



TARC NEWSLETTER

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

May/June 2010

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Review of the 2010 Oklahoma Legislature

By: John F. Gajda

The Second Session of the 52nd Oklahoma Legislature adjourned on May 28th with a last minute flurry of activity. The outcome of many attempts at passing legislation was in question until the last week of the session and the approval of the final budget agreement didn't come until that final day.

Back in February, at the start of the session, a list of 31 newly filed non-appropriation bills that had the greatest potential to impact the lives of people with developmental disabilities and their families were identified. Very early in the session many of these bills failed to advance and became dormant. The language of some dormant bills survived as amendments to bills that did advance and were passed. Most just died. Of the 31, eleven progressed through the legislative process, were signed by the Governor and became law. A list of these eleven bills is included in this newsletter.

What was gained and what was lost for people with developmental disabilities and their families this legislation?

- The lives of two advisory boards was extended – the Electronic and Information Technology Accessibility Advisory Council (HB2281) and the Group Homes for Persons with Developmental or Physical Disabilities Advisory Board. (HB2282)
- New guidelines for regulating handicapped parking were established. (HB2567)
- The guidelines for the cash and counseling program run by the Health Care Authority that provides alternatives for long-term care were modified. (HB2596)
- An income tax check off was created for the Multiple Sclerosis Society. (HB2710)
- An annual assessment on each contracted community-based service provider was established and the assessment was targeted for additional state match on Medicaid dollars to expand services. (HB2828)
- A scholarship programs for special needs students was created. (HB3393)

There is an article in this newsletter that provides more details about this bill.

Please see "Legislature" 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:

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- The definition of “employment” as related to services provided by DHS personal care programs was modified. (SB1280)
- Long-term care facilities will now be prohibited from hiring an individual who plead guilty or no contest or received a deferred sentence for certain crimes. (SB1289)
- A Direct Care Advisory Council to coordinating training and other matters between different care systems was created. (SB1819)

One piece of legislation that initially failed emerged from the process under the cover of another bill. The language in SB 1657 that requires certain health insurance companies cover the same illnesses for children with autism as they do children without such a diagnosis was added as an amendment to SB 2045 and this bill was signed by the Governor. There is an article in this newsletter that provides more details about this bill.

There of course are the bills that were filed and did not make it through the legislative process. They covered a wide range of topics. Some are real losses. Failure of others is a relief. The bills that failed would have:

- Created a sales tax exemption for hearing aides. (HB 2298)
- Required operators of motorized wheelchairs to display a warning flag. (HB 2542)
- Required co-payments families receiving service from SoonerCare. (HB2542)
- Made it a felony to knowingly mistreat a vulnerable adult. (HB2701)
- Placed sheltered workshops under the same rules and regulations as adult day care centers. (HB2744)
- Required health insurance plans to continue coverage for dependent children with developmental disabilities up to age 25. (HB2902)
- Required liability insurance for nursing facilities. (HB 3062)
- Established residence, for school purposes, of a child in the School for the Deaf or School for the Blind in the district in which the parents, guardians or person holding custody lives. (HB3117)
- Directed the State Board of Education to develop a funding mechanism for local schools for the excessive costs of high-need students . (HB3170)
- Required that a teacher certified in the education of students with visual impairments or a certified orientation and mobility specialist be part of an evaluation team for students with visual impairments. (HB3331)
- Created a freestanding developmental disabilities services agency outside of DHS. (HB3374)
- Required health insurance plans to provide coverage for an autistic disorder. (SB1219)
- Expanded disability hunting and fishing license eligibility. (SB1278)
- Changed language in employment discrimination statutes from “handicapped person” to “person with a disability.” (SB1315)
- Required DHS to replace glasses, hearing aids and other assistive devices of employees at state resource centers which were broken while at work. (HB1315)
- Required plans in the state high risk health insurance pool cover treatment of autism spectrum disorders. (HB 1316)
- Created the Rights of People and Elderly with Disabilities Act. (SB2331)

Bills Approved & Signed by Governor

Bill	Principal Authors	Description
HB 2281	Wright, John A. (H)	Recreates the Electronic and Information Technology Accessibility Advisory Council until July 1, 2014.

