



# TARC NEWSLETTER

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

## June 2009

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## REPORT ON THE 2009 OKLAHOMA LEGISLATIVE SESSION

By TARC Executive Director John F. Gajda.

The 2009 session of the Oklahoma Legislature completed its work early, although not all would agree, and adjourned early.

For people with developmental disabilities and their families the session produced few wins which are summarized below.

### Appropriations

Funding is the force that drives programs and services. This year was marked by a decrease in the state dollars that were available to the legislature for appropriations. Consequently none of the gaps and shortages in the service system for people with disabilities were addressed by the legislature this year. The good news is that things could have been worst. If it were not for the Federal stimulus funds from the American Recovery and Reinvestment Act (ARRA) the legislature appropriated this year, funding levels to agencies would have been far lower. Appropriations to major agencies of concern are summarized below but the detailed work plans as to how specific programs will be impacted are not yet all available. The use of the ARRA money this year sets a larger gap that will have to eventually be offset by state revenue.

	FY'09 Total	FY'10 State	FY'10 ARRA	FY'10 Total	% Change
State Department of Education	2,531,702,553	2,404,447,551	167,559,651	2,572,007,202	+1.6%
Office of Disability Concerns	412,769	392,769		392,769	-4.8%
Department of Human Services	559,107,190	479,356,473	71,355,640	550,712,113	-1.5%
Department of Rehabilitative Services	30,053,770	30,453,770		30,453,770	+1.3%
J.D. McCarty Center	4,452,961	4,089,389	363,572	4,452,961	0.0%
Health Care Authority	872,122,261	663,336,492	316,460,502	979,796,994	+12.3%
Department of Health	72,028,113	73,030,278	1,330,652	74,360,930	-0.9%

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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:

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**Autism**

Although for the second year in a row the advocacy efforts on behalf of individuals on the autism spectrum meet with little success, one measure was approved. That measure was SB 135 that provides for the licensing of Applied Behavior Analysts in Oklahoma. Although legislators argued that this measure will address the shortage of providers, it did not address funding for the service. The bill also authorized contracts with independent third party providers for services offered by SoonerStart and authorized the University Hospital to expand the pilot outreach program of behavioral intervention to children with autism. In all cases the bill did not provide additional funding.

**Insurance**

The advocacy for a mandate to cover treatment for autism sparked a debate within the legislature over insurance mandates. The only affirmative result that emerged from the debate was the creation of a Task Force on the Review of Health Insurance Mandates.

**Special Education**

The State Department of Education was instructed by HB 1763 to provide training to special education due process hearing or appeal officers.

**Zoning**

A zoning bill, HB 1414, was amended late in the session to include notification requirements for zoning changes requested for treatment facilities, transitional living facilities, halfway houses and any house or facility that may be used for medical or non-medical detoxification. This bill has a potential negative impact on the development of community based programs, including those for people with developmental disabilities.

**Service Coordination**

The Aging Service Division of DHS was authorized to implement an Aging and Disability Resources Consortium to streamline access to services.

**Boards**

The membership of one board, the Electronic and Information Technology Accessibility Advisory Council, was modified and another board, the Group Homes for Persons with Developmental Disabilities Advisory Board was recreated until July 1st of 2010.

**Hunting**




If you are a hunter with disabilities this was a good year. HB 1761 authorized an individual with a disability to hunt with a longbow with a device that permits the bow to be mechanically drawn.

Overall this is not an impressive list of advances for people with disabilities and their families. A complete review of all the disability related action at the legislature this year follows.

## Developmental Disability Related Legislation Considered by Topic

Certainly every bill that comes before the legislature has the potential to impact the lives of all citizens of Oklahoma, including those with disabilities. The following is a summary of the major bills that were considered by the Oklahoma Legislature this year that had a potential impact specifically on people with developmental disabilities and their families organized by topic.

Each has been coded to indicate their final status and the potential impact on people with disabilities. Most are dormant and did not make it through the legislative process. The point in the legislative process at which they became dormant varies. Many did not make it out of the committee to which they were first assigned but some made it far enough into the process to almost become law.

