



# TARC NEWSLETTER

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

## May 2008

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## End of 2008 Legislative Session Nears

*by John F. Gajda, TARC Executive Director*

With less than a month left, the work of the Second Session of the 51st Oklahoma Legislature is winding down.

Normally the session continues until the last Friday in May (May 30th this year) but there has been a commitment to adjourn a week earlier this year, on May 23rd. This has put additional pressure on members of the legislature to complete the remaining business.

Bills that are still alive have now been passed by both the House and the Senate and sent to the Governor for his signature (assuming that both chambers passed identical versions) or are in a conference committee where representatives from both chambers are trying to work out differences between the content of House and Senate versions that were approved. Only four of the original list of 19 bills tracked by TARC since the beginning of the session have made it.

Despite the tenacity of families and supporters and the broad support from individual legislative members, Representative Ron Peters of Tulsa has single handedly prevented committee passage of Nick's Law (see related story on page 2) and all other bills that were attempting to impose additional insurance mandates.

The legislature has passed HB 2276 and sent it to the Governor who signed it on April 29th. This bill provides the general appropriations for operation of state government in FY '09 that begins July 1, 2008. It is described as a standstill budget that uses a combination of certified revenues, carryover funds and other available money. There is about \$19m that is potentially available for additional appropriations and in the remaining weeks of session legislators will work toward directing these remaining funds to other state priorities.

This budget is not good news for people with disabilities. The Department of Human Services, Office of Disability Concerns, and J.D. McCarty Center received no additional funding. The Department of Rehabilitation

*please see "2008 Session" 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)

## **“2008 Session,” from page 1**

Services, which had had to stop providing services to new clients this year, received a 5% cut in funding. Because of increased operating costs, particularly personnel related requirements, the need to annualize funding of services provided for only a portion of the current fiscal year, and decreased federal funds, a standstill budget means program cuts next fiscal year for most state agencies.

There are a few contentious issues that continue to pop up in amendments to outstanding bills, but with little money on the table the legislature will likely be content to pack their bags early to start their re-election campaigns and leave advocates to survey the results of the session.

## **The TARC Tracking List**

<b>Bill</b>	<b>Principal Authors</b>	<b>Status</b>	<b>Last Status Change</b>	<b>Description</b>
HB 2703	Steele, Kris (H)	Conference Requested	4/29/08	Establishes requirements for Medicaid claims on all purchased wheeled mobility.
SB 1192	Adelson, Tom (S) and Sullivan, Daniel (H)	Governor Signed	4/23/08	Modifies the process by which DHS investigates community services workers or Medicaid personal care assistants.
SB 1405	Brown, Bill (S) and Wright, John (H)	Governor Signed	4/28/08	Decreases the number of appointed members of the Advantage Waiver and Developmental Disability Services Rate Review Committee.
SB 2071	Jolley, Clark (S) and Miller, Kenneth (H)	Conference Requested	4/29/08	Establishes a comprehensive autism training program at the University of Central Oklahoma.

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## **Outlook for “Nick’s Law” Bleak**

House Speaker Chris Bengé announced on May 1, 2008 that he does not plan to schedule a vote on legislation that would require health insurers to cover autistic children, despite pleas from parents that the bill be heard. The measure has been approved by the Senate.

Responding to the speaker’s comments, Senator Jay Paul Gumm, the principle advocate for the measure, said “It is regrettable the Speaker has closed his door on ‘Nick’s Law’ for this legislative session - without so much as a hearing in what is supposed to be ‘The People’s House.’ For the fourth time this year, House Republican leadership has turned its back on Oklahoma’s children with autism and their families.”

“The Speaker’s denial of even a vote on this critical issue begs the question: ‘What are they afraid of?’ The answer simply is this: they know Nick’s Law will pass on a straight ‘up or down’ vote in the House of Representatives.”

“Many of us are committed to continuing this fight for thousands of Oklahoma children and their families. They deserve a vote on the floor of the House of Representatives. One man cannot, nor should not, silence the voices of these families, these children and their duly elected representatives.

