



TARC NEWSLETTER

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

May 2009

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It's Almost Over

By TARC Executive Director John F. Gajda.

The 2009 Session of the Oklahoma Legislature is quickly coming to a close. Out of the original list of bills selected for monitoring because they affect people with developmental disabilities there is actually only one under active consideration. As you can see five bills were signed by the governor in April. The Senate version of another bill, HB 2027, which creates a licensing process for behavioral analysts was passed and signed by the Governor after this report was prepared. The Senate version was SB 135. That leaves only SB 321, that impacts licensing of long-term care administrators in ICR/MR facilities, under active consideration. All other bills originally tracked have been voted down or failed to advance and became dormant.

Gov. Henry signed SB 135 on May 4th. When signing the bill Henry said, "I commend authors of Senate Bill 135 for working to increase services for children with autism, but this is just one very small step in the effort to help affected Oklahoma families."

"There is nothing wrong with this bill, just like there is nothing wrong with a pack of shingles at a construction site. If you try to put the shingles on before you pour the foundation, you are doomed to failure." -Senator Gumm

"Many people have rightfully questioned whether this legislation will actually produce significant new services if insurance doesn't cover the cost of treatment and parents can't afford to pay the bill. To provide comprehensive assistance to the families of children with autism, we must also approve legislation extending insurance coverage to treatment of this developmental disability."

Advocates who have been working for insurance coverage for the treatment of autism for two years now couldn't agree more and are disappointed that their efforts meet resistance from legislative leadership at every turn.

The author of SB 135, Senator Ron Justice, was optimistic about the bill and said that the measure will increase the number of trained specialists to treat autism spectrum disorders while allowing the open market to adjust coverage based on the demand of services. "We found after a recent state pilot program that our state's shortage of trained providers has made it difficult for these families to get autism services, even when they have financial assistance," said Justice. "This bill will help address that problem and give families dealing with this disorder more options for treatment."

SB 135 provides for the enactment of a licensing process for national Board

Please see "Adjournment" 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)

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Certified Behavioral Analysts as well as the enhancement of existing state programs to train doctors in autism diagnosis and treatment.

“Every step we can take towards early detection and treatment of autism spectrum disorders will greatly benefit those with autism and their families,” said Justice. “This is the first step in that effort. In the long run, early intervention and proper treatment will reduce the costs associated with autism, and will help Oklahoma’s youth with this disorder be able to reach their full God-given potential.”



Under the bill, the University Hospitals Authority (UHA) will also establish a program modeled after Early Foundations, an outreach program that provides early intensive behavioral intervention for children with autism. The UHA will establish the program in a county where an Early Foundations program does not currently exist.

The new law will go into effect November 1, 2009.

Senator Jay Paul Gumm, who has been the legislative champion for insurance coverage was less optimistic. He commented that “Sadly, this bill will do nothing to relieve the pressure on families struggling to care for children with autism. The measure was designed to relieve political pressure on legislators who refuse to even consider ‘Nick’s Law,’ which would require health insurance to cover diagnosis and treatment of autism.

“There is nothing wrong with this bill, just like there is nothing wrong with a pack of shingles at a construction site. If you try to put the shingles on before you pour the foundation, you are doomed to failure. As Governor Henry wisely noted when he signed the bill, the foundation is insurance coverage of autism. Absent that, Senate Bill 135 is doomed to failure.”

“The therapists that will be trained under this bill will be unable to make a living in Oklahoma because families will still be unable to afford the applied behavioral analysis therapies they offer – just as they are today. The reason is that there is nothing in Senate Bill 135 that would even remotely help families bear the cost of this critical treatment.”

“More than one child per day in Oklahoma is being diagnosed with autism. That means more than one child per day is being lost because they are ‘aging out,’ getting too old for the therapies to reach. Again, this bill does nothing to help those children today.”

“For anyone to suggest that ‘relief is on the way,’ is simply not consistent with the bill. Statements like that are irresponsible and provide only the falsest of hopes to families who are begging lawmakers for real help. Families deserve better than the sham being perpetrated on them by legislators who have neither the courage nor willingness to support ‘Nick’s Law.’”

Specific bills of interest may have come, some dying and others being passed, but the one remaining critical action by the legislature is the budget for State Fiscal Year 2010 that begins on July 1st. Appropriation bills are still being worked on. To some extent this work is being delayed while lawmakers study the impact and possible uses of Federal stimulus funds. The one remaining deadline is May 11 for all Conference Committee Reports. The ultimate deadline of course is May 22 when the Legislature must adjourn.