<b>Status Key:</b>	<b>Impact Key:</b>
D- <u>D</u> ormant	 Would be beneficial to people with developmental disabilities
F- <u>F</u> ailed	 Would not be beneficial to people with developmental disabilities
G- Passed and signed by <u>G</u> overnor	 Unclear Impact
V- Passed but <u>V</u> etoed by Governor	

**Programs and Services**

A number of bills addressed various aspects of programs and services for people with developmental disabilities

**HB 1019** G



Rep. John Wright

Recreates the Group Homes for Persons with Developmental or Physical Disabilities Advisory Board.

**HB 1424** G



Rep. Eric Protor

Requires treatment facilities, transitional living facilities, halfway houses and any house or facility that may be used for medical or nonmedical detoxification to mail notification to property owners within a 1/4 mile radius if zoning changes are proposed.

**HB 1778** D **In Senate**



Rep. Tad Jones

Would have re-appropriated and redesignated funds to direct services of the SoonerStart Early Intervention Program.

**HB 1842** F **In Senate Committee**



Rep. Rex Duncan

Would have created the Oklahoma Licensed Interpreter Act and the Oklahoma Board of Licensed Interpreters for the Deaf and Hard-of-Hearing making it unlawful to practice interpreting in the state without a license.

**HB 1893** G



Rep. Rex Duncan

Authorizes DHS's Aging Services Division to work corroboratively with other 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.

**SB 321** D **In House Committee**



Sen. Anderson, Patrick

Would have authorized DHS's Aging Service Division to collaborate with other 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. (Similar to HB 1893)

**SB 871** G



Sen. Patrick Anderson

Modifies membership of the Electronic and Information Technology Accessibility Advisory Council.

**SB 934** V



Sen. Patrick Anderson

Would have included anti-psychotic drugs as exempt from prior-authorization and restriction from Health Care Authority's Utilization Review Board.

**SB 1097** D **In Senate Committee**



Sen. Constance Johnson

Would have modified the membership of the Commission for Rehabilitation Services, increasing its membership from three to seven.

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**Autism**

The fight to improve service for children with autism continued in the Oklahoma Legislature for the second year.

**HB 1312** F **In House Committee**



Rep. Mike Brown

Would have created Nick's Law, requiring any individual or group health benefit plan to provide coverage for the treatment of an autistic disorder. It limits coverage to persons under age 21 and sets maximum benefit of \$50,000 per year for behavioral therapy.

**HB 1841** D **In House Committee**



Rep. Collins Wallace

Would have created Nick's Law, requiring any individual or group health benefit plan, to provide coverage for the treatment of an autistic disorder. The bill would have limited treatment to that which is prescribed by the treating physician, limiting coverage to persons under age 21 and setting a max benefit of \$75,000 per year for behavioral therapy.

**HB 1968** D **In House Committee**



Rep. Chris Bengé

Would have created the Autism Services Improvement Act. (Shell Bill)


**HB 1969** D **In House Committee**



Rep. Chris Bengé

Would have created the Autism Services Act (Shell Bill)

*"Report" Continued on pg. 4*

**HB 2027** D **In House to adopt Senate**   
Rep. Kris Steele **Amendments (similar to SB 135 that was approved)**

Would have required persons wishing to practice as a licensed behavior analyst or a licensed assistant behavior analyst to apply to DDS within DHS. The measure also directed 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.

**SB 1** D **In Senate Committee**   
Sen. Jay Paul Gumm

Would have created Nick's Law which required any individual or group health benefit plan to provide coverage for the treatment of an autistic disorder. It states that coverage must include all therapies, treatments, diagnoses, testing medicines and supplements prescribed by a licensed physician, including behavioral therapy. Max: \$75,000.

**SB 46** D **In Senate Committee**   
Sen. Mary Easley

Would have required any individual or group health benefit plan to provide coverage for the treatment of an autistic disorder. It states that coverage is subject to a diagnosis of an autistic disorder by a licensed physician or behavioral practitioner. The bill limits coverage to individuals under age 21. Coverage must include all therapies, treatments, diagnoses, testing, medicines, and supplements prescribed by a licensed physician including behavioral therapy. It sets a maximum benefit for behavioral therapy of \$75,000 per year for three years.

