



TARC NEWSLETTER

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

August 2008

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A Commentary

by John F. Gajda, TARC Executive Director

I suspected it all along but now I have confirmed it. Hypocrisy lives in the halls of the State Capitol!

If you walked the halls of the Oklahoma Legislature this year trying to convince legislators to support insurance coverage for autism, you may have the impression that the majority of your Senators and Representatives are opposed to imposing mandates on health insurance providers. At least that was my impression.

Much to my surprise, when I was reviewing bills signed by Governor Brad Henry, I came across Senate Bill 1168 authored by Senators Owen Laughlin of Woodward and Jay Paul Gumm of Durant and Representatives Jeff Hickman of Dacoma, Brian Renegar of McAlester and Dan Sullivan of Tulsa.

The bill prohibits insurance plans from excluding claims that occur in conjunction with the arrest or pretrial detention of a policy holder.

Now that sounds like a health insurance mandate to me. But just to make sure I wasn't missing something I asked five people in my office. All agreed that indeed it was a mandate on insurance providers.

Doing some research, I found that the principle author of the bill, Senator Owen Laughlin, was asked on the senate floor if this bill imposed a mandate on insurance companies and he conceded that it did. He rationalized that this mandate was ok, since it only applied to a limited number of individuals in a very specific circumstance. In the final vote on the bill, all Senators and Representatives agreed with the author since the bill was approved 46 to 0 in the Senate and 95 to 0 in the House. Even Representative Ron Peterson and Speaker Chris Benge, who fought bills to mandate coverage for autism or anything else on the principle that they were opposed to mandates, voted for this bill.

If your Senator or Representative told you they would not support bills that would require insurance coverage for autism because they were opposed to insurance mandates, ask them about their vote for SB 1168 when they ask for your vote this fall.

No one should ever accuse the Oklahoma legislature of being consistent.



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)

The State of Children in Oklahoma

by John F. Gajda, TARC Executive Director

If my inbox is any indicator, many studies of social indicators are released in the middle of the calendar year. While I usually focus on those that deal with disabilities or people with disabilities several recent studies that analyzed the status of children in the U.S. caught my attention.

I was reminded by these three recently released national studies on the status of children that children with disabilities in Oklahoma are affected by the same things that impact the lives of all children in the state. In fact, children with disabilities are more vulnerable to many of the social indicators these studies considered. Each of these studies looks at the status of children from a slightly different perspective but the results for Oklahoma's children are similar and not very encouraging.

The Annie E. Casey Foundation's *2008 Kids Count Data Book* ranks states based on the sum of the state's standing on each of ten measures of the condition of children. These measures include the percentage of low-birthrate babies; infant mortality rate; child death rate; teen death rate; teen birth rate; percentage of teens who are high school dropouts; percentage of teens not attending school and not working; percentage of children living in families where no parent has full-time, year-round employment; percentage of children living in poverty; and, percentage of children in single-parent families. Based on these factors, Oklahoma ranks 43rd among the 50 states. Many of these factors such as low birth rate and teen birth rate are related to the occurrence of disabilities in children. Other factors point to the hard life of children in Oklahoma that is only magnified when the child has a disability. More information about this study can be found at www.kidscount.org



Another study, funded by the Commonwealth Fund, examined variations in the health care provided to children across states. It was titled *U.S. Variations in Child Health Systems Performance, a State Scorecard*. This analysis focused on 16 indicators of child health system performance that were grouped into five categories. The categories and associated factors were: access – uninsured children and uninsured low-income children; qual-



ity – children receiving all recommended doses of five key vaccines, children with both medical and dental preventive care visits, children with problems who receive mental health care, children with a medical home, children whose doctor followed-up after they were referred to specialty care, children who needed specialty care getting those referrals, and hospital admissions for pediatric asthma; costs – state total personal health spending, family premium for employee health insurance; the “potential to lead healthy lives” – young children at risk of developmental delays, and infant mortality; and equity – the difference between children of different income, race/ethnicity and insurance coverage who had a medical home and both medical and dental preventive care visits. All states were ranked on each indicator that made up the five dimensions of performance. The state rankings for the indicators of each of the dimensions listed above were averaged to arrive at an overall ranking of states on each dimension. The final state rankings for each dimension were then averaged to determine a final overall state ranking for each state and the District of Columbia. Oklahoma achieved a ranking of 51st under this methodology. Children with disabilities typically have greater health care needs than the average child and are more seriously impacted when the health care system does not do a good job serving children. More information and a full copy of this study can be found at www.commonwealthfund.org under the publications link.