“This is just another round of what we knew would be a long and difficult fight. These children are worth fighting for. Many of us will continue fighting for them - no matter the odds - even if House Republican leaders are content with turning their back on Oklahoma’s autistic children and their families.”

## Arc of the United States Announces New Executive Director



Peter Berns has been named Executive Director of The Arc of the United States. Having recently served as Executive Director of the Maryland Association of Nonprofit Organizations and Chief Executive Officer of the Standards for Excellence Institute, Peter brings the highest level of leadership and excellence in organizational development to this position. Berns replaces Sue Swenson, who resigned at the end of 2007.

After an extensive national search, The Arc is excited to have selected Berns to lead the organization into a new era of growth and development. He brings over 20 years of nonprofit management experience, governmental relations, advocacy and academia to this assignment. As a public policy advocate, he was instrumental in reforming state and federal Medicaid regulations improving life for persons with disabilities and their families.

Berns is scheduled to begin his new post the week of May 12th.

Source: The Arc of the U.S.

## New Web Community Brings Together Parents of Visually Impaired Children



When parents learn their child has a visual impairment, it can be overwhelming. Parents wonder, "Will my child fall behind at school?" or "Will my child make friends?" or "Will my child have a successful career?" With only 93,600 visually impaired school-aged children in the U.S., over half of whom have additional disabilities, it's easy for families facing vision loss to feel alone.

To help these families connect with each other and give busy parents, grandparents and other caretakers a place to find comprehensive resources and support 24 hours a day, the American Foundation for the Blind (AFB) and the National Association for Parents of Children with Visual Impairments (NAPVI) today launched FamilyConnect™, an online, multimedia

community for parents and guardians of children with visual impairments.

Located at [www.familyconnect.org](http://www.familyconnect.org), FamilyConnect gives parents access to message boards where they can talk to other parents, compelling videos featuring real-life families, parenting articles, a mom-authored blog, a glossary of more than 30 eye conditions, and links to local resources. The site also features sections dedicated to multiple disabilities, technology, education, and every age group from infants to teens.

A recent NAPVI/AFB survey of parents of children with visual impairments showed that parents/guardians turn most commonly to physicians (82%), educators (76%), and web sites (65%) for information and support regarding their children's vision problems. This is consistent with national statistics from the 2006 Pew Internet & American Life Project that show 80 percent of American adult Internet users have searched for health information online. For parents living in rural areas with fewer resources, the web is particularly important to finding relevant, trustworthy information and the right services.

In addition to joining a community of parents, visitors to [www.familyconnect.org](http://www.familyconnect.org) can create a personal profile and receive information on news and events based on their child's age, eye condition, and location. Families can also find articles written by parents and professionals on topics such as:

- Finding the Right Eye Care Professionals for Your Child
- Developmental Milestones: What Do They Mean?
- Your Child's Individualized Educational Program
- Friendship in the Teen Years
- College Life Begins

In designing this web site, AFB and NAPVI partnered with leading national organizations and hundreds of local agencies that serve children who are visually impaired to keep FamilyConnect content complete and up to date. AFB and NAPVI also solicited input from families across the country.

The goal of [www.familyconnect.org](http://www.familyconnect.org) is to provide connections and support. By providing accurate information and creating a forum for meaningful discussion, families and their visually impaired children will feel empowered to reach their full potential.

Source: AFB

## New Genetic Syndrome Linked to Missing DNA

People who lack a certain large segment of DNA have a previously unrecognized syndrome characterized by mental retardation, seizures, and slight physical abnormalities, according to a genetic analysis conducted by Howard Hughes Medical Institute (HHMI) investigator Evan E. Eichler at the University of Washington School of Medicine and a team of international collaborators.

The deleted DNA segment is responsible for just a small percentage of cases of mental retardation, but “when you think about how common mental retardation is,” Eichler says, “this deletion has a significant impact on human health.”

The new discovery adds to a rapidly growing list of mental and physical disabilities caused by the loss or duplication of sizable pieces of DNA. While each individual “structural variant” is rare, together they constitute a major health issue. “When you look at these things collectively,” Eichler says, “they contribute to a heavy burden of disease.”