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HB 2282	Wright, John A. (H)	Recreates until July 1, 2014, the Group Home for Persons with Developmental or Physical Disabilities Advisory Board.
HB 2567	Wesselhoft, Paul (H)	Modifies language to require municipalities and political subdivisions of the state with authority to regulate the standing or parking of vehicles to extend special parking privileges to a physically disabled person with the proper item displayed on that person's vehicle.
HB 2596	Morrisette, Richard (H)	Creates the Empower-OK Act, directing the Oklahoma Health Care Authority's cash and counseling program to include provisions ensuring that existing benefits are not terminated or decreased as a result of developing the program; that consumers receive a monthly budget based on the needs of the individual; authority for consumers to use the budget to obtain personal care services and make home modifications to suit the needs of the individual; and counselors available to work with consumers to develop and revise individual budgets.
HB 2710	Wallace, Collins (H)	Creates up to a \$25 state income tax checkoff provision for a donation for the benefit of the Multiple Sclerosis Society. It also creates the Multiple Sclerosis Society Revolving Fund to be administered by the Department of Health for the purpose of providing grants to the Multiple Sclerosis Society.
HB 2828	Peters, Ron (H)	Authorizes the Oklahoma Health Care Authority to annually assess a Home-Based Support Quality Assurance Assessment on each contracted community-based service provider. It directs payments of the Home-Based Quality Assurance Assessment by contracted community-based service providers to be an allowable cost for Medicaid reimbursement purposes. It also creates the Home-Based Quality Assurance Fund to be expended by the Oklahoma Health Care Authority for Medicaid services provided by contracted community-based service providers.
HB 3393	Nelson, Jason (H)	An Act relating to special education; creating the Lindsey Nicole Henry Scholarships for Students with Disabilities Program Act; stating intent; specifying procedures and initial date; establishing eligibility requirements for students; requiring certain notice; establishing eligibility requirements for a private school; specifying certain compliance requirements for participants; requiring forfeiture for failure to comply; establishing formula for maximum scholarship amount; providing for calculation of scholarship amount; providing for payments; clarifying responsibility for certain additional costs; precluding liability and providing for codification.
SB 1280	Anderson, Patrick (S)	Modifies the definition of "employment" under the Employment Security Act as it relates to home services as part of a program administered by the Department of Human Services.
SB 1289	Coates, Harry (S)	Expands circumstances under which a long-term care facility employer is prohibited from hiring an individual to include if the results of a criminal history background check reveal he/she plead guilty or no contest to or received a deferred sentence for certain crimes.

SB 1819	Crain, Brian (S)	Creates the Direct Care Worker Advisory Council to make recommendations on maximizing profitability, minimizing redundancy, introducing uniformity and certification, and it directs the council to report those recommendations to the governor, speaker of the House and president pro tempore of the Senate by Nov. 30, 2011.
SB 2045	Brown, Bill (S)	All individual and group health insurance policies that provide medical and surgical benefits shall provide the same coverage and benefits to any individual under the age of eighteen (18) years who has been diagnosed with an autistic disorder as it would provide coverage and benefits to an individual under the age of eighteen (18) years who has not been diagnosed with an autistic disorder.

New Oklahoma Budget Approved

On the last day of the 2010 Legislative session the budget for the State Fiscal Year 2011, that begins on July 1st, was finally approved.

Concerns about the worsening state fiscal picture permeated the legislative session but it was a last minute leadership compromise that was a combination of appropriation cuts and revenue enhancing measures that allowed the Legislature to pass a budget bill and adjourn on schedule.

HIGHLIGHTS OF THE FY -11 BUDGET

Total appropriations for FY '11 are \$6.714 billion.

- 7.2 percent decrease (-\$517.5 million) from the initial FY -10 budget and 3.5 percent decrease (-\$245.4 million) from the final FY -10 budget after mid-year cuts;
- FY -11 state budget will be slightly less than the budget in FY -07.

The economic downturn, along with the ongoing phase-in of tax cuts and the proliferation of tax exemptions, led to precipitous revenue declines in FY -10 and FY-11.

- FY-10 General Revenue collections are projected to be 25 percent below pre-downturn levels (FY-08);
- Revenues are expected to recover by only \$104 million (2.3 percent) in FY-11;
- Next year's GR is projected to remain 20 percent below levels of five years ago, FY-06.