The final study of U.S. Children was conducted by the Every Child Matters Education Fund. The report is titled *Geography Matters: Child Well-Being in the States*. The organization looked at ten indicators of child well being to arrive at an overall vulnerability index for each state. The factors considered included deaths of infants per 1,000 live births; deaths per 100,000 Children Aged 1-14; deaths per 100,000 Teens Aged 15-19; births to Teen Mothers (15-19); births to women receiving late or no prenatal care; children living in poverty; uninsured children; juvenile incarceration rate; child abuse fatalities; and per capita child welfare expenditures. Based on factors Oklahoma received an overall ranking of 47th among all 50 states. The report concludes that children

please see “Oklahoma Children” on pg. 3

“Oklahoma Children” from page 2

do much better in some states than others. Unfortunately Oklahoma is one of those states where they do not do as well. You can download a full copy of this report at www.eveychildmatters.org.

After reading these studies I can only conclude that compared to children in other states the lives of children in Oklahoma are difficult. Although these three studies use some similar and many identical factors to reach their conclusions each has added some unique dimensions to examining the status of children. After reading many points made in these reports I couldn't help but think “no wonder families who have children with disabilities have such a difficult time.” Children with disabilities are being affected by the same negative factors that are impacting the lives of all children in Oklahoma. The well-being of children with disabilities is inevitably tied to the well-being of all children in the state.

As advocates, when we are tempted to divide into groups that include only those who are identically situated, we need to remember this bigger picture. Children with disabilities in Oklahoma will only be as well off as the least fortunate children in our state.

New ADA Resources

Two new resources are available for those interested in learning more about the Americans with Disabilities Act:

- The U.S. Department of Justice, Civil Rights Division has issued an updated version of their Technical Assistance (TA) CD ROM. This CD ROM contains regulations, technical assistance documents and ADA status reports. Copies can be ordered online at <http://www.ada.gov/cd%20order%20forms/cdrequest-form.htm> or by calling the DOJ TA Line at 800-514-0301 (voice) or 800-514-0383 (TTY).

- The U.S. Census Bureau released the *Americans with Disabilities Act (ADA) Facts for Features*, which contains facts to be used for publications for the anniversary of the ADA. The categories include population distribution, specific disabilities, on the job, income and poverty, and education. These facts were drawn from the *Americans with Disabilities: 2002 Census Bureau Report*. For more information go to <http://www.census.gov/Press-Release/www/releases/archives/cb08ff-11.pdf>.

Source: Monday Morning in Washington

Alcohol Binges Early in Pregnancy Increase Risk of Infant Oral Clefts



A new study by researchers at the National Institute of Environmental Health Sciences (NIEHS), part of the National Institutes of Health, shows that pregnant women who binge drink early in their pregnancy increase the likelihood that their babies will be born with oral clefts.

The researchers found that women who consumed an average of five or more drinks per sitting were more than twice as likely as non-drinkers to have an infant with either of the two major infant oral clefts: cleft lip with or without cleft palate, or cleft palate alone. Women who drank at this level on three or more occasions during the first trimester were three times as likely to have infants born with oral clefts.

The study was conducted in Norway, which has one of the highest rates of oral clefts in Europe. The investigators contacted all families of newborn infants born with clefts between 1996 and 2002. The study included 573 mothers who had babies born with cleft lip with or without cleft palate and cleft palate only; as well as 763 mothers randomly selected from all live births in Norway. The average age of the mostly married mothers was 29 years.

The researchers found increased risks of orofacial clefts among infants whose mothers reported binge-level drinking of an average of five or more drinks per occasion during the first-trimester compared to non-drinkers. Risk was further increased among women who drank at this level most frequently.

One of the most severe outcomes of heavy maternal drinking is fetal alcohol syndrome, a lifelong condition that causes physical and mental disabilities, including craniofacial malformations. There has been little research to determine if alcohol consumption is related to oral cleft risk.