Eichler’s team discovered the missing DNA segment after screening more than 700 British and Italian patients with mental retardation or seizure disorders. Two unrelated individuals had identical deletions of about a million and a half DNA “letters” on one of the two copies of chromosome 15.

A subsequent analysis of more than 2,000 people with mental retardation turned up nine people with missing DNA on the same part of chromosome 15. All nine had mild to moderate retardation and common physical characteristics, including full, upturned lips and abnormalities in their fingers and hands. Seven of the nine also had epilepsy or abnormal brain activity. Genetic tests of more than 2,000 people without mental retardation turned up none with the deletion.

The newly discovered syndrome accounts for approximately 3 of every 1,000 cases of mental retardation. That may not seem like much, but Eichler estimates that similar deletions and rearrangements of DNA may account for 15 to 20 percent of mental retardation.

Source: HHMI

## What You Should Know Before Applying for Social Security Disability Benefits



Answers to frequently asked questions about the application process for disability benefits, including how Social Security decides if an individual is disabled.

This information has recently been updated, and can be accessed by visiting: <http://www.disabilityinfo.gov/digov-public/public/DisplayPage.do?parentFolderId=170>.

## New High School/High Tech Guide

A new High School/High Tech (HS/HT) Program Guide, produced by ODEP and the National Collaborative on Workforce and Disability, reflects effective practices nationwide.

The guide includes information on lessons learned as HS/HT has evolved from a locally-administered to a state-administered national program model based on *Guidepost to Success*. To view the guide, visit <http://www.dol.gov/odep/pubs/publicat.htm#pubs>.

## Tips for Human Resource Professionals Employing People with Disabilities

A new resource including articles, checklists, a glossary, and links to useful disability resources to help human resource (HR) professionals better understand the Americans with Disabilities Act (ADA) is now available. Also included is information on job accommodations and the employment process as it relates to people with disabilities.

This information has recently been updated, and can be accessed by visiting: <http://www.disabilityinfo.gov/digov-public/public/DisplayPage.do?parentFolderId=13>.

Source: All information above from Monday Morning in Washington

## New Disaster Course for People with Disabilities

The Public Health Foundation is offering a free Internet course for health professionals who may work with people with disabilities in times of disaster. The course has twelve objectives focusing on the needs of, and communicating with, individuals with disabilities.

The course also has a component requiring creative problem solving in responding to possible scenarios a person may face when assisting people with disabilities during an emergency.

The course, Public Health Foundation, Ready Willing and Able Online Training (#1010882), is available at: <https://www.train.org/DesktopModules/eLearning/CourseDetails/CourseDetailsForm.aspx?tabid=62&CourseID=1010882>

Source: The Public Health Foundation



## GovBenefits.gov: Your Benefits Connection

GovBenefits.gov is a partnership of Federal agencies with a shared vision - to provide improved, personalized access to government assistance programs. The partnership aims to:



1. Use the Internet to connect citizens to government benefit program eligibility information
2. Increase access to information, particularly for people with disabilities
3. Reduce expense and difficulty of doing business with the government
4. Continue to add programs to become the single source for Federal, state, and local government benefit programs

GovBenefits.gov can help visitors determine if there are government benefits available to them. The online screening tool is free, easy-to-use, and completely confidential. Names, phone numbers, Social Security numbers, or any other information that could be used to identify you are not required to use the tool. Visitors to the site answer a series of questions about themselves, and then GovBenefits.gov returns a list of government benefit programs the individual may be eligible to receive along with information about how to apply.

Whether it's a direct payment, loan, insurance, training, or other services - there may be government benefit programs available to help you. To get started, go to the homepage, choose either Locate Federal or State Benefits, Browse by Category, or Get Results by Questionnaire.

Source: GovBenefits.gov

## Autism Summer Symposium

The Autism Summer Symposium is an intensive 7-day training designed to provide:

- An opportunity for teachers and other service providers to gain first hand knowledge about autism from kids and families.
- An opportunity for teachers and other service provider to work hands-on with kids with autism ages 2-10.
- An opportunity for families and providers to learn and work together in partnership.