One major budget of interest to people with developmental disabilities and their families is the funding for the Oklahoma Department of Human Services. In his comments at the April 28th Human Services Commission meeting, Director Howard Hendricks painted a gloomy picture for DHS in the upcoming fiscal year. He projected a SFY 2010 minimum need of \$665,781,072 for the agency that is being driven mostly by the ADvantage Waiver and Senior Services which save long-term budget costs for nursing home care by the Oklahoma Health Care Authority. Costs are also being driven some by heavier safety net utilization such as food stamps. He projected a smaller appropriation to DHS for SFY 2010 than for SFY 2009. He was not optimistic about the use of federal stimulus money to save the day because stimulus funds are tied to specific program expectations. He said that the only presently understood source of stimulus funds to help with shortfall is the increase in Federal match for the Medicaid program. He pointed out that even with this increased match from stimulus funds the gap needed to fund DHS for SFY 2010 will be short by at least \$47 million based on current projections. He did suggest that with the increased Federal match on Medicaid, finding state funds to move people off the DDS waiting list would go further and would create jobs while meeting unmet service needs.

As the final details are worked out on appropriations we need to remember that “the devil is in the details” and the Oklahoma Legislature sometimes takes an indirect approach to micromanaging programs when they approve funding and those of us who care about services need to be prepared to react quickly in this last month of the session. We can’t let our guard down until adjournment.

Bill	Principal Authors	Status/Date Updated Last	Description
HB 1019	Wright, John A. (H)	Governor Action-Signed 4/13/09	Recreates the Group Homes for Persons with Developmental or Physical Disabilities Advisory Board.
HB 1761	Enns, John (H)	Governor Action-Signed 4/22/09	Allows for hunting with a traditional longbow with a mechanical bow draw device to hold the bow mechanically at full or partial draw for people with permanent disabilities.
HB 1763	Enns, John (H)	Governor Action-Signed 4/22/09	Requires the Department of Education to provide training to special education due process hearing officers to ensure that they are knowledgeable in special education law and legal procedure.
HB 1893	Peterson, Pam (H)	Governor Action-Signed 4/20/09	Authorizes the Department of Human Services' Aging Services Division to work corroboratively with other national, state and local agencies and community groups to establish a single-point-of-entry concept for aging and disability groups in Oklahoma, referred to as an Aging and Disability Resource Consortium Initiative.
HB 2027	Steele, Kris (H)	Senate Amendments-Read 4/15/09	Requires persons wishing to practice as a licensed behavior analyst or a licensed assistant behavior analyst to apply to the Developmental Disabilities Services Division within the Department of Human Services. The Measure also directs the University Hospitals Authority to use funds for primary care provider evaluation training for providers in the Sooner SUCCESS program to acquire skills necessary to evaluate children with autism spectrum disorders. It directs the Developmental Disabilities Services Division to establish an applied behavioral analysis research pilot project. The measure also directs the Oklahoma State Regents for Higher Education to establish a program modeled after Early Foundations, an outreach program that provides early intensive behavioral intervention for children with autism.
SB 0479	Lamb, Todd (S)	Conferees Named-Senate to GCCA 4/30/09	Modifies definition of "long-term care administrator" under the Nursing Home Care Act to exclude bed requirements as they relate to intermediate care facilities for the mentally retarded. It exempts administrators providing health or habilitation services for mentally retarded or developmentally disabled persons from meeting current license requirements.
SB 0871	Russell, Steve (S)	Governor Action-Signed 4/13/09	Modifies membership of the Electronic and Information Technology Accessibility Advisory Council.