**SB 135** G   
Sen. Ron Justice

Provides for licensing of persons wishing to practice as a licensed behavior analyst or a licensed assistant behavior analyst. It also directs the Department of Health to use funds for specialized training for providers in the SoonerStart program to acquire skills necessary to treat children with autism spectrum disorders. The measure also directs the Oklahoma State Regents for Higher Education to expand the Early Foundations program.

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### Insurance

Insurance and insurance mandates continued to be a controversial topic this legislative session. Insurance mandates are of particular significance as advocates fight on to improve services for children with autism in Oklahoma.

**HB 1975** V   
Rep. Lewis Moore

Would have required legislation mandating health coverage or offering of a health coverage by health insurance to only be introduced in odd-numbered years and heard in even numbered years.

**HB 2026** G   
Rep. Kris Steele

Created the Health Care for Oklahomans Act which created a 'no-mandate' health insurance product and a high deductible health insurance product coupled with a health savings plan.

**SB 822** G   
Sen Cliff Branan

Establishes the Task Force on the Review of Health Insurance Mandates.


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### Protective Services

People with disabilities are particularly vulnerable to abuse and neglect throughout their lives. For adults, adult protective services is in charge of investigating complaints of abuse and neglect. These bills which impact the investigative process are an important part of protecting adults with disabilities.

**HB 1519** D **In House Committee**   
Rep. Scott Inman

Would have changed the Perspective Services for Vulnerable Adults Act to the Perspective Services for Vulnerable Persons Act and broadened sections and definitions of what constitutes a vulnerable person and what constitutes abuse, neglect, or other mistreatment of that person.

**HB 1627** D **In Senate Committee**   
Rep. Anastasia Pittman

Would have modified language and reporting order for the Protective Services for Vulnerable Adults Act.

**SB 351** D **In Senate Committee**   
Rep. Andrew Rice

Would have required reports of abuse, neglect or exploitation of vulnerable adults to be reported to the Department of Human Services and the municipal police department or county sheriff's office.

*"Report" Continued on pg. 5*

**Education**

Education in general and special education specifically, is the major service most children and people with disabilities receive so laws impacting the delivery of education services are of particular importance.

**HB 1062** D **In House Committee** 

Rep. Ben Sherrer

Would have expanded the list of employees to whom the State Board of Education may provide annual salary bonuses to include orientation and mobility instructors.

**HB 1512** D **In Senate on General Order** 

Rep. Gus Blackwell

Would have made exempt certain schools meeting certain standards from liability for not providing necessary services to autistic children.

**HB 1628** D **In House Committee** 

Rep. Anastasia Pittman

Would have required that the evaluation of a student with a visual impairment be joined by a teacher certified in the education of students with visual impairment and would have directed the State Department of Education to offer teachers, administrators and personnel training in aspects and issues of the visually impaired.

**HB 1763** G 

Rep. John Enns

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 2004** D **In Senate Committee** 

Rep. Harold Wright

Would have required school administrators, teachers, and other school employees to be trained to recognize, accommodate, and assist students with mental health issues.

**HB 2126** D **In Senate on General Order** 

Rep. Mike Shelton

Would have stated 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 307** D **In Senate Committee** 

Sen. Jim Wilson

Would have directed the Oklahoma attorney general to intervene and represent a public school district in any legal proceeding to enforce state and federal laws relating to educating children with disabilities.

**SB 971** D **In House on General Order** 

Sen. John Sparks

Would have allowed 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.

**SB 1057** D **In Senate Committee** 

Sen. Clif Branan

Would have modified language related to rehabilitative education and training for the visually impaired.

**Taxation**

The fight to create special tax credits for certain medical devices or treatment for people with disabilities was attempted again this session but the result was the same as in prior years. People with disabilities failed to receive the benefit of tax exemptions that other special groups have.

**SB 51** D **In Senate Committee** 

Sen. Debbe Leftwich

Would have granted a tax credit for expenditures made to purchase medically necessary foods used in the treatment of phenylketonuria.