In order to balance the FY-11 budget and minimize the severity of cuts to essential public services, the Legislature and Governor authorized over \$1.3 billion in additional revenues, including:

- \$373 million (total remaining balance) from the state's

Rainy Day Fund;

- \$539 million in federal funds from the 2009 stimulus bill (American Recovery & Reinvestment Act);
- Stimulus dollars were used to support education and Medicaid.
- Some \$450 million from an array of mostly one-time revenue enhancements, including:
 - Suspending and deferring payment of certain tax credits;
 - Issuing and refinancing bonds;
 - Enhanced tax collection compliance;
 - Fee and permit increases;
 - Transfers of cash balances.
- Use of non-recurring revenues and deferred payments leave large budget holes for FY-12 and FY-13. FY-11 funding is expected to avert deeper cuts to core services but not to restore services and staffing to pre-downturn levels.
- All but four agencies will receive less appropriations in FY-11 than in FY-09 (Health Care Authority, Commission of Land Office, Election Board, Rehabilitation Services);
- Some 40 state agencies –more than half of all appropriated agencies will have absorbed funding cuts in FY-10 and FY0-11 of at least 15 percent compared to FY-09;
- However, in some cases, appropriations cuts have

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been partly offset by fee increases or other revenues. The Legislature has also approved measures to fund voluntary buy-outs, promote savings and efficiencies, and give agencies and schools greater spending flexibility.

Most state agencies and school districts will continue to be hard-pressed to accomplish their core missions with significantly reduced staffing and resources.

**NOTE: These highlights were prepared by the Oklahoma Policy Institute. For more detailed information Download OK Policy's 6-page FY '11 Budget Highlights that provides a set of policy points, charts and tables that will allow you to understand the decisions that were made can be at <http://okpolicy.org/files/FY11Highlights.pdf>. Go to the main budget page on our website, <http://okpolicy.org/fy-10-fy-11budget-information>, for a full array of resources and materials.*

Although the SFY 2011 funding for services will remain low, the situation could have been much more serious. It was an outcry from concerned advocates who contacted legislative leadership and many of whom attended rallies at the Capital in the last weeks of the session that convinced legislators that they needed to enhance revenue rather than let near draconian budget cuts go into effect. The full impact on specific programs of interest to people with developmental disabilities and their families will become clearer in weeks to come as state agencies develop budget work plans for SFY 2011.

More details will follow in the next edition of the TARC Newsletter.



New Online Tool Furthers Equality in the Workplace for People With Disabilities

The U.S. Department of Labor recently unveiled a new tool to help America's employers ensure their employment policies and practices do not discriminate against qualified individuals with disabilities. The online Disability Nondiscrimination Law Advisor helps employers quickly and simply determine which federal

disability nondiscrimination laws apply to their business or organization, as well as their responsibilities under them.

Source: Fusion - E-newsletter for Chapters of The Arc

Supporting People with Disabilities Who Are Aging

Aging is an important issue for the families we serve and the focus of the recent issue of Impact, published by the University of Minnesota's Institute on Community Integration and Research and Training Center on Community Living. This publication provides valuable insight from self-advocates, siblings, researchers, and service providers about supporting people with intellectual and developmental disabilities who are aging. Impact offers fresh perspectives and the latest news from the field, which we hope you can use to increase the effectiveness of your own programs. Go to <http://ici.umn.edu/products/impact/231/> to download a copy of the publication

Source: Fusion - E-newsletter for Chapters of The Arc

Autism Conference Set for November

Families, agencies, and professionals continue to work to improve the lives of Oklahoma individuals with autism spectrum disorders, their families, and all those who educate and provide services for them. The 2nd annual Oklahoma Statewide Autism Conference will be held November 19-20, 2010 at the Embassy Suites Hotel and Conference Center in Norman, Oklahoma. Conference presentations include those on medical and health, education and social skills, and family support and advocacy. Save the date! Registration material will be available this summer.



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US Labor Department Unveils Tool to Help Employers Understand Nondiscrimination Laws.

The U.S. Department of Labor today unveiled a new tool to help America's employers ensure their employment policies and practices do not discriminate against qualified individuals with disabilities.



"Today, we made it easier for employers of all sizes to access the talents of the 36 million Americans with disabilities," said Assistant Secretary of Labor for Disability Employment Policy, Kathleen Martinez. "By providing this interactive and easy-to-use online tool, both workers and employers can readily access and understand their rights and responsibilities under our federal disability nondiscrimination laws."

The online Disability Nondiscrimination Law Advisor, available at <http://www.dol.gov/elaws/odep.htm>, helps employers quickly and simply determine which federal disability nondiscrimination laws apply to their business or organization and their responsibilities under them. It asks users to answer a few relevant questions in order to take into account relevant variables, such as nature of organization, size of staff and whether the business or organization receives federal financial assistance. Based on the responses provided, the advisor then generates a customized list of federal disability nondiscrimination laws that likely apply, along with easy-to-understand information about employers' responsibilities under them.