Bills that have Become Dead or Dormant within the Last Month

HB 1512	Blackwell, Gus (H)	General Order-Senate 3/31/09	Exempts certain schools meeting certain standards from liability for not providing necessary services to autistic children.
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HB 1627	Pittman, Anastasia (H)	Second Reading- Referred to Senate Committee 3/17/09	Modifies language and reporting order for the Protective Services for Vulnerable Adults Act.
HB 1778	Jones, Tad (H)	Senate Introduction and First Reading 3/02/09	It re-appropriates and redesignates \$2,204,037 from education Leadership Oklahoma to Academic Achievement Awards and \$1,354,329 from staff development to direct services of the Sooner-Start Early Intervention Program.
HB 1887	Richardson, Phil (H)	Second Reading- Referred to Senate Committee 3/17/09	Removes language prohibiting individuals who have been convicted or who entered a plea other than not guilty to a felony from being eligible for community sentencing. It modifies language related to a level of service inventory, allowing an offender with a moderate or high range on the inventory to be eligible for community punishments if the district attorney has consented to eligibility for an offender who has a mental illness or developmental disability or a co-occurring mental illness or substance abuse disorder.
HB 2004	Wright, Harold (H)	Second Reading- Referred to Senate Committee 3/18/09	The bill requires school administrators, teachers, and other school employees to be trained to recognize, accommodate, and assist students with mental health issues.
HB 2126	Shelton, Mike (H)	General Order-Senate 3/31/09	States that either a parent or teacher of a child or school district may initiate a request for an initial evaluation to determine if the child has a disability.
SB 0321	Anderson, Patrick (S)	Second Reading- Referred to House Committee 3/11/09	Authorizes the Aging Service Division of the Department of Human Services to collaborate with other national, state and local agencies to establish a single point-of-entry concept for aging and disability groups in the state, which is to be referred to as the Aging and Disability Resource Consortium Initiative.
SB 0971	Sparks, John (S)	House Committee- Laid Over 4/01/09	Allowing related services personnel, as identified in policies for special education by the Department of Education, to be provided with the opportunity to participate in training applicable to their field that will enable them to maintain professional licensure.

Numbers You Need: Key Oklahoma Economic and Budget Trends- 2009

This would be a good time for a reminder: Don't shoot the messenger! April's edition of Numbers You Need provides further evidence of the worsening economic situation in Oklahoma and the nation. The state's seasonally-adjusted unemployment rate hit 5.5 percent in February, which is up from 5.0 percent in January but still well below the national rate of 8.1 percent. Personal income for the final quarter of 2008 rose by a meager 0.1 percent in Oklahoma and fell by 0.2 percent nationally. Meanwhile, state revenue collections in March fell steeply for the third straight month, coming in 19.1 percent below last year's amount and 17.2 percent below the certified estimate. The silver lining may be that inflation in the South region rose by 0.5 percent in February due in large part to rising energy prices, taming fears of deflation and providing some hope that the oil and gas sector may be rebounding. Access the full two-page fact sheet at www.okpolicy.org.

Source: OK Policy Institute

Three Weeks to Adjournment: Budget and Tax Policy Updates

With just three weeks to go before the Oklahoma legislature's scheduled adjournment, major decisions remain on the state budget for the upcoming year. OK Policy wants to call your attention to some new and recent analyses that looks at where things stand with the budget process and some key unresolved policy choices.

- Although a formal agreement on the FY '10 budget has yet to be announced, news of the main outlines of a deal between House and Senate leaders is circulating around the Capitol. This new entry on the OK Policy blog, "Bringing the Pain", looks at what the agreement may look like, what it may mean for state services, and why the budget outlook beyond next year looks even more worrisome;

- A tax provision in the American Recovery and Reinvestment Act of 2009 (ARRA, or federal stimulus package) could make the state's budget gap \$46 million larger through a provision known as bonus depreciation. A new OK Policy fact sheet explains bonus depreciation and makes the case for how and why Oklahoma should avert worsening our budget situation and having to implement deeper budget cuts by simply "decoupling" from the federal bonus depreciation provision;

- Under provisions of the stimulus bill, Oklahoma could be eligible for \$75.9 million in federal funds that could avert or minimize tax increases on business and benefits cuts to laid off workers, provided that the state enacts modest and worthwhile changes to its Unemployment Insurance (UI) program. A recent brief looks at the UI reforms contained as part of the stimulus bill, what Oklahoma must do to become eligible for the additional federal funds, and why enacting these reforms is in the state's interest; and

- Over the past five years, producers have claimed \$339 million in exemptions, or rebates, from the gross production tax. Most gross production tax exemptions are set to expire on June 30, 2009. The Legislature is considering bills that would extend the exemptions through 2012. OK Policy has released a fact sheet that examines the gross production tax and exemptions, along with a press release stating that as the state begins to wrestle with enormous and prolonged budget shortfalls, this seems to be the right time for policy makers to consider whether there should be some appropriate

caps placed on the amount of tax rebates that can be claimed. (The Oklahoman disagreed, but praised our "masterful analysis" of the issue.)