**SB 312** D **In Senate Committee** 

Sen. Debbe Leftwich

Would have provided a sales tax exemption on hearing aids.

*“Report” Continued on pg. 6*

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## Miscellaneous

Some bills that were considered did not fall into other categories. They are listed individually below.

**HB 1761**



Rep. John Enns

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 1887**



**In Senate Committee**



Rep. Phil Richardson

Would have changed language allowing more offenders who had a mental illness or developmental disability or a co-occurring mental illness or substance abuse disorder to be eligible for community punishments.

**SB 479**



**In Conference Committee**



Sen. Todd Lamb

Would have exempted administrators of ICR/MR facilities from meeting current license requirements.

## DISABILITY AGENCY DIRECTOR REOPENS EMPLOYMENT SERVICES TO HUNDREDS OF OKLAHOMANS WITH DISABILITIES

Hundreds of job-seeking Oklahomans with disabilities began receiving vocational rehabilitation and employment assistance when Department of Rehabilitation Services (DRS) Director Mike O'Brien, Ed.D., reopened services on May 18 to those on a waiting list since Jan. 2007.

The agency's efforts to control expenditures provided the funding required to open the waiting list. However, \$7.6 million in one-time stimulus funding through the "American Recovery and Reinvestment Act of 2009" is expected to keep services open for all eligible Oklahomans for the next 12-15 months.

"The Federal Rehabilitation Act, which governs vocational rehabilitation and employment programs, requires DRS to control costs by delaying assistance to

new applicants who are placed in three categories based on the significance of their disabilities," Mike O'Brien said. "When DRS doesn't have enough funds to serve everyone, the act requires that they serve those with the most significant disabilities on a priority basis because those individuals need the most help with employment."

At the time the waiting list opened on May 18, DRS was serving 12,442 clients with more significant barriers to employment and others who had employment plans in place when the waiting list began.

The group of 440 eligible applicants with disabilities categorized as less significant had to wait until funds were available to pay for their services.

The state earns four federal match dollars for every state dollar appropriated for vocational rehabilitation and employment. The high match is an indication of strong federal support, allowing DRS to generate revenue by qualifying for federal funds that would otherwise go to other states.

"DRS' immediate goal is faster turnaround on job placement," O'Brien said, but economic stimulus dollars will allow them to put money directly in the hands of local employers and non-profits, who will provide on-the-job training and permanent employment to Oklahomans with disabilities across the state.

"The first group of 440 from the waiting list is just the beginning," O'Brien explained. "They expect many more individuals to apply for vocational rehabilitation and employment assistance now that the services are open again to everyone who qualifies."

In 2008, DRS' Vocational Rehabilitation and Visual Services divisions provided counseling, medical and psychological services, job training and other individualized services to 12,500 Oklahomans whose disabilities make it difficult to work. Federal reports show that 2,246 became employed and no longer needed DRS services. These individuals collectively earned \$45.5 million and paid \$6.8 million in taxes last year.

For more information about DRS services, visit [www.okdrs.gov](http://www.okdrs.gov) or phone 800-845-8476.

Source: Oklahoma DRS

# President Releases Detailed Budget Request for FY 2010

## Most Discretionary Disability programs Level Funded, Some Receive Increases

President Obama released the details of his Administration's Fiscal Year 2010 Budget Request on May 7. Of the \$3.56 trillion to be spent, \$1.2 trillion is reserved for non emergency domestic spending. This amount is about \$10 billion more than the FY 2010 Budget Resolution adopted by the Congress.

Since the Administration's budget proposal was prepared in a short time with limited staff, there are discrepancies in some of the figures that need to be sorted out. Overall, this budget request falls short of the disability community's expectations on key disability program funding priorities. Some of this disappointment may be owed to reverting back to funding levels prior to the significant increases for certain disability programs provided under the American Recovery and Reinvestment Act.

The action now shifts to the Congress, where the House and Senate Appropriations Committees will begin marking up their appropriations bills in June. Given the several high profile Congressional priorities (e.g. health care and energy), it is unclear whether the Congress will complete action on all twelve FY 2010 appropriations bills by the start of the new fiscal year on October 1.