Source: NIH

Visit us on the web at
www.ddadvocacy.net



Presidential Candidates' Disability Forum Makes History



On Saturday, July 26, 2008, the 18th anniversary of the Americans with Disabilities Act, thousands of people with disabilities, their families, friends, employers, and care providers convened in Columbus, Ohio or watched via live webcast as history was made.

Republican presumptive nominee John McCain and, on behalf of Democratic presumptive nominee Barack Obama, Senator Tom Harkin (D-IL) participated a national forum on disability policy.

Senator Harkin stressed the need for economical self-sufficiency, self-determination, and passage of the ADA Amendments Act (H.R. 3195, S. 1881) and the Community Choice Act (H.R. 1621, S. 799) as vehicles to achieve these goals. He also noted that Senator Obama is the first presidential candidate to have a dedicated disability policy advisor.

Speaking last, Senator McCain articulated his support of the ADA in 1990, as well as various bills to support veterans with acquired disabilities. However, he stated his opposition to the Community Choice Act, citing its cost as a barrier. Senator McCain expressed that all Americans should live to the best of their ability and said he “supported the idea of the House-passed ADA Amendments Act.”

Source: Monday Morning in Washington

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!

TARC Newsletter

Congressional Bill Introduced to Improve Community-Based Services



Senators John Kerry (D-MA) and Charles Grassley (R-IA) recently introduced the Empowered at Home Act, (S. 3327) in the U.S. Congress.

The bill has four basic parts. First, it will improve the Medicaid home and community-based services (HCBS) state plan option by giving states more flexibility in determining eligibility and by increasing the services states can offer under the program. This is expected to create greater options for individuals in need of long-term supports. In return states could no longer cap enrollment and services would have to be offered throughout the entire state.

The other three sections would address: spousal impoverishment protections for the HCBS option; tax-related provisions to support caregivers and promote purchase of private long-term care insurance; and grants for states to invest in organizations and systems that can help to ensure a sufficient supply of workers, promote health, and ensure more consumer-centered HCBS.

Both Senators Kerry and Grassley are members of the Senate Finance Committee and Sen. Grassley is the ranking minority member of the committee which would have jurisdiction over the bill.

Source: Capitol Insider



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.

18th ADA Anniversary Celebrated by Disability Advocates



Determined to Strengthen Landmark Civil Rights Legislation

July 26, 2008 marked the 18th anniversary of the signing of the Americans with Disabilities Act (ADA). This landmark civil rights legislation prohibits discrimination against individuals with disabilities in employment, public services, public accommodations, transportation and telecommunications.

In Oklahoma, 635,170 people ages five and over have disabilities that may qualify for ADA protection, according to the U.S. Census Bureau's *American Community Survey 2006*. This figure doesn't include 31,214 individuals living in nursing homes and institutions for the chronically ill.

The report indicates that 383,676 work-age Oklahomans have some type of disability with an employment rate of 38.4% compared to 75.3% among people without disabilities.

In recent years, a series of U.S. Supreme Court decisions narrowed coverage and anti-discrimination protections under the ADA, allowing employers to say a person is "too disabled" to do the job, but not "disabled enough" to be protected by the ADA.

"The U.S. House of Representatives passed H.R. 3195, which is the Americans with Disabilities Act Amendments of 2008, also known as the ADA Restoration Act, on June 25th," said Jean Jones, legislative information representative for the Oklahoma Department of Rehabilitation Services (DRS). Oklahoma representatives voted unanimously for the bill, which was approved by a House floor vote of 402 to 17.

"The legislation would restore ADA coverage for people whose disabilities are mitigated by use of medicine, assistive devices, prosthetics and similar means and provide clarity for the definition of conditions that qualify as a disability under the ADA," Jones explained.

Disability advocates have now shifted their attention to the U.S. Senate, which is expected to modify S. 1881, the Senate's ADA Restoration bill, to match the House

version. They tried, but were unable to get Senate passage of that legislation before the ADA anniversary was celebrated today [July 26th].

