifies that an impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active;

- provides that an individual subjected to an action prohibited by the ADA (e.g., failure to hire) because of an actual or perceived impairment will meet the “regarded as” definition of disability, unless the impairment is transitory and minor;
- provides that individuals covered only under the “regarded as” prong are not entitled to reasonable accommodation; and
- emphasizes that the definition of “disability” should be interpreted broadly.

The Act retains the ADA’s basic definition of “disability” as an impairment that substantially limits one or more major life activities, a record of such an impairment, or being regarded as having such an impairment. The ADA Amendments Act is effective as of January 1, 2009.

Source: www.DisabilityInfo.gov, Monday Morning in Washington, and the Kaiser Network

Visit us on the web at
www.ddadvocacy.net



Legislation Passed to Freeze Funding to Many Government Programs

Both Houses of Congress recently passed legislation that would keep most of the federal government operating under a Continuing Resolution (CR) until March 6, 2009.

Specific appropriations for the Departments of Defense, Homeland Security and Veterans Affairs and Military Construction are included in the bill. Virtually all human service programs would be frozen at FY 2008 levels.

Further, the CR does not provide additional funding for the administrative costs of the Social Security Administration (SSA). This will have a substantial impact on SSA’s ability to reduce the disability hearing backlog and provide services to the public because the agency would need \$457 million above the FY ’08 level just to keep pace with inflation in FY ’09. This bill now awaits action by the President.

Source: Monday Morning in Washington



Autism News Roundup

Researchers Study Facial Structures, Brain Abnormalities to Reveal Formula for Earlier Detection of Autism

Recently, Harvard researchers reported that children with autism have a wide range of genetic defects, making it nearly impossible to develop a simple genetic test to identify the disorder. Now, University of Missouri (MU) researchers are studying 3-D imaging to reveal correlations in the facial features and brain structures of children with autism spectrum disorder (ASD), which will enable them to develop a formula for earlier detection of the disorder. The researchers anticipate their work also will reveal genetic clues that can direct additional research. Autism is a brain disorder characterized by a complex of social, communication and behavioral difficulties.

“When you compare the faces and head shapes of children with specific types of autism to other children, it is obvious there are variations. Currently, autism diagnosis is purely behavior based and doctors use tape measurements to check for facial and brain dissimilarities. We are developing a quantitative method that will accurately measure these differences and allow for earlier, more precise detection of specific types of the disorder,” said Ye Duan, assistant computer science professor in the MU College of Engineering. “Once we have created a formula, we can pre-screen children by performing a quick, non-invasive scan of each child’s face and brain to check for abnormalities. Early detection is crucial in treating children and preparing families.”

The U.S. Department of Defense awarded Duan, in collaboration with researchers at the MU Thompson Center for Autism and Neurodevelopmental Disorders, a \$110,000 grant to create a facial imaging system that will make identical measurements of the faces of children with ASD. Additionally, the NARSAD Foundation, the world’s leading charity dedicated to

mental health research, awarded Duan the prestigious Young Investigator Award and \$60,000 to fund 3-D imaging of various segments of the brain in children with ASD. The projects also are supported by a \$100,000 contribution from other MU sources and \$30,000 in the Thompson Center Research Scholar Funds.

“Instead of looking at brain structures slice-by-slice in an MRI (magnetic resonance image), we developed

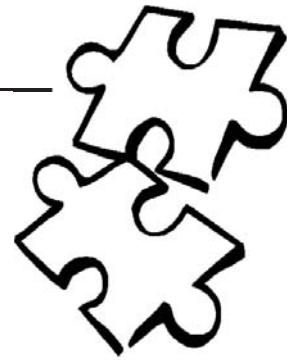
“When you compare the faces and head shapes of children with specific types of autism to other children, it is obvious there are variations. We are developing a quantitative method that will accurately measure these differences and allow for earlier, more precise detection of specific types of the disorder.”

tools to create 3-D representations of the structures in order to visualize and make comparisons,” said Kevin Karsch, a research assistant in Duan’s computer graphics lab, MU senior and Goldwater Scholar. “Using the 3-D representations, we are comparing the brain structures of autistic children to those of non-

autistic children.”