The laws addressed by the Disability Nondiscrimination Law Advisor include:

- Titles I and II of the Americans with Disabilities Act of 1990
- Section 188 of the Workforce Investment Act of 1998
- Section 504 of the Rehabilitation Act of 1973, as amended (as it pertains to federal financial assistance)
- Section 503 of the Rehabilitation Act of 1973, as amended
- The Vietnam Era Veterans' Readjustment Assistance Act of 1974, as amended

The advisor also can help employees, job applicants and people applying for or participating in federally funded programs learn more about their rights under these laws. In addition, it includes a Guide on Employ-

ing People with Disabilities that outlines resources available to help employers comply with disability nondiscrimination laws.

The Disability Nondiscrimination Law Advisor is one of a series of Employment Laws Assistance for Workers and Small Businesses, or "elaws," Advisors developed by the Labor Department's Office of the Assistant Secretary for Policy, working with other department agencies, to help employers and employees understand federal employment laws. To access this set of advisors, visit the elaws website at <http://www.dol.gov/elaws/>. To learn more about the Labor Department's efforts to increase employment opportunities for people with disabilities, visit <http://www.dol.gov/odep>.

Senate Committee Approves Legislation to Change Label of 'Mental Retardation' to 'Intellectual Disability'

On May 26, the U.S. Senate Health, Education, Labor and Pensions Committee approved, by voice vote, a bill titled Rosa's Law (S. 2781) that would change references to the words 'mental retardation' in numerous existing laws to 'intellectual disability'. The bill, introduced by Senator Barbara Mikulski (D-MD) and Michael B. Enzi (R-WY) is aimed at eliminating the terms 'mental retardation' and 'mentally retarded' from the U.S. federal law books. Before approving the measure, the panel adopted, by unanimous consent, a Mikulski substitute amendment that would specify that the bill is not intended to change coverage, eligibility, rights, responsibilities or definitions in existing laws and that the bill also is not intended to require states to make similar changes to state laws. Read the text of this legislation at <http://thomas.loc.gov/cgi-bin/query/z?c111:S.2781>:



Rosa's Law coincides with the publication of the 11th edition of the definition manual titled Intellectual Disability: Definition, Classification, and Systems of Supports by the American Association on Intellectual and Developmental Disability (AAIDD). This is the first definition manual where AAIDD presents an official definition for "intellectual disability", the condition formerly referred to as mental retardation.

Source: AAIDD

Governor Signs Scholarship Bill for Special Needs Students

On June 8, 2010 Gov. Brad Henry signed a bill providing scholarships to special needs students. House Bill 3393, by Nelson and state Sen. Patrick Anderson, would allow students with disabilities who have an individualized education program (IEP) to qualify for a scholarship to attend any public or private school that meets the accreditation requirements of the State Board of Education.

The legislation had strong support from many families of children with autism who lobbied for passage of the law.

The legislation has been named the Lindsey Nicole Henry Scholarships for Students with Disabilities Program Act to honor the memory of the governor's daughter, who died of a rare neuromuscular disease as an infant.

"We are very honored that Governor and Mrs. Henry have allowed us to name this important piece of legislation after their daughter who passed away at seven months of age," said Wanda Felty, parent of a child with multiple disabilities. "The simple fact is there is often an unspoken bond among parents of special needs children, and although Lindsey Nicole's life was short, she helped shape the type of people the Henrys are. We appreciate their compassion and understanding of our plight, and we certainly appreciate the Governor's support of this bill."

"We want to make it clear, neither the Governor, nor his wife, nor his staff nor anyone connected to him asked for this change. Instead it was suggested to him as a way to honor the memory of his daughter and let it be known for generations to come that she, and her parents, are helping to improve the lives of special needs children across the state," said state House Speaker Pro Tempore Kris Steele, R-Shawnee. "Especially given that this program was passed in the waning days of the last legislative session of Governor Henry's tenure, we think this action is both appropriate and warranted."

Lindsey Nicole was the twin of the Henrys' oldest daughter, Leah. Lindsey died at seven months of age due to complications from a rare genetic disorder.

The scholarship program created through House Bill 3393 would not require new spending, but would merely redirect existing state funds that are currently spent on the student.

Other states with similar laws include Florida, Georgia, Utah, Ohio and Arizona. The Florida program has been in place since 1999 and now serves approximately 20,000 students with special needs. House Bill 3393 closely mirrors the Florida and Georgia laws. The approval of HB 3393 raises many questions for families of children with disabilities. The answers to the few key questions below were taken directly from the language in the law.

When will the Scholarship program begin?

Scholarships shall be awarded beginning with the 2010-2011 school year.

Under what conditions is the scholarship awarded?

