

TARC NEWSLETTER

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

January 2006

CONTENTS

Look Before You Leap in 2006.....	1
DD Groups Oppose Alito Nomination	2
Mental Health Parity	2
Emergency Preparedness	2
Congressional Update: FY 2006 Appropriations, Budget Resolution	3
Letter of Intent	4
Folic Acid Awareness Week ..	4
DDSD Seeks Direct Support Nominations	5
Family Health History Tool Now Online	5
Special-Needs Youth Soccer Program.....	5
Evaluating Toys for Children with DDs	5
New MR Fact Sheet	5
Local Marfans Resource	5
Calendar of Events	6

Look Before You Leap in 2006

by John F. Gajda, TARC Executive Director

Happy New Year!

I like to begin each year by looking out over the coming months and surveying the advocacy issues that I will have to face in the coming year. On the horizon of this dawning new year, 2006, I see two major decisions that will have to be made by Oklahoma voters.

The first, of course, is selecting among the candidates in the general election in November to determine who will fill many key offices and represent us in Washington and Oklahoma City during the coming years. There also will be a series of primaries leading up to this ultimate face-off between candidates. Although on the federal level it is a so-called "off year election" because we will not be voting for president, all members of the U.S. House of Representatives will be up for reelection. On the state level, all statewide office holders such as the Governor, Lieutenant Governor, and Attorney General will be up for reelection as will all members of the Oklahoma House of Representatives and half of the members of the Oklahoma Senate.

The second decision is a likely vote on a measure that will further limit state taxes. If I am to believe the political rhetoric I have been hearing about this so-called taxpayer bill of rights measure (also referred to as TABOR for short), we are all starting the new year standing at a fence looking out over a greener pasture beyond because in 2006 we will be able to vote to approve this proposal and create a new and improved State of Oklahoma. An initiative petition has been circulated to collect signatures to get this measure on the ballot and what are claimed to be enough signatures have been filed with the Secretary of State. The process of reviewing the petition and deciding when the measure will be put on the ballot is underway and, although the final determination has not been made, there is a good possibility that Oklahomans will be voting on this proposal in 2006.

Please see 2006, pg. 2



Affiliated with
The Arc



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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2006, from pg. 1

The identity of the wise person who first cautioned “look before you leap” has long been forgotten as the expression has become a part of our everyday language. But as we move from 2005 into 2006 the sentiment has never been timelier than it is today for Oklahoma voters who care about people with disabilities.

Whenever there is some sentiment against government in general or what it has done or failed to do, it always seems that we blame “those other guys” rather than our own personal representatives we vote for in our districts. Consequently voters tend to go back election after election and vote for their favorite candidates — again with some vague promise that things will be different. The reality is that the vast majority of the people we have been electing each year haven’t supported the issues that are important to people with disabilities and their families.

This year, before we vote for “more of the same” consider if your vote will really mean a better life for people with disabilities and their families. We also need to be just as cautious about those candidates who promise change for change sake under some ideological or political banner such as “conservative.” They may sound appealing but what will the impact of their beliefs be on people with disabilities?

The possibility of lower taxes is, on the surface, an enticing possibility to most of us. But, do we really believe that Oklahoma state government is doing all it should do for people with disabilities? Will limiting revenue improve this? Do you remember the sorry state of funding for services for people with disabilities in Oklahoma just two years ago? Revenue is much better now, but just as sure as the revenue picture in Oklahoma has improved and become bleak in the past, we will go through this cycle again. Do we want to further limit options in the future?

As we move into 2006 and reflect on the decisions we will be making at the ballot box, we need to look carefully at the issues and opportunities for choice we will be given and seek out the realities for people with disabilities. Many options that will be offered by referendum and candidates for public office may appear intriguing on the surface but we need to take a long look before we commit our support. What may be appealing on the short term may not be in the best long-term interest of people with disabilities.

Look before you vote in 2006!