Over 300 national and state organizations from a broad coalition of business, disability, civil rights, faith-related, veterans and other groups have signed a letter, which will be sent to every U.S. senator to demonstrate widespread support for the ADA Amendments Act of 2008.

"The Americans with Disabilities Act has directly benefitted Oklahomans with disabilities, employers and taxpayers by helping qualified people with disabilities go to work and participate fully in their communities," Department of Rehabilitation Services Director Linda Parker said. "Working Oklahomans with disabilities become taxpayers who no longer rely on disability benefits and social services. They have a better quality of life and more disposable income, which is great for their communities and our state as a whole."

The Department of Rehabilitation Services (DRS) provides rehabilitation, employment and educational services for Oklahomans with disabilities. The agency also helps employers recruit qualified employees with disabilities and advises on workplace accessibility, assistive technology and tax incentives for compliance with the Americans with Disabilities Act.

Source: OK DRS

Candidate Forum in Oklahoma City



Individuals with disabilities are encouraged to attend a forum to learn about legislative candidates and their positions on current disabilities issues.

The forum will be held on Saturday, August 23 from 10:00 a.m.-12:00 p.m. at the Oklahoma History Center, 2401 N. Laird Ave. in Oklahoma City.

Contact Theresa Hamrick, 405-951-3579, for additional information or accommodation requests. RSVPs are requested and forms will be available for attendees to register to vote. The event is sponsored by the Heartland Council of the Blind and the Oklahoma Rehabilitation Council.

Cheerleading Team for Children with Disabilities Seeking Members in Tulsa Area

Tulsa Cheer Academy is forming a cheerleading team for children with special needs in the Tulsa area.

The *Shining Stars* cheer team will be a competitive cheer squad for special needs athletes ages 5 and up. Competitive cheerleading builds coordination, self-confidence, and discipline. There will be trained adult coaches as well as junior coaches, who are also TCA cheerleaders, working with athletes.

Team members will practice on Fridays from 6:15-7:15 p.m. and will compete in approximately four competitions. The team is open to boys and girls, and everyone “makes” the team. Team members with varying disabilities are welcome.

Cost for participation is \$120 for uniform rental, as well as \$45.00 per month for tuition (4 week session). There will also be competition fees that will be discussed at parent meetings.

For more information, contact Michelle Adams at 918-289-1071 or specialcheer1@sbcglobal.net.



Conference Concludes Hiring People with Disabilities Is Beneficial

On June 3 and 4, hundreds of leaders from business, government, and non-profit organizations convened in Washington, D.C., to discuss how today's global marketplace has the power to open doors to employment for people with disabilities. One message resonated loud and clear—hiring people with disabilities is good for business.

Employees with disabilities have proven they have a positive impact on businesses' bottom line. They adapt to different situations and circumstances. They add to the range of viewpoints businesses need to succeed, offering fresh ideas on how to solve problems, accomplish tasks, and implement strategies.

To learn more about the disability dividend, visit: <http://www.dol.gov/odep/pubs/fact/diverse.htm>, to read *Diverse Perspectives: People with Disabilities Fulfilling Your Business Goals*.

Source: U.S. Department of Labor

State Autism Profiles

The Centers for Disease Control and Prevention (CDC) presented new findings that revealed as many as one in 50 children in the United States are now diagnosed with autism. While no known cure is yet available, autism is treatable. Many states are responding to what is now described as an epidemic by offering more services for children and adults with autism.

Easter Seals and the Autism Society of America have partnered together to prepare a state-of-the-state report of autism services in the 50 states, the District of Columbia and Puerto Rico. The profiles highlight the number of children with autism who have received the state's special education services, state insurance coverage for autism if available, Medicaid services specific for individuals with autism, educational programs provided to students with autism or training that focused on autism, special education criteria, other state-led resources, and sponsors of autism legislation.

For information on Oklahoma's autism services, visit http://www.easterseals.com/site/PageServer?pagename=ntlc8_autism_state_profiles_oklahoma.

Source: Easter Seals
August 2008

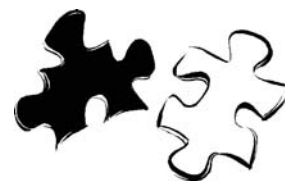
Zac Browser Eases Frustration of Internet Use for Children with Autism

After searching unsuccessfully for an appropriate web browser for his six-year-old grandson with autism, John LeSieur decided to make his own. LeSieur's grandson, Zackary, became easily frustrated with all of the options and keys of a computer and traditional web browser.