The parent or legal guardian of a public school student with a disability may exercise their parental option and request to have a Lindsey Nicole Henry Scholarship awarded for the child to enroll in and attend a private school and the scholarship shall be awarded if:

- The student has spent the prior school year in attendance at a public school in this state. For purposes of this section, "prior school year in attendance" means that the student was enrolled in and reported by a school district for funding purposes during the preceding school year; and
- The parent or legal guardian has obtained acceptance for admission of the student to a private school that is eligible for the program and has notified, in writing, the school district of the request for a scholarship at least sixty (60) days prior to the date of the first scholarship payment. For purposes of continuity of educational choice, the scholarship shall remain in force until the student returns to a public school or graduates from high school. If the residence of the student changes, the district of residence shall assume responsibility for the scholarship. At any time, the parent or legal guardian of the student may remove the student from the private school and place the student in another private school that is eligible for the program
- If the parent or legal guardian requests a Lindsey Nicole Henry Scholarship and the student is accepted by the private school pending the availability of a space for the student, the parent or legal guardian of the student shall notify the school district sixty (60) days prior to the first scholarship payment and before entering the private school in order to be eligible for the scholarship when a space becomes available for the student in the private school.

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What schools are eligible?

To be eligible to participate in the Lindsey Nicole Henry Scholarships for Students with Disabilities Program, a private school shall notify the State Department of Education of its intent to participate. The notice shall specify the grade levels and services that the private school has available for students with disabilities who are participating in the scholarship program. The State Department of Education shall approve a private school as eligible to participate in the scholarship program upon determination that the private school:

- Meets the accreditation requirements set by the State Board of Education or another accrediting association approved by the State Board of Education;
- Demonstrates fiscal soundness by having been in operation for one (1) school year or providing the State Department of Education with a statement by a certified public accountant confirming that the private school desiring to participate is insured and the owner or owners have sufficient capital or credit to operate the school for the upcoming year by serving the number of students anticipated with expected revenues from tuition and other sources that may be reasonably expected. In lieu of a statement, a surety bond or letter of credit for the amount equal to the scholarship funds for any quarter may be filed with the Department;
- Complies with the antidiscrimination provisions of 42 U.S.C., Section 2000d;
- Meets state and local health and safety laws and codes;
- Will be academically accountable to the parent or legal guardian for meeting the educational needs of the student;
- Employs or contracts with teachers who hold baccalaureate or higher degrees, or have at least three (3) years of teaching experience in public or private schools, or have special skills, knowledge, or expertise that qualifies them to provide instruction in subjects taught;
- Complies with all state laws relating to general regulation of private schools; and
- Adheres to the tenets of its published disciplinary procedures prior to the expulsion of a scholarship student.



What are the responsibilities of parents?

- the parent or legal guardian shall select the private

school from the schools approved for eligibility ...and apply for the admission of the child,

- the parent or legal guardian shall request the scholarship at least sixty (60) days prior to the date of the first scholarship payment,
- any student participating in the scholarship program shall attend throughout the school year, unless excused by the school for illness or other good cause, and shall comply fully with the code of conduct for the school,
- the parent or legal guardian shall fully comply with the parental involvement requirements of the private school, unless excused by the school for illness or other good cause, and
- upon issuance of a scholarship warrant, the parent or legal guardian to whom the warrant is made shall restrictively endorse the warrant to the private school for deposit into the account of the private school.
- A participant who fails to comply with this subsection forfeits the scholarship.



What funding amount will the private school receive?

The maximum scholarship granted for an eligible student with disabilities shall be a calculated amount equivalent to the local and county revenue for the school district which is chargeable in the State Aid formula, state-dedicated revenue, and state-appropriated funds per weighted average daily membership generated by that student for the applicable school year. The weighted average daily membership shall be determined using the grade and disability weights only. The maximum scholarship amount shall be calculated by the State Board of Education for each year the student is participating in the scholarship program; The amount of the scholarship shall be the amount calculated above or the amount of tuition and fees for the private school, whichever is less, minus up to five percent (5%) of the scholarship amount which may be retained by the school district as a fee for administrative services rendered.

How will payments be made?

The initial payment shall be made after the school district verifies admission acceptance and enrollment. Quarterly payments shall be made upon verification of continued enrollment and attendance at the private school. Payment shall be made by the school district with an individual warrant made payable to the parent

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or legal guardian of the student and mailed by the school district to the private school that the parent or legal guardian chooses. The parent or legal guardian shall restrictively endorse the warrant to the private school for deposit into the account of the private school.