Administration officials noted that additional changes to the budget request could be made later this year depending on the state of the economy, deficit projections and possible rescissions (cuts to programs made by the Administration if not rejected by the Congress).

Under the proposed budget, most disability discretionary programs would be frozen or slightly increased. Of particular concern is the Administration's priority to increase early childhood programs, yet the IDEA Early Intervention and Preschool programs remain frozen at current levels. The only disability program the Administration proposed to eliminate is the Department of Labor's Work Incentives Grants which funds improved accessibility in the workforce development system. A summary of key budget proposals follows:

### Social Security Administration (SSA)

**Administration.** The cost of administering the

Social Security Administration's programs is appropriated on an annual basis under the term "Limitation on Administration Expenses (LAE)." SSA's LAE for FY 2009 was \$10.587 billion. The President has requested an increase of \$1.016 billion, or 9.6 percent, for a total of \$11.603 billion. This amount will help the agency cover the on-going costs of administering the Social Security retirement, survivor, and disability programs and the Supplemental Security Income (SSI) program. It will also allow SSA to continue its significant efforts to eliminate the huge backlogs in decisions on disability claims.



**Reviews and Redeterminations.** The Administration proposes an additional \$485 million for SSA to perform Continuing Disability Reviews (CDRs) and SSI Redeterminations. These reviews evaluate whether beneficiaries are still disabled for purposes of the Social Security disability and SSI programs. The reviews result in program savings when people who are determined no longer disabled are removed from the disability programs

**Benefits.** While Social Security and SSI benefits are not subject to the appropriations process, the proposed budget does include the President's estimates for benefits to be paid in FY 2010, including expected Cost of Living Adjustments (COLAS). The projection is that there will be no COLA in benefits for 2010. This is due to the status of the overall economy. The amount of adjustment for benefits payments in any one calendar year are dependent on inflation measured in the third quarter (ending September 30) of the previous calendar year. SSA's budget estimate for FY 2010 reveals expectations that there will be no measurable inflation in the third quarter of calendar year 2009. If Medicare co-payments continue to rise, Social Security beneficiaries could see a reduction on the value of their Social Security benefits.

### Department of Health and Human Services

**Medicaid Real Choice Systems Change Grants.** A decrease of \$2.5 million is proposed for these grants which are used by states to assist in designing and implementing improvements to community-based support systems. The total for FY 2010 would be \$2.5 million. However, another section of the budget documents indicates that the grants will be cut by \$2 million from

*"Budget" Continued on pg. 8*



\$5 million (rather than \$2.5 million).

**Medicaid Money Follows the Person Grants.** The Budget Request seeks an increase from \$359 million in FY 2009 to \$474 million in FY 2010, an increase of \$115 million. Money Follows the Person provides the states with an increased match for moving individuals out of institutions and into community-based settings.

**Medicaid Institutional Alternatives.** A 4.19 percent growth projection is made in the Budget Request for the use of the “institutional alternatives” - personal care, home health services, and home and community-based services.

**Centers for Disease Control and Prevention.** \$142.0 million – a \$4 million increase over FY 2009 level – is requested for the National Center on Birth Defects and Developmental Disabilities (NCBDDD). The mission of the NCBDDD is to promote the health of babies, children and adults and enhance the potential for full, productive living. One of the Center’s primary goals is to promote health and wellness among people with disabilities of all ages.

**National Institutes of Health.** \$1.314 billion – a \$19 million increase over FY 2009 – is requested for the Eunice Kennedy Shriver National Institute Child Health and Human Development. The Institute conducts and supports research on all stages of human development, from preconception to adulthood, to better understand the health of children, adults, families, and communities.

**Developmental Disabilities Act.** The Budget Resolution proposes level funding for DD Act programs. DD councils would maintain funding of \$74 million, Protection and Advocacy systems would stay at \$40 million, and University Centers would hold at \$38 million. Similarly, Projects of National Significance funding would remain unchanged at \$14 million.

**Autism and Other Developmental Disabilities.** The Administration requested that the autism and other developmental disability program at the Health Resources and Services Administration received a \$6 million increase. These programs support early detection and intervention, training and research programs.