For more information and to connect to the OK Policy-blog go to www.okpolicy.org

Source: OK Policy Institute

New Fact Sheet Examines Gross Production Taxes and Exemptions

Oklahoma Policy Institute released a new fact sheet on April 28th on Oklahoma's gross production tax that takes a specific look at the tax exemptions that are offered for different forms of oil and gas production. Over the past five years, producers have claimed \$339 million in exemptions, or rebates, from the gross production tax, with almost three-quarters of the rebates claimed for deep well drilling and horizontally drilled wells. Most gross production tax exemptions are set to expire on June 30, 2009; the Legislature is considering bills (HB 2026 and SB 313) that would extend the exemptions through 2012.

"As the state begins to wrestle with what looks to be enormous and prolonged budget shortfalls, this seems to be the right time for policy makers to carefully review the tax breaks being offered to oil and gas producers and to consider whether there should be some appropriate caps placed on the amount of tax rebates that can be claimed," said David Blatt, OK Policy's Director of Policy.

The state currently caps the rebates that can be claimed for deep wells drilled below 15,000 feet at \$25 million per year. Most other exemptions are uncapped but can be claimed only when the average annual index price of natural gas is below \$5.00 per MCF or the price of oil is below \$50 per barrel. Exemptions for horizontally drilled wells are subject to neither a cap nor a price trigger; the state paid out over \$35 million in rebates for horizontal drilling in FY '08.

"Applying the cap that is currently in place for deep well drilling to other exempted production, or creating an overall cap on gross production tax rebates would create greater budget certainty over the coming years," said Blatt. "We know that schools, social services, public safety and other vital areas of the state budget are looking at deep cuts. In this environment, limiting the tax



"Tax" Continued on pg. 6

breaks offered to producers seems a reasonable way to minimize the impact of cuts to core services and ensure that sacrifices are shared.”

A recent study by Oklahoma City University business professor Steve Agee found that state tax incentives ranked last among ten variables cited by Oklahoma oil industry executives as affecting their decision to drill.

According to OK Policy’s fact sheet, Oklahoma accounts for 8.8 percent of total U.S. natural gas production and 3.2 percent of crude oil production, ranking 3rd and 5th among the 50 states respectively. The state collected \$1.168 billion from gross production taxes in FY ‘08, of which \$808.2 million, or 69.2 percent, was from the gross production tax on natural gas, and \$360.2 million, or 30.8 percent was from the gross production tax on oil. Gross production taxes represented 14 percent of total states taxes in FY ‘08, ranking behind only the personal income tax and the sales tax as a top source of state tax revenues.

Source: OK Policy Institute



New Fetal Alcohol Syndrome Reports Available

The Centers for Disease Control and Prevention recently completed new publications available on their web site at www.cdc.gov/fasd under the “What’s New” heading (hardcopies are available to order online as well). The three publications include:

- FASD Competency-Based Curriculum Development Guide for Medical and Allied Health Education and Practice
- Reducing Alcohol-Exposed Pregnancies: A Report of the National Task Force on FAS and Fetal Alcohol Effect
- A Call to Action: Advancing Essential Services and Research on FASDs -- A Report of the National Task Force on FAS and Fetal Alcohol Effect

Source: Monday Morning Memo

Advocates and Family Members are Urged to Communicate with Congress about Health Care Reform

Fixing the health care system is one of the top priorities of the Obama Administration. The White House has actively been working to learn about what Americans most want to see in health care reform.

At a recent White House meeting, leaders from national disability organizations, including The Arc and UCP, had

an opportunity to explain what people with disabilities most need in their health care system. Two of the most important needs discussed were:

- The choice of receiving long term services and supports in their own communities rather than in institutions
- Not having to impoverish themselves in order to qualify for long term services and supports.

Though Administration officials expressed a strong commitment to people with disabilities at the meeting, the community cannot take for granted that long term services and supports will be addressed as part of health care reform.

Congress is in the process of putting together a health care reform bill. To ensure issues such as long term services and supports be addressed as part of the health care reform, advocates and family members must continue to communicate with Members of Congress. For information on the two critical long term services and supports bills that we want included in health care reform legislation, see: www.passthcommunitychoiceact.org or www.passtheclassact.org.