Will the school district have to pay any additional costs?

A school district shall not be responsible for any additional costs associated with special education and related services incurred by the private school for the student including the cost of teachers, equipment, material, and special costs associated with the special education class.

There will be many issues that must be addressed as this bill is implemented. For more complete details parents should review a complete copy of HB 3393. A copy of the law can be downloaded from the legislative website at <http://www.lsb.state.ok.us/> using the Text of Measures button under the Legislative Information System column.

New Book Dispels Myths and Provides Insights into Issues in End-of-Life Care for People with Developmental Disabilities

While care for people with developmental disabilities has undergone revolutionary improvements, it still isn't unusual to have some continue to wonder why people with developmental disabilities should consider aggressive medical management in specific situations. Further, palliative care for people with intellectual disabilities is inherently controversial and ridden with medical, ethical, and legal complexities for which most professionals receive little training and can turn to very few resources for help. For the first time, End-of-Life Care for Children and Adults with Intellectual and Developmental Disabilities presents a comprehensive framework under which professionals and families can make decisions that are thoughtful, ethical, and most importantly, respect the wishes of individuals with disabilities. The book is written by a diverse group of authors, including physicians, nutritionists, gerontologists, and social workers.

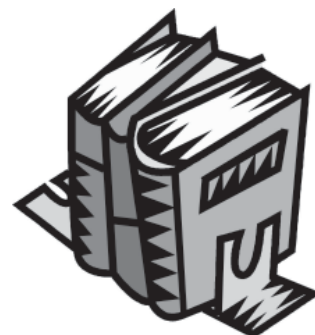
"Caring for people who are medically fragile or who have life-remitting conditions is emotionally laden. By dispelling some of the myths and providing information on various medical, legal, and ethical issues, David Helm and I hope that people can make decisions that are timely and sensitive and conform to the wishes and needs of those involved," says co-editor of the book Sandra L. Friedman, MD. Dr. Friedman is section head of Neurodevelopmental and Behavioral Pediatrics at the Children's Hospital in Denver, Colorado.

End-of-Life Care is unique in that the book brings back the focus of palliative care decisions on respect, dignity, and the needs of the person with whom, or for whom, decisions are being made. Dr. Friedman explains, "While in many instances, there is no 'right' or 'wrong' way to approach a particular issue related to end-of-life care, certain fundamental ethical tenets underlie the process of making decisions and providing care. Decisions must be made respecting individual preferences and respecting family values within medically indicated treatment plans."

End-of-Life Care is divided into five sections where readers can learn: (1) Critical events that have affected the current state of palliative care and practice in medicine, law, and ethics; (2) Information regarding medical conditions encountered at the end of life.

These include neurological, pulmonary, gastrointestinal, endocrinal, and sensory problems as well as issues associated with behavior, orthopedic and bone health, infections, and metabolism; (3) An in-depth discussion on the many controversies such as Do-Not-Resuscitate Orders and Persistent Vegetative State associated with end-of-life care and guidelines for making decisions that are thoughtful, respectful, and ethical; (4) Strategies on how to address the social, emotional, and spiritual needs of patients, their families, and caregivers; and (5) Practical guidelines and resources on how to support children, adults, and their families in planning for the end of life.

To read reviews and a chapter excerpt, and to purchase End-of-Life Care for a special pre-publication price, visit <http://bookstore.aaid.org>.



Source: AAIDD

Landmark Chemical Legislation Introduced to Protect the Health of American Families

The Environmental Health Initiative (EHI) of AAIDD joined a broad coalition of more than 200 public health and environmental organizations, called Safer Chemicals, Healthy Families, to announce its support for the newly introduced “Safe Chemicals Act of 2010”. The Senate bill was introduced on April 15 by Senator Lautenberg, and Congressmen Waxman and Rush released a discussion draft of legislation. The long-awaited, landmark legislation would overhaul the way the federal government protects the public from toxic chemicals.

“We at AAIDD urge Congress to strengthen the Environmental Protection Agency’s (EPA) authority to take swift action on the worst chemicals – the ones that we already know are linked to disease and disability, and that accumulate in our bodies,” said Joyce Martin, Director of Health Policy, Environmental Health Initiative at AAIDD. “We look forward to a bill that protects all of us, and especially the most vulnerable, from dangerous chemicals.”

While there are differences between the House and Senate versions of the legislation, the bills include a number of essential reforms that would substantially improve public health protections, including requiring chemical companies to develop and make publicly available basic health and safety information for all chemicals and requiring chemicals to meet a safety standard that protects vulnerable sub-populations, including pregnant women and children.