The Symposium is a collaborative effort of the Oklahoma State Department of Education, Special Education Services; Center for Learning and Leadership; Child Study Center, School Support Services, Project PEAK and Early Foundations: Autism Model and Outreach Project Youth and Family Services, Inc.; Oklahoma Developmental Disabilities Council; and the Oklahoma Autism Network.

The symposium will be held June 5-6 and June 9-13 in Oklahoma City. Parents and their children interested in registration information should contact Dianne Mathis, 405-271-6824 x45143 or email [dianne-mathis@ouhsc.edu](mailto:dianne-mathis@ouhsc.edu).



Source: Sooner Success

A black and white photograph of a young child with light-colored hair, smiling broadly. The child is wearing a light-colored shirt. The photo is partially obscured by the TARC logo.	<p><i>Help TARC by becoming a member today.</i></p>
<p><b>TARC</b> <i>helps families</i></p>	<p>Call 1-800-688-TARC or visit <a href="http://www.ddadvocacy.net">www.ddadvocacy.net</a> to become a member of TARC.</p>

## HUD and Justice Department Release New Guidance on the Fair Housing Act



New guidance recently released by the Departments of Housing and Urban Development (HUD) and Justice (DOJ) reinforced the right of persons with disabilities to make “reasonable modifications” to their dwellings if a structural change to their dwelling or to a common area of the building or complex in which they live is needed so that they can fully enjoy the premises.

The guidance is designed to help housing providers and homeowners’ associations better understand their obligations and help persons with disabilities better understand their rights regarding the “reasonable modifications” provision of the federal Fair Housing Act (FHA). The guidelines are available online at both <http://www.usdoj.gov/crt/housing/fairhousing/> and <http://www.hud.gov/offices/fheo/disabilities/>.

Source: Monday Morning in Washington

## Minnesota DD Council Announces Policy Advocacy Center

The Minnesota Council on Developmental Disabilities has added a Public Policy Action Center to their web site.

The resource is designed for people with disabilities, family members, concerned citizens, and others seeking disability policy information from numerous sources. The site will provide immediate access to the latest on Federal legislation, information on how to contact your elected officials, Federal departments, and a host of other Federal resources. In addition, the Action Center provides links which enable visitors to track state and local issues, contact their elected officials, and information on the history of disability policy.

Content has been carefully assembled so that users can click in and be able to find information that is the most up-to-date available. Access the site at [www.partnersinpolicymaking.com/ppac1.html](http://www.partnersinpolicymaking.com/ppac1.html).

Source: Minnesota Council on Developmental Disabilities

## Report on Child Maltreatment

*Child Maltreatment* is an annual publication that provides national and state findings on referrals for child maltreatment, substantiated cases, and types of abuse and neglect. The report includes information on perpetrators of maltreatment, child protective services (CPS) workload, and preventive and post investigation services.



Children who were reported with any of the following risk factors were considered as having a disability: mental retardation, emotional disturbance, visual or hearing impairment, learning disability, physical disability, behavioral problems, or another medical problem. In general, children with such risk factors are undercounted, as not every child receives a clinical diagnostic assessment from CPS agency staff. Nearly 8 percent (7.7%) of victims had a reported disability. In addition, children with disabilities were 52% more likely to experience recurrence of maltreatment than their peers without disabilities. Child Maltreatment 2006 is now available online at [www.acf.hhs.gov/programs/cb/pubs/cm06/index.htm](http://www.acf.hhs.gov/programs/cb/pubs/cm06/index.htm)

Source: [www.acf.hhs.gov](http://www.acf.hhs.gov)

## Web Site for Education Publications Redesigned



The ED Pubs (Education Publications) web site has undergone an extensive redesign. New features include: *News*, *Featured Items*, *Hot Topics*, *Find Publications*, a student page, a parents page, and pages for teachers and Administrators, as well as a link to Spanish language materials. Visit the site at: <http://edpubs.ed.gov/>

Source: U.S. Department of Education

Visit us on the web at [www.ddadvocacy.net](http://www.ddadvocacy.net)



# Autism News Roundup

## First National Autism Registry Shows Notable Impact on Autism Research in Opening Year

The Kennedy Krieger Institute commemorated World Autism Awareness Day and National Autism Awareness Month with the one-year anniversary of the Interactive Autism Network (IAN), the first national autism registry.