Source: Monday Morning Memo



Let Your Voice be Heard at May’s Public Hearings

This is an opportunity for consumers to provide feedback through public hearings on the proposed amendments and updates to the Department of Rehabilitation Services State Plan for Vocational Rehabilitation Services (Title 1) and Supported Employment Service (Title VI).

Monday, May 18, 2009

Great Plains Technology Center
Building 600 • Room 656
4500 West Lee Blvd. • Lawton, Oklahoma
1:00 P.M. to 3:00 P.M.

Tuesday, May 19, 2009

Department of Rehabilitation Services
2nd Floor Conference Room
3535 NW 58th Street • Oklahoma City, OK
4:00 P.M. to 6:00 P.M.

Wednesday, May 20, 2009

TSHA • Conference Room
8740 East 11th Street • Tulsa, Oklahoma
1:00 P.M. to 3:00 P.M.

Copies of the document will be available May 11th by calling the Oklahoma Rehabilitation Council at (405) 951-3579 or toll free at (800) 569-7974 or email thamrick@drs.state.ok.us. Copies will be available on the DRS website at <http://www.okrehab.org/whatsnew.html> the week of May 11th or by calling DRS at (800) 845-8476.

The Office for Victims of Crime Releases Second Training Package Produced by The Arc of Riverside County



The Arc of Riverside County's new training video and educational package for first responders to abuse victims with disabilities has been released by the United States Department of Justice's Office for Victims of Crime (OVC) and is available for free through that agency. The video, called "Victims with Disabilities: Collaborative, Multidisciplinary First Response" was created and produced by a collection of experts in the fields of law enforcement, clinical psychology and services for people with intellectual disabilities under the able leadership of The Arc's Nora J. Baladerian, Ph.D. The free video comes with additional educational materials and can be ordered online at <http://www.ojp.gov/ovc/new/pubs.htm>.

According to the OVC, the group's latest film "demonstrates effective techniques for first responders who have been called to the scene of a crime in which the victim has a disability. This educational multimedia package not only provides guidelines for interacting with adult and adolescent victims of crime who have communication and/or intellectual disabilities, but also helps law enforcement personnel gain a deeper understanding of the lives, personal attributes, and abilities of individuals with disabilities."

The Arc of Riverside County's earlier production, released two years ago, focused on how to effectively interview victims with various disabilities. This video, also released by the Department of Justice's Office for Victims of Crime in 2007, is called "Victims of Crime: The Forensic Interview – Techniques for Interviewing Victims with Communication and Cognitive Disabilities." This production, which has been received with great enthusiasm, is also available free and can be ordered online at <http://www.ojp.gov/ovc/new/pubs.htm>. Dr. Baladerian views this latest project with satisfaction, "Working on this video with The Arc team has been extremely rewarding," she said. "People with disabilities are abused and victimized at a much higher rate than those without disabilities, and law enforcement personnel need to understand how best to handle these cases and individuals. Often prosecutors, victims,

professionals and law enforcement underestimate the contributions that victims and witnesses with disabilities can make in their own defense and to the criminal justice process." Confirming Baladerian's claim about abuse rates, what little research exists shows that people with disabilities are abused at rates 3.5 to 10 times more often than those without disabilities regardless of age. Those with intellectual disabilities are particularly affected by this injustice.

When they enter the criminal justice system as victims, the perpetrators of crime against them are less often charged. When charges are made, they are less often convicted. If convicted, these studies also show they are given lighter sentences. This DVD helps these professionals develop knowledge, skills and positive attitudes that enhance the chances of a successful prosecution. Those who can benefit from this DVD include law enforcement officers, child and adult protection workers, forensic interviewers, prosecutors and judges, among others.