National Disability Groups Oppose Alito Nomination

On January 9, 2006, the Senate Judiciary Committee began the confirmation process for Judge Samuel Alito, nominated for the U.S. Supreme Court. Three national disability rights groups have announced opposition to Judge Alito’s nomination. ADA Watch/National Coalition for Disability Rights (NCDR), the National Council on Independent Living (NCIL), and the Bazelon Center for Mental Health Law joined Rep. Barney Frank, D-Mass., in calling for the U.S. Senate to reject Alito’s confirmation. The groups are concerned that Alito’s nomination to replace the moderate Sandra Day O’Connor might portend a rollback in civil rights protections for people with disabilities.

Source: Capitol Insider, Vol. 10, Issue 51, published by DPC

Senate Extends Mental Health Parity Law by One Year

On December 22, 2005, the Senate by voice vote passed a bill (HR 4579) that would extend for one year a mental health parity law under which health insurers cannot place caps on annual or lifetime mental health benefits unless they place similar caps on medical and surgical benefits. This extends a 1996 law that was scheduled to expire on December 31, 2005. The House had passed a similar bill earlier that month.

Harkin Introduces Emergency Preparedness Legislation

On December 16, 2005, Senator Tom Harkin, D-Iowa, introduced the Emergency Preparedness and Response for Individuals with Disabilities Act of 2005 (S. 2124), addressing the needs of individuals with disabilities in emergency planning and relief efforts.

The bill would create a Disability Coordinator in the U.S. Department of Homeland Security, reporting directly to the Secretary. The Coordinator would develop curriculum for first responder training, ensure accessibility of emergency and evacuation information, and provide guidance about the rights of individuals with disabilities in emergencies and relocation. The act would require that 30% of temporary housing for disaster victims be accessible.

Source: Capitol Insider, Vol. 11, Issue 1, published by DPC

Congress Completes Action on FY 2006 Appropriations, Leaves Budget Reconciliation Unresolved

As the first session of the 109th Congress came to a conclusion in December, the final two Fiscal Year 2006 appropriations bills were sent to the President for his signature three months after the start of the fiscal year. Both bills markedly impact federal spending for disability discretionary spending.

FY 2006 Department of Defense Appropriations

The Congress passed the FY 2006 Defense Department appropriations bill, but only after stripping out the controversial Arctic oil drilling provision. This bill has grave implications for all federal discretionary spending because it contains a 1% across-the-board cut in all discretionary spending except programs that serve veterans. This cut will reduce discretionary spending by \$8 billion.

FY 2006 Department of Labor - Health and Human Services - Education Appropriations

For the first time in decades, the Congress actually provides less funding for these three departments than in the previous year. Total FY 2006 funding is almost \$170 million lower than the FY 2005 appropriation. Overall spending in each department is cut.

Disability programs in the departments, which constitute more than 90% of all disability discretionary spending, are mostly frozen or receive small increases, with the exception of the Supported Employment State Grant Program (20% cut) and the Office of Disability Employment Programs (40% cut). These funding percentages do not take into consideration the 1% across-the-board cut. As a result, very few, if any, disability programs will actually see an increase in FY 2006, and this is especially true once the 1% cut is applied. Thus, the bleak appropriations picture, anticipated after the enactment of the FY 2006 Budget Resolution last spring, has fully materialized.

FY 2006 Budget Reconciliation

While the first session of the 109th Congress has ended, Congress still has some unfinished work to meet its entitlement spending reduction goals. House and Senate conferees completed action on the Budget Reconciliation bill in December, settling on \$39.7 billion in cuts to entitlements. Conferees agreed that Medicaid would be cut by \$6.9 billion over 5 years while \$2.1 billion was added to Medicaid for hurricane relief and to support the Family Opportunity Act and the Money Follows the Individuals Demonstration Program. The House of Representatives passed the conference report by a six-vote margin, after a rare all-night Sunday session. Sixteen House members failed to vote.

The conference report is bad news for people with disabilities and their families nationwide.