Launched in April 2007 by the Kennedy Krieger Institute, the IAN Project facilitates the exploration of causes, treatments, and the search for a possible cure to autism. As an online network that links parents to researchers, the IAN Project is accelerating the pace of autism research in two important ways. First, parents – the people who know the most about their child – provide valuable data to researchers without having to leave their home or office. Second, children with autism are matched with local and national research studies for which they qualify.

To date, more than 22,000 individuals have joined the IAN Project, making it the largest collection of autism data in the world. Represented in the registry are families from all 50 states, as well as the District of Columbia, American Samoa, Northern Mariana Islands, Guam, Marshall Islands and Palau.

“By facilitating opportunities for parents of children with autism and researchers to connect, the IAN Project has taken a lead role in fostering dialogue and mutual understanding amongst the many stakeholders in the autism community,” said Dr. Paul Law, Director of the Interactive Autism Network at Kennedy Krieger Institute in Baltimore, Maryland. “It has ultimately created an invaluable opportunity to change the face of research as we know it.”

From data collected thus far, the IAN Project has revealed significant insights, including:

- **Maternal Depression:** Of those enrolled in the IAN Project, 46 percent of mothers with children with autism reported a diagnosis of depression, versus the general population where approximately 20 percent

of women are faced with clinical depression in their lifetime.

- **Autism Treatments:** Most children with autism are on 5 or more different treatments at any given time, 67 percent of which are not covered by insurance. Parents have reported they spend an average of \$500/month on treatments.

These insights emphasize the tremendous financial and emotional support that must be provided to

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families of children with autism, and opens the door for researchers to further investigate treatments that are viable for scientific study, as well as pursue new lines of study, as in the case of parental depression.

According to Dr. Law, the IAN Project is well

positioned to facilitate many of these studies going forward. To date, more than 60 researchers from respected institutions across the country have applied to utilize IAN data, including: National Institute of Mental Health, Harvard Medical School, Yale Medical School and Mt. Sinai School of Medicine.

“We are just now beginning to scratch the surface of the complex issues associated with autism. Although we have made some strides, much more work remains to be done. By informing and educating even more families and researchers across the country about the IAN Project, we can continue to organize and mobilize the autism community’s research efforts,” said Dr. Gary Goldstein, President and CEO of Kennedy Krieger Institute.

The IAN Project is run by the Kennedy Krieger Institute and funded by Autism Speaks. Parents and researchers may participate in IAN and learn more about the initiative by visiting [www.IANProject.org](http://www.IANProject.org).

Source: Kennedy Krieger Institute



# TULSA ADVOCATES FOR THE RIGHTS OF CITIZENS WITH DEVELOPMENTAL DISABILITIES

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

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## 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, children, their families, and the dedicated people who work with this challenging population. The contents do not necessarily represent the official position of TARC.

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**Want your name removed from our mailing list?**

Call 918-582-8272 or 1-800-688-8272 or email [tarc@ddadvocacy.net](mailto:tarc@ddadvocacy.net) with your name and address!

## 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, May 14  
6:00-7:30 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, May 28 - 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

**jUNTOS!**  
Support Group for Hispanic Families

Next Meeting: Monday, May 26  
7:00 to 8:30 p.m.  
Martin Regional Library,  
2601 S. Garnett

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

**links**  
in support, in information, in friends.  
Support Group for Adults with Asperger's Syndrome

Next Meeting:  
Wednesday, May 21  
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, May 29  
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

**1<sup>ST</sup> TULSA PEOPLE FIRST**  
Tulsa People First  
TARC

Next Meeting:  
Tuesday, May 13  
Western Sizzlin'  
6510 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, May 20, 6:15 p.m.  
Creek County Literacy Center, 15 N. Poplar

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

For more information, contact Mindy Littlefield, 378-5632