**Respite.** The Lifespan Respite Care Act received \$2.5 million in the President’s Budget Request, the same amount it received when it was first funded in FY 09.

These respite systems are to provide easy access to an array of affordable, quality respite services; ensure flexibility to meet diverse needs; and assist with locating, training, and paying respite providers.

**Title XX Social Services Block Grant.** This program receives level funding at \$1.7 billion in the President’s Budget Request. The SSBG funds states to help them achieve a wide range of social policy goals, which include preventing child abuse, increasing the availability of child care, and providing community-based care for the elderly and persons with disabilities.

**Maternal & Child Health Block Grant.** This program receives level funding at \$662 million in the President’s Budget Request. The Maternal and Child Health Block Grant’s purpose is to improve the health of all mothers, children, and their families, especially for those with low-incomes or limited availability of care and those with special health care needs.

**Department of Education**

All special education funding (IDEA) is level funded. The President did not request funding for the new model comprehensive transition and postsecondary programs for students with intellectual disabilities or the other new higher education programs for students with disabilities.

**Vocational Rehabilitation Title I State Grant Program.** This program received a \$111 million (3.7%) cost of living increase for FY 2010, from \$2.974 billion to \$3.085 billion. The majority of the other VR programs would receive level funding.

**Supported Employment State Grants.** Funding for this program is frozen at the FY 2009 level of \$29 million.

**The National Institute for Disability & Rehabilitation Research (NIDRR).** NIDRR funding increased by \$3 million in the President’s Budget Request.

Source: National Policy Matters



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# COPAA RELEASES REPORT DETAILING 143 INCIDENTS OF AVERSIVE INTERVENTIONS IN SCHOOL PROGRAMS

The Council of Parent Attorneys and Advocates, Inc. (COPAA) released a report asking Congress to stop the use of restraints, seclusion, and aversives upon children with disabilities in school. The report entitled, [Unsafe In The Schoolhouse: Abuse Of Children With Disabilities](#), details 143 incidents of the use of abusive interventions against children with disabilities in school. The report also includes suggested legislative remedies.

The Council of Parent Attorneys and Advocates (COPAA) is a national nonprofit organization of parents, advocates, and attorneys who work to protect the civil rights of children with disabilities and ensure that they receive appropriate educational services.

In March-April 2009, COPAA conducted a survey that identified 143 cases in which children were subjected to aversive interventions. They received reports of children subject to prone restraints; injured by larger adults who restrained them; tied, taped and trapped in chairs and equipment; forced into locked seclusion rooms; made to endure pain, humiliation and deprived of basic necessities, and subjected to a variety of other abusive techniques.

Of the survey respondents, 71% had not consented to the use of aversive interventions; 16% had, but many believed the interventions would only be used in limited circumstances where there was an imminent threat of injury. Moreover, 71% reported that the children involved did not have a research-based positive behavioral intervention plans; 10% did (but parents often said that the plan was not followed). 84% of children restrained were under 14 years of age, with 53% aged 6-10.

The use of abusive interventions primarily occurred in segregated disability-only classrooms or in private seclusion rooms, away from the eyes of witnesses, with only 26% of the respondents reporting incidents in the regular classroom. Almost every disability category was represented: Autism/Asperger's Syndrome (cited by 68% of the survey respondents), ADD/ADHD (27%); Developmental Delay, Emotional Disturbance, Intellectual Disability and Speech/Language Impairment (14%-20% of respondents); Specific Learning Disabilities (11%), and others. Many parents also indicated that their children had Down Syndrome, epilepsy, Tourette Syndrome and other specific conditions.