- It would cut human services entitlement spending by almost \$40 billion over 5 years.
- Medicaid would be cut by \$6.9 billion, with new Medicaid spending increased by \$2.1 billion for new benefits to hurricane victims and expanded eligibility under the Family Opportunity Act and the Money Follows the Individuals Demonstrations.
- The report would save about \$1 billion by delaying back payments to SSI beneficiaries.
- The report reauthorizes the Temporary Assistance for Needy Families program with onerous work requirements that make it almost impossible for recipients with disabilities or those caring for family members with disabilities to meet them. States would be put in a financial predicament for maintaining these individuals in the TANF program, and would be mandated to meet a 50% work participation rate or face penalties.

The Senate then voted 51 to 50 to pass the Budget Reconciliation bill, with Vice President Dick Cheney casting the tie-breaking vote. Prior to the final vote, however, a "point of order" was allowed, stripping several non-germane provisions from the bill. This "point of order" now necessitates another House vote before the bill can be sent to the President for signature.

Since the House had already adjourned, Speaker Dennis Hastert, R-Ill., attempted to have the measure passed by unanimous consent, a move stymied by Minority Leader Nancy Pelosi, D-Calif., who objected. Thus, the House's action on the Budget Reconciliation has been delayed until it returns for its second session, scheduled for January 31.

The Arc of the United States, United Cerebral Palsy, and numerous advocacy groups continue to oppose the Budget Reconciliation bill because its provisions will hurt Medicaid beneficiaries, as well as SSI and TANF recipients. The upcoming House vote represents the last likely opportunity for disability advocates to defeat this very harmful bill. The Arc and United Cerebral Palsy have posted action alerts for the last push to urge House members to vote against the conference report. To see the action alert, visit www.thearc.org, go to the Get Involved link and navigate to "Action Center," and contact your House member today.

Sources: DPC News & Information Bulletin, December 23, 2005 and DCP Capitol Insider, Vol. 11, Issue 1

Letter of Intent Vital for Communication to Future Caregivers

Free Form Available Online from Attorney-Author L. Mark Russell

“How can you, as a parent, be assured that your son or daughter will lead as complete a life as possible after your death? What can you do to make sure your hopes and aspirations are realized?”

These are questions posed by attorney L. Mark Russell, co-author of *Planning For The Future: Providing a Meaningful Life for a Child with a Disability After Your Death*.

Russell says that writing a letter of intent is a critical step in the planning process. “This critical document permits parents to communicate vital information about their son or daughter to future caregivers.”

He stresses that parents are the experts on their own child. “You receive a lot of important advice from professionals, but no one understands your son or daughter’s needs and desires better than you. If you become incapacitated or die, it is vital that future caregivers have access to your knowledge,” he says.

Future caregivers might be relatives, friends, or professionals – anyone who will care for a child when a parent is no longer able to do so. Russell asks parents to consider whether or not future caregivers know:

- all the pertinent information about the child’s medical history
- the names, addresses, and phone numbers of all the professionals who serve the child
- the names of professionals who you think should be avoided
- where parents would like the child to live, or even if they don’t know exactly, the type of place that should be considered
- the recreational activities that make the child happiest
- the type of work, if any, that a son or daughter should do
- and all the other information necessary to care for a son or daughter.

Russell tells a story about one mother who wrote in her Letter of Intent about her 9-year-old son with a seizure disorder, “Don’t forget that my child only takes his medication with cherry Jell-O.” He says it is vital to put this kind of information in a letter to future caregivers.

Parents may access a free downloadable Letter of Intent Form at www.specialneedslegalplanning.com.

TARC Promotes Folic Acid Awareness Week, Jan. 9-15, 2006



TARC is joining with the National Council on Folic Acid (NCFA) in launching National Folic Acid Awareness Week, January 9-15 2006. This initiative promotes awareness of folic acid consumption as a key strategy for optimal health, particularly among women of childbearing age.

Folic acid is a B-vitamin necessary for proper cell growth. The U.S. Public Health Service recommends that all women of childbearing age consume 400 micrograms of folic acid by taking a multivitamin daily and eating fortified grains, in addition to a variety of foods as part of a healthy diet.

In particular, women of childbearing age should take folic acid to help prevent a pregnancy affected by a neural tube birth defect (NTD), a serious birth defect of the brain and spine. Spina bifida, the most common NTD, is the leading cause of childhood paralysis and presents lifelong challenges for affected families. Research has shown that if

adequate amounts of folic acid are consumed before pregnancy, up to 70% of neural tube defects can be prevented.