“Learning disability groups, along with our coalition partners at Safer Chemicals, Healthy Families, have been advocating for this day for over two years. Our many staff meetings and testimonies on Capitol Hill have driven home the message that developing brains need protection from toxic chemicals and that the health cost of continuing present policy is too high in both intellectual damage and health care dollars,” said Maureen Swanson, Director of the Healthy Children Project of the Learning Disabilities Association of America (LDA).

The Safe Chemicals Act would amend the federal Toxic Substances Control Act of 1976 (TSCA). The current TSCA law is widely acknowledged to be ineffective. TSCA ‘grandfathered in’ 62,000 chemicals in

use at the time it passed without requiring any testing or demonstration of safety. In the ensuing three decades under TSCA, EPA has required testing for only a few hundred of those chemicals and has only partially restricted five. Meanwhile, a growing body of science has documented widespread human exposures to toxic chemicals in everyday products, and has linked those exposures to the rising incidence of a number of serious chronic diseases and disorders, including reduced fertility, learning and developmental disabilities, breast and prostate cancer, and certain childhood cancers

Senator Frank Lautenberg, sponsor of the bill, stated that “America’s system for regulating industrial chemicals is



broken. Parents are afraid because hundreds of untested chemicals are found in their children’s bodies. EPA does not have the tools to act on dangerous chemicals, and the chemical industry has asked for stronger laws so that their customers are assured their products are safe.”

AAIDD and the coalition called for improvements in three critical areas. As currently drafted, the legislation would:

- Allow hundreds of new chemicals to enter the market and be used in products for many years without first requiring them to be shown to be safe.
- Not provide clear authority for EPA to immediately restrict production and use of the most dangerous chemicals, even persistent, bioaccumulative, and toxic (PBT) chemicals like asbestos and lead, which already have been extensively studied and are restricted by governments around the world.
- Would not require EPA to adopt the National Academy of Sciences’ recommendations to incorporate the best and latest science when determining the safety of chemicals, although the Senate bill does call on EPA to consider those recommendations.

“Leaders in the learning and developmental disabilities field, and especially those of us who represent the autism community, look forward to working with Congress to develop a workable and defensible chemical policy for the nation,” said Donna Ferullo, Director of Research Programs, The Autism Society . “This can best be accomplished by closing loopholes for review of new chemicals and strengthening EPA’s authority to take swift action on the worst.”

Source: AAIDD



Measure Providing Insurance Fairness for Children with Autism Signed by Governor

Starting Nov. 1, parents of children with autism will have greater protection when it comes to more fair treatment by insurance companies. A bipartisan effort this legislative session resulted in a bill to make certain health insurance companies cover the same illnesses for children with autism as they do children without such a diagnosis.

This measure began as a stand-alone bill – SB1657 – filed by Senator Jay Paul Gumm but this bill failed to advance and became dormant early in the session.

The bill with the assurance that was signed by the Governor is SB 2045. When SB 2045 was before the Senate, Senator Gumm discussed the issue with Sen. Bill Brown, chair of the Senate Committee on Retirement and Insurance, and a bipartisan agreement was struck to include the language in the dormant bill (SB1657) as an amendment to SB 2045. Senators overwhelmingly approved and the amended bill passed both the Senate and House of Representatives.

This measure was signed by the governor on April 26th.

“During my work with families who have children with autism, this was one of their highest priorities,” said Senator Gumm. “We have families who have children with autism who pay their premiums and expect to be treated fairly. This amended bill will ensure that very thing.”

The senator said dozens of families told him some insurance companies routinely deny claims filed on behalf of children with autism for illnesses and maladies unrelated to the diagnosis of autism. Such claims were denied because Oklahoma does not require health insurance policies to cover diagnosis and treatment of autism and most insurers specifically exclude autism.

“For me,” Gumm said, “Regardless of anyone’s stand on whether insurers should be required to cover diagnosis and treatment of autism, one fundamental fact remains: If a child with autism breaks an arm on the playground or gets sick, they should be covered the same as any other child.” He called this bill a critical step toward fairness for families who are struggling with autism.

New Findings May Accelerate Autism Testing and Treatment

A leading autism researcher at McMaster University is co-principal investigator for a team of international scientists who have uncovered more key changes in the DNA of individuals with autism.

The researchers reported that individuals with ASDs tended to carry more insertions and deletions affecting their genes - called copy number variants (CNV) - than did people in the control group. Some of these CNVs appeared to be inherited, while others are considered new, because they are found only in offspring with autism and not in the parents. Dozens of new “autism risk genes” were discovered, including some that might be helpful in early diagnosis.