Among the incidents of abuse reported to COPAA are these:

- 9 year old boy with autism in Tennessee was restrained face-down in his school's isolation room for four hours. One adult was across his torso and another across his legs, even though he weighed only 52 pounds. His mother was denied access to him, as she heard him scream and cry. He received bruises and marks all over his body from the restraints. He was released to his mother only after she presented a due process hearing notice under the IDEA.
- An 11 year old South Carolina girl was being restrained with beanbags on the floor, and the school attempted to use a straightjacket restraint on her. As a result of advocacy by her attorneys, the restraints were terminated. Her curriculum was changed to be more age appropriate because her behaviors likely resulted from being bored with curriculum. A new crisis plan was put into place to avoid restraint: if the student became aggressive toward staff, the staff would break away from the student and briefly leave the classroom. Using this plan, the child quickly calmed down and went to her desk area. Previously, the school district had requested that the parent take the child home early on regular basis; parents report this has not happened for the last 2 months. With the new behavioral plan, the child has made substantial progress in school.

COPAA stresses the importance of adopting effective laws to keep children safe. These include mandatory PBS, statutory prohibitions on the use of restraints, seclusion, and aversives, and strong enforcement mechanisms to hold school district accountable for violations.

Congress should act immediately to ban prone and mechanical restraints, all restraints that interfere with breathing, locked seclusion rooms, and the application of painful aversives. In addition, physical restraint may only be permitted when there is an imminent threat of serious injury to self or others. School districts and their personnel must be held accountable for any violations of the law, and parents must have all legal remedies to pursue justice. All children must receive comprehensive positive behavioral intervention plans, and schools must provide training on PBS, the harms of aversive interventions, and the applicable legal requirements. Schools must also monitor and report the number of aversive interventions. The full report can be accessed at [http://www.copaa.org/pdf/UnsafeCOPAA\\_May\\_10\\_09.pdf](http://www.copaa.org/pdf/UnsafeCOPAA_May_10_09.pdf)

Source: COPAA.org

## Nine new X chromosome genes associated with learning disabilities

A collaboration between more than 70 researchers across the globe has uncovered nine new genes on the X chromosome that, when knocked-out, lead to learning disabilities. The international team studied almost all X chromosome genes in 208 families with learning disabilities - the largest screen of this type ever reported.

Remarkably, the team also found that approximately 1-2% of X chromosome genes, when knocked-out, have no apparent effect on an individual's ability to function in the ordinary world. The publication - a culmination of five years of scientific collaboration - emphasizes the power of sequencing approaches to identify novel genes of clinical importance, but also highlights the challenges researchers face when carrying out this kind of study.

Estimates suggest that the prevalence of learning disability is 2-3%. Learning disability is significantly more common in males than in females and genetic causes have long been sought on the X chromosome: males have only one X chromosome and so a gene mutation on the X is more likely to have an effect in males than in females.

"We sequenced 720 out of the approximately 800 known genes on the X chromosome in more than 200 families affected by X-linked learning disabilities," explains Professor Mike Stratton, from the Wellcome Trust Sanger Institute. "This is the largest sequencing study of complex disease ever reported."

In part because of their apparent effects in males, X-linked disorders have been well studied by geneticists over the past 25 years. Conceived by Dr. Lucy Raymond, from the University of Cambridge, and Professor Mike Stratton, the collaborative study harnessed DNA sequencing to detect as many new abnormal genes as possible. In the future similar strategy will be used to find disease causing sequence variants implicated in other complex genetic diseases.

Some characteristics in common could be identified in patients with variants in the same gene. However, in many, learning disability was the only feature. The newly identified genes play roles in a wide range of biological processes suggesting that disruption to many cellular machines can damage the nervous system.

"As well as these important new gene discoveries relating to learning disability, we have also uncovered a small proportion - 1% or more - of X chromosome protein-coding genes that, when knocked out, appear to have no effect on the characteristics of the individual," explains Mike Stratton. "It is remarkable that so many protein-coding genes can be lost without any apparent effect on an individual's normal existence - this is a surprising result and further research will be necessary in this area."

This finding will also act as a warning to geneticists. Large-scale studies are designed to uncover associations between knocked-out genes and disease. However, this study shows that a small proportion of gene knock-outs have no discernible effect on the individual. In future studies, researchers must therefore be cautious about assuming that the presence of a knocked out gene in an individual with a particular disease means that the knocked out gene is causing the disease.