Duan’s facial and brain imaging work will focus on two ASD subgroups hypothetically identified by Judith Miles, the William and Nancy Thompson Endowed Chair in Child Health at the Thompson Center. She has observed and distinguished children with a tendency toward more physical and brain abnormalities and smaller heads as having complex autism. Only about 20 percent of affected children fit this subset. The other 80 percent are classified as having essential autism. Miles also has identified physical similarities in facial structure and increased cranium size among those in the essential group and has speculated that the traits may be related to brain abnormalities.

Source: University of Missouri





**TULSA ADVOCATES FOR THE RIGHTS OF CITIZENS
WITH DEVELOPMENTAL DISABILITIES**

16 EAST 16th STREET SUITE 405
TULSA, OKLAHOMA 74119-4447

NON-PROFIT
ORGANIZATION
U.S. POSTAGE
PAID
TULSA,
OKLAHOMA
PERMIT #909

RETURN SERVICE REQUESTED

The TARC newsletter is published monthly by the Tulsa Advocates for the Rights of Citizens With Developmental Disabilities, Inc., to inform readers about issues and legislative action that affect adults and children with developmental disabilities, their families, and professionals working in the field of developmental disabilities. The contents do not necessarily represent the official position of TARC.

HELP TARC HELP FAMILIES – BECOME A MEMBER TODAY!

Families in Transition

Families in Transition is a support group for parents of adult children with developmental disabilities.

NEXT MEETING:
Wednesday, November 12
6:30-7:45 p.m.
Goldie's Patio Grill
4401 E. 31st St. in Tulsa

RSVP to Amie Farinella, 918-582-8272

Connections Asperger's Group

Next Meeting:
Wednesday, October 22 - 4:30 p.m.
Hardesty Library, 8316 E. 93rd St.

The "Connections" Asperger's Group is a social skills group for adolescents and young adults with Asperger's Syndrome. The group meets monthly. Contact Sherilyn or Amie at 918-582-8272 for more information.

Hispanic Parents Support Group
El Grupo Hispano de Apoyo a Padres de Familia

Next Meeting: Monday, October 27
7:00 to 8:30 p.m.
Central Library,
400 Civic Center

Contact Zaida at 918-582-8272 for more information.



links to support. to information. to friends.

Support Group for Adults with Asperger's Syndrome

Next Meeting:
Wednesday,
October 15
6:30-8:00 p.m.

Brookside Library, 1207 E. 45th Pl.

Links is a support group for adults with Asperger's Syndrome. Contact Amie Farinella, 918-582-8272 for more information.

Day Makers Activities group for adults with developmental disabilities

Contact: Amie, 918-582-8272

Tuesdays • 10:00-11:30 a.m.
Gatesway Foundation-Mabee Gym
1217 E. College in Broken Arrow

Thursdays • 1:00-2:30 p.m.
McClure Recreation Center
7440 E. 7th Street in Tulsa

MOMS & DADS SUPPORT GROUP

Next Meeting:
Thursday,
October 30
7:00-9:00 p.m.

Kirk of the Hills Presbyterian Church
4102 E. 61st St., Room B-8

The mission of the Moms & Dads Support Group is to nurture and support families whose children have a developmental disability, to encourage positive strategies in dealing with challenges, and to share in the joys of raising our children.

For more information, contact Sherilyn, 918-582-8272

1ST TULSA PEOPLE FIRST

Tulsa People First
©TARC

Next Meeting:
Tuesday, October 14
Golden Corral,
8144 E. 21st St.

Dinner-5:30 p.m.
Meeting-6:30 p.m.

For more information, contact Amie at 918-582-8272

Support Group for Families of Children with Special Needs in Sapulpa

Next Meeting: Tuesday, October 21, 6:15 p.m.
CREOKS Behavioral Health, 23 E. Ross in Sapulpa

Childcare is not provided, but please take advantage of Sapulpa's great Respite Care Program

For more information, contact Mindy Littlefield, 378-5632