The Zac Browser for Autistic Children allows children to play games, listen to music, and do a variety of other activities without the worry of violent or adult websites and distractions such as pop-ups. The Zac Browser is free and available online for anyone to use. It can be downloaded or run directly from www.zacbrowser.com.

ABC news recently profiled the invention, and the full story is available at: <http://abcnews.go.com/Technology/WireStory?id=4988861&page=1>.

Source: www.abcnews.com



Autism News Roundup

Common Mechanisms May Underlie Autism's Seemingly Diverse Mutations

Many of the seemingly disparate mutations recently discovered in autism may share common underlying mechanisms, say researchers supported in part by the National Institute of Mental Health (NIMH), a part of the National Institutes of Health (NIH). The mutations may disrupt specific genes that are vital to the developing brain, and which are turned on and off by experience-triggered neuronal activity.

A research team led by Christopher Walsh, M.D., Ph.D., and Eric Morrow, M.D., Ph.D., of Harvard University, found two large sections missing on chromosomes in people with autism and traced them to likely inherited mutations in such genes regulated by neuronal activity. They report their findings in the July 11, 2008 issue of *Science*. The study was also supported in part by the NIH's National Center for Research Resources, National Human Genome Research Institute, Eunice Kennedy Shriver National Institute of Child and Human Development, and the National Institute on Neurological Disorders and Stroke.

The study breaks new ground for complex disorders like autism, taking advantage of a shortcut to genetic discovery by sampling families in which parents are cousins. The researchers found genes and mutations associated with autism in 88 families from the Middle East, Turkey and Pakistan in which cousins married and had children with the disorder.

"The emerging picture of the genetics of autism is quite surprising. There appear to be many separate mutations involved, with each family having a different genetic cause," explained NIMH Director Thomas R. Insel, M.D. "The one unifying observation from this new report is that all of the relevant mutations could disrupt the formation of vital neural connections during a critical period when experience is shaping the developing brain."

Earlier studies had suggested that the individually rare mutations are present in at least 10 percent of

sporadic cases of autism, which is the most common form.

The researchers used a technique that pinpoints from a relatively small group of families genes responsible for disorders that can be amplified by parenthood among relatives, which can increase transmission of recessive diseases. Evidence had hinted at such transmission in autism, and the large amount of genetic information obtainable from such families reduced the need for a much larger sample including many families with multiple affected members.

The ratio of females to males with autism - normally one female to four males - was less lopsided in such families in which parents share a common recent ancestor, suggesting a doubling of the rate of autism,

due to recessive causes on non-sex-linked chromosomes. Also, autism-linked spontaneous deletions and duplications of genetic material were relatively uncommon in these families, suggesting recessive inherited causes.

The researchers found multiple different genetic causes of autism in different individuals

with little overlap between the families in which parents shared ancestry. Yet a few large inherited autism-linked deletions, likely mutations, in a minority of families stood out. The largest turned out to be in or near genes regulated, directly or indirectly, by neuronal activity.

"Autism symptoms emerge at an age when the developing brain is refining the connections between neurons in response to a child's experience," explained Walsh. "Whether or not certain important genes turn on is thus dependent on experience-triggered neural activity. Disruption of this refinement process may be a common mechanism of autism-associated mutations."

Source: NIH

"A research team...found two large sections missing on chromosomes in people with autism and traced them to likely inherited mutations in such genes regulated by neuronal activity."



TULSA ADVOCATES FOR THE RIGHTS OF CITIZENS WITH DEVELOPMENTAL DISABILITIES

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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, August 13
6:30-7:45 p.m.
Full Cup Cafe,
4634 E. 31st St. in Tulsa

RSVP to Amie Farinella, 918-582-8272

Connections Asperger's Group

Next Meeting:
Wednesday, August 27 - 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, August 25
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, August 20
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, August 28
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

Next Meeting:
Tuesday, August 12
Tally's Good Food Cafe,
1102 S. Yale Ave.
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, August 19, 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