“This study will lead to a paradigm shift when it comes to our understanding of the root causes of autism and indeed other neurodevelopmental disorders,” said Szatmari, director of the Offord Centre for Child Studies at McMaster.

“Previously it was believed that autistic individuals share common genetic variations in a few genes. This research points to the fact that genetic variations are actually rare, meaning individuals with autism are genetically quite unique. But as we discover more and more of these variants, the number of cases of ASD we can explain increases substantially.”

Scherer, director of The Centre for Applied Genomics at SickKids, said: “We now know several of the genes involved in autism and for the first time, we are able to tie many of these genes into the same biological pathways involved in brain function.”

“Knowing these autism genes are linked, we can begin to develop therapies to target the common pathways involved.”

The study found that for about 10 per cent of the families studied, there are some genetic clues that may assist in the early diagnosis of autism or related complications. The Canadian researchers say the next step is to set up a way that all families can have access to this testing.

Source: McMaster University

How Health Reform Helps the People of Oklahoma

President Obama signed into law an historic package of health reforms that will dramatically improve the state of health care across America. The new health reform law will guarantee that everyone—businesses large and small, seniors, children, those who currently have insurance and those who don't—have access to health coverage they can afford.

These fact sheet was designed to highlight the following issues that people in Oklahoma face that the new health reform law addresses:

Cracks Down on Insurance Company Abuses

- Insurers will no longer be able to deny you coverage because of a pre-existing condition or drop your coverage when you get sick.
- Insurers will no longer be able to charge higher premiums based on your gender or health status.
- Oklahomans have been paying more for coverage and getting less. Insurers finally will be required to spend more of our premium dollars on actual medical care and quality measures.

Ends Runaway Premiums for the Middle Class

- Uninsured Oklahomans will be able to gain coverage

through a competitive marketplace called an “exchange.” By forcing insurance companies to compete, exchanges will drive down costs, guarantee choice, and put consumers in control.

- People with moderate incomes (for example, a family of four making up to \$88,000) will get help paying their premiums.

Provides Financial Security and Stability

- All of Oklahoma’s 575,000 seniors and people with disabilities on Medicare will no longer have to pay for preventive services, and many will have more help paying for prescriptions.
- Health reform will set limits on how much families will have to spend on health care out of their own pockets (on copayments, deductibles, etc.).
- Insurers will no longer be able to put yearly or lifetime limits on how much they will pay for your care if you get sick.
- Health reform will reduce the federal deficit by \$138 billion in the next 10 years and will save \$1.2 trillion more in the following two decades.

Expands Coverage, Saves Lives

- Young adults can stay on their parents’ health plans up to the age of 26.
- Health reform will save lives. Without reform, an estimated 5,000 Oklahomans would have died prematurely due to a lack of health coverage over the next decade.
- 394,000 uninsured Oklahomans will gain insurance coverage by 2019.

Source: Families USA

TARC CALENDAR OF EVENTS

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

Links Meets the 3rd Wednesday of each month:

June 16th	July 21st	Aug. 18th
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Meetings are held at TARC's new office:
2516 East 71st St., Suite A
Tulsa, OK 74136-5531
6:00 pm- 7:45 pm

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 • 10:00-11:00 a.m.
Gatesway Foundation-Mabee Gym
1217 E. College in Broken Arrow
Thursdays • 1:00-2:30 p.m.
Whiteside Park, 4009 S. Pittsburgh,
Tulsa, 74135

Hispanic Parents Support Group
El Grupo Hispano de Apoyo a Padres de Familia
Meets last Tuesday of each month

June 29th	July 27th	Aug. 31st
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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.



Connections Asperger's Group

Connections meets the 4th Wednesday of each month:

June 23rd	July 28th	Aug. 25th
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Hardesty Regional Library
8316 E. 93rd St.

4:30 pm- 6:00 pm

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.

MOMS & DADS SUPPORT GROUP

Moms and Dads meets the last Thursday of each month:

June 24th	July 29th	Aug. 26th
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7:00 pm-9:00 p.m.
TARC Office
2516 East 71st St., Tulsa

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 meets the 2nd Tuesday of each month:

June 8th	July 13th	Aug. 10th
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Dinner 5:30 p.m.
Meeting 6:30 p.m.

For more information call

Amie Farinella at
918-582-8272

Families in Transition

Families in Transition is a support group for parents of adult children with developmental disabilities and meets Quarterly

The next meeting will be:

Aug. 11th

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