Source: The Arc of Riverside County

The National Council on Disability Releases Two Reports on Disability Policy

The annual "progress report" to the President and Congress calls for a new integrated approach to disability policy within the Federal Government. The report focuses on the current quality of life of people with disabilities in America and the emerging trends that should be factored into both the design and evaluation of the Federal Government's disability policies and programs in the coming years including affordable, accessible housing, employment, poor access to health care, the institutional bias in Medicaid, access barriers to technology, and negative public attitudes about people with disabilities. The Disability Policy Collaboration will be releasing a special report for chapters of The Arc and affiliates of UCP outlining key findings and how they related specifically to people with intellectual and developmental disabilities. See: http://www.ncd.gov/newsroom/publications/2009/Progress_Report.doc

"Federal Employment of People with Disabilities" finds that current efforts to employ people with disabilities in the Federal Government have not worked well, but makes several recommendations to improve the situation. See: <http://www.ncd.gov/newsroom/news/2009/r09-582.htm>

Source: The National Council on Disability

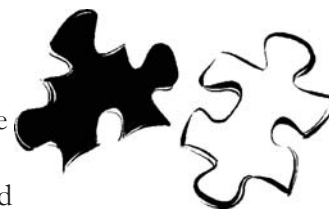
THE ARC OF THE U.S. CALLS FOR ACTION ON THE FEDERAL LEVEL TO ADDRESS AUTISM SPECTRUM DISORDER (ASD)

According to the Centers for Disease Control and Prevention (CDC) on the prevalence of Autism Spectrum Disorders (ASD), approximately 1 in every 150 American children has a potential diagnosis of ASD. Continued research is needed to document trends in the growth of ASD, as well as research into and development of effective interventions. In 2006, President Bush signed into law the Combating Autism Act of 2006 (PL 109-416) to authorize more research on ASD through the National Institutes of Health (NIH) and CDC. The Act also provides the first step to expand the interdisciplinary training of health professionals to identify and support children with ASD and their families. However, greater commitments are also needed to expand access to services such as early identification, diagnosis, early intervention, education, family support, and long-term services and supports to better meet the needs of individuals with ASD and related developmental disabilities. Individuals with ASD and their families need access to accurate information about scientifically-based interventions. The training of a wide range of interdisciplinary professionals also needs to be a top priority so that the findings coming out of our research institutions can be translated and made available to parents and providers across the country as quickly as possible.

On April 2, Sens. Durbin (D-IL), Casey (D-PA), and Menendez (D-NJ) introduced the Autism Treatment Acceleration Act (S. 819). This bill, originally drafted with President Obama when he was in the Senate, incorporates some of the provisions of the Expanding the Promise to Individuals with Autism Act introduced by Sen. Clinton in the last Congress, but also adds several new provisions to accelerate the development of a services system to meet the needs of individuals with autism spectrum disorders and related developmental disabilities.

The bill creates demonstration projects to increase access to quality health care services and coordination of care as well as to develop and provide an array of services to adults with autism spectrum disorders; develops a national multimedia campaign to increase public education and awareness about healthy milestones and autism throughout the lifespan; establishes a national network to link research and service initiatives at the federal,

regional, state and local levels; and, establishes an Interdepartmental Coordinating Committee to coordinate Federal activities relating to research, services, and programs for individuals with autism spectrum disorders.



The bill also establishes multiyear national training initiative on autism and a technical assistance center to significantly develop and expand interdisciplinary training and continuing education on autism spectrum disorders. These training initiatives will promote and engage in training for health, allied health, and educational professionals to identify, diagnose, and provide interventions for individuals with ASD; collect data; provide technical assistance; and work to expand training on and disseminate of information regarding effective, lifelong interventions, educational services, and community supports, including training for criminal justice system personnel and emergency first responders.

A requirement that health insurers cover the diagnosis and treatment of autism spectrum disorders, including Applied Behavior Analysis, assistive communication devices and other effective treatments is also added.

The bill was referred to the Health, Education, Labor and Pensions Committee. No corresponding bill has been introduced in the House.

The 111th Congress should:

- Provide the necessary funds to focus our country's researchers on explaining the apparent increase in prevalence, on finding the causes, and on determining the most effective ways of supporting children and adults with Autism Spectrum Disorders by fully funding the Combating Autism Act
- \$143.5 million to expand, intensify, and coordinate the activities of the National Institutes of Health with respect to research on autism spectrum disorder.
- \$19.5 million for the CDC's Disabilities Surveillance and Research Program.
- \$47 million to increase awareness, reduce barriers to screening and diagnosis, promote evidence-based interventions, and train professionals.
- Support the Autism Treatment Acceleration Act and other legislation that addresses the direct service and interdisciplinary training needs associated with the increasing number of individuals with Autism Spectrum Disorders. Contact your member of Congress to urge them to support this bill.