The research comes towards the end of a long process of gene cataloguing in this field. Scientists believe that there are likely to be more undiscovered genes that contribute to X-linked learning disabilities; however, variants at what are expected to be lower frequency will become increasingly difficult and costly to uncover. The next challenge is to implement this improved knowledge of the complex of genes that lead to learning disabilities in clinical practice.

Although in most cases improved treatments remain to be developed, information about a genetic condition can provide support to affected families. The information can also help to inform reproductive choices.

Source: The Arc

## New Guide on Positive Behavior Support Strategies for Children with DD in Schools

The American Association on Intellectual and Developmental Disabilities (AAIDD) has issued a new guide titled Designing Positive Behavior Support Plans. This practical book helps professionals think critically about how to approach a student's problem behavior proactively. The guide is for special education teachers, service providers, students, as well as parents of children with developmental disabilities. To read book details, customer reviews and a chapter excerpt, and purchase an AAIDD book, visit <http://bookstore.aaid.org>.



## **CITALOPRAM NO BETTER THAN PLACEBO TREATMENT FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS**

Citalopram, a medication commonly prescribed to children with autism spectrum disorders (ASD), was no more effective than a placebo at reducing repetitive behaviors, according to researchers funded by the National Institute of Mental Health (NIMH) and other NIH institutes. The study was published in the June 2009 issue of *Archives of General Psychiatry*.

“Parents of children with autism spectrum disorders face an enormous number of treatment options, not all of which are research-based,” said NIMH Director Thomas R. Insel, M.D. “Studies like this help us to better understand which treatments are likely to be beneficial and safe.”

The researchers say their findings do not support using citalopram to treat repetitive behaviors in children with ASD. Also, the greater frequency of side effects from this particular medication compared to placebo illustrates the importance of placebo-controlled trials in evaluating medications currently prescribed to this population.

Citalopram is in a class of antidepressant medications called selective serotonin reuptake inhibitors (SSRIs) that is sometimes prescribed for children with ASD to reduce repetitive behaviors. These behaviors, a hallmark of ASD, include stereotypical hand flapping, repetitive complex whole body movements (such as spinning, swaying, or rocking over and over, with no clear purpose), repetitive play, and inflexible daily routines.

Past research suggested that some children with ASD have abnormalities in the brain system that makes serotonin, a brain chemical that, among many other functions, plays an important role in early brain development. Children with obsessive compulsive disorder (OCD) may also have serotonin abnormalities and have repetitive or inflexible behaviors. OCD is effectively treated with SSRIs, leading some researchers to wonder whether similar treatment may reduce repetitive behaviors in children with ASD. So far, studies have produced mixed results, but SSRIs remain among the most frequently prescribed medications for children with ASD.

Researchers in the Studies to Advance Autism Research and Treatment (STAART) network, funded by five NIH institutes, conducted a six-site, randomized controlled trial comparing the effectiveness and safety of using the SSRI citalopram (Celexa) versus placebo to treat repetitive behaviors in children with ASD. The study included 149 participants, ages 5-17, who had autism, Asperger disorder, or pervasive developmental disorder-not otherwise specified (PDD-NOS).

After 12 weeks of treatment, roughly 1 out of 3 children in both groups-32.9 percent of those treated with citalopram and 34.2 percent those treated with placebo-showed fewer or less severe repetitive symptoms.

“Adverse symptoms were common in both groups, probably reflecting common childhood ailments as well as the changing nature of symptoms associated with ASD,” according to Bryan King, M.D., director of child and adolescent psychiatry at Seattle Children’s Hospital and lead author on the study. However, reports of increased energy, impulsiveness, decreased concentration, hyperactivity, diarrhea, insomnia, and dry skin were more common in the citalopram group.

According to the researchers, the study results may challenge the underlying premise that repetitive behaviors in children with ASD are similar to repetitive and inflexible behaviors in OCD.

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:  
August 12th**

Contact Amie Farinella, 918-582-8272  
For more information

**Connections Asperger's Group**

**Next Meeting:  
Wednesday, June 24th 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, June 29th  
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, June 17th  
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, June 25th  
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

**Next Meeting:  
Mazzio's  
11th and Elgin**

**June 9th**  
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, June 16th, 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