Source: The Arc



Autism News Roundup

RISK OF AUTISM TIED TO GENES THAT INFLUENCE BRAIN CELL CONNECTIONS

In three studies, including the most comprehensive study of autism genetics to date, investigators funded in part by the National Institutes of Health have identified common and rare genetic factors that affect the risk of autism spectrum disorders. The results point to the importance of genes that are involved in forming and maintaining the connections between brain cells.

“These findings establish that genetic factors play a strong role in autism spectrum disorder,” says Acting NIH Director Raynard Kington, M.D., Ph.D. “Detailed analysis of the genes and how they affect brain development is likely to yield better strategies for diagnosing and treating children with autism.”

Autism spectrum disorders (ASD) comprise a group of disorders with core symptoms that include social interaction problems, poor verbal and nonverbal communication and repetitive behaviors. These disorders range from severe (autism) to mild (Asperger’s syndrome), and in total affect some 1 in 150 American children, about three-quarters of whom are boys. Researchers theorize that the social parts of the brain are underdeveloped in ASD.

“Previous studies have suggested that autism is a developmental disorder resulting from abnormal connections in the brain. These three studies suggest some of the genetic factors which might lead to abnormal connectivity,” says Thomas Insel, M.D., director of NIH’s National Institute of Mental Health (NIMH).

All three studies were genome-wide association studies, which are undertaken to find clues about the causes of complex disorders. Typically, these studies involve scanning the genome - the entire set of DNA - for small differences between people who have a disorder and people who do not.

Previous studies of twins with ASD, other children with ASD and their relatives provided evidence of a strong genetic contribution. Yet until now, only a few genetic risk factors had been identified, and most of those turned out to be rare, with unclear significance for ASD in the general population. Researchers came to realize that the genetics of ASD is complex.

“There are going to be many genes involved in causing autism,” says Dr. Hakonarson. “In most cases, it’s likely that each gene contributes a small amount of risk, and interacts with other genes and environmental factors to trigger the onset of disease.”

In their large study, Dr. Hakonarson and his colleagues found several genetic variants that were commonly associated with ASD, all of them pointing to a spot between two genes on chromosome 5. The researchers also found that a group of about 30 genes that encode cell adhesion proteins were more strongly associated with ASD than all other genes in their data set. In the developing brain, cell adhesion proteins enable neurons to migrate to the correct places and to connect with other neurons.

A second study showed that ASD is associated with a variation near two other genes. “We are starting to see genetic pathways in ASD that make sense,” says Dr. Pericak-Vance.

Finally, in a third study, reported in *Nature*, Drs. Hakonarson and Schellenberg led a search for genes that were duplicated or deleted in individuals with ASD. In the rare cases where those variations occurred, many tended to affect genes involved in cell adhesion. Others tended to affect genes involved in the ubiquitin-proteasome system, a cellular waste disposal system that probably affects the turnover of adhesion proteins at the cell surface. Together, the three new studies suggest that genetic differences in cell-to-cell adhesion could influence susceptibility to ASD on a large scale. For more information about autism, visit http://www.ninds.nih.gov/disorders/autism/detail_autism.htm or <http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders/index.shtml>

Project Studies Vocational Rehabilitation

Services Models for Individuals with ASD

A project funded by the National Institute on Disability and Rehabilitation Research is focusing on issues and strategies for improving employment outcomes for individuals with autism spectrum disorders. By creating and synthesizing knowledge about transition and employment services and outcomes, the Vocational Rehabilitation and Autism Spectrum Disorders project will highlight service models and related resources for improving outcomes for consumers with ASD. For more information go to www.autism.sedl.org.

Source: National Institute of Health



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.

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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:

**May 13th
6:30 p.m.**

Goldies 4401 E 31st St

Contact Amie Farinella, 918-582-8272
For more information about the next meeting.

Connections Asperger's Group

Next Meeting:
Wednesday, May 27th-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, May 25th
7:00 to 8:30 p.m.**
St. Thomas Moore Catholic Church,
2720 S. 129th E. Ave., Tulsa

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, May 20th
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 28th
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:
Ryan's Steakhouse
10934 E 21st St
Tulsa, OK 74129
(918) 437-3610

May 12th
Dinner 5:30
Meeting 6:30

For more information please contact Amie Farinella
918-582-8272

Support Group for Families of Children with Special Needs in Sapulpa

Next Meeting:
Tuesday, May 19th, 6:30 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