“We know that taking 400 micrograms of folic acid before and very early in pregnancy from fortified foods or a multivitamin can help prevent NTDs by up to 70%. Considering that half of all pregnancies are unplanned, it is especially important that all women of childbearing age take folic acid daily to help prevent NTDs – even before they are thinking of becoming pregnant,” says Sherilyn Walton, TARC Family Support Coordinator. Emerging research shows that folic acid may reduce the risk of birth defects, such as cleft lip, cleft palate and heart defects, the risk of cardiovascular disease, Alzheimer’s disease, and colon, cervical and breast cancer.

To request a free brochure about folic acid (in English or Spanish), contact TARC at 918-582-8272. For more information about folic acid and National Folic Acid Awareness Week, visit the TARC website at www.ddadvocacy.net under the “What’s New” link.

DDSD Seeks Nominees for Direct Support Awards

The Oklahoma Department of Human Services, Developmental Disabilities Services Division (DDSD) has issued a call for nominations for Direct Support Services Awards. The awards will be given to outstanding Habilitation Training Specialists (HTS) who demonstrate excellence, creativity and commitment in supporting persons with developmental disabilities to lead full and productive lives.

To nominate an HTS for consideration, nominators may request a form from Sheree Powell at DDSD by calling 405-521-4972 or writing to Sheree.Powell@okdhs.org

The winners of the Direct Support Services Awards will be honored during a special ceremony at the 2006 Governor's Conference on Developmental Disabilities, March 13-14, 2006, in Midwest City. The deadline for nominations is **January 16, 2006**.

Site Evaluates Toys for Children with DDs

The holiday season may have wound to a close, but it is never too late to judge the appropriateness of a toy for a child with special needs. A new web-based resource has been launched to provide the information parents and professionals need to make the best toy choices. The AblePlay Rating System gives a snapshot of the toy's appropriateness for children with special needs. At the heart of the system are the comprehensive AblePlay™ Toy Reviews, which detail the "hows and whys" of each product, specifically for children with disabilities. For information, visit www.ableplay.org.

Surgeon General Releases Web-Based Health History Tool

My Family Health Portrait is a web-based tool designed to help families gather and share their health information. The tool, released as part of the U.S. Surgeon General's Family Health Initiative, organizes information into a printout that an individual can use, in partnership with a health professional, to determine whether he or she is at increased risk for six common diseases with a known genetic contribution, and for other conditions that may run in families.

Users can highlight certain diseases, such as diabetes, and produce personalized diagrams or charts for each family member that can then be used to develop individualized diagnosis, treatment, and prevention plans. The tool is intended for use by individuals, families, and professionals in understanding the importance of collecting a family health history and in making the process of gathering the information easier. The tool is available in English and Spanish at <https://familyhistory.hhs.gov/>



Help TARC by becoming a member today.

Youth Special Needs Soccer Program Recruiting Players

The Tulsa-based TOPSoccer Special Needs Soccer Program is recruiting children with disabilities aged 4 to 19 to participate in its Spring 2006 season. The goals of the program are to teach basic soccer skills, which incorporate turn-taking, following directions, and building gross motor and social skills. All skill levels are welcome.

To offer parents a more typical sports experience, TOPSoccer pairs the children who need on-field assistance with a "soccer buddy" so that parents may enjoy the event from the sidelines.

Families interested in the program may register their child at www.metrotulasoccer.com. For additional information, call 918-298-0190, Ext. 3.

New MR Fact Sheet Offered to Parents

Clinicians at the Children's Hospital in Boston have developed a new fact sheet titled "Answers to Parents' Questions on Mental Retardation" that explains what mental retardation is to parents who receive a diagnosis for their child. Visit www.communityinclusion.org/publications/pub.php?page=res9

Marfan Resource Available Locally

Oklahoma has two telephone support volunteers for families affected by Marfan Syndrome, a heritable condition that affects the connective tissue. Contact Mendie Campbell at 918-341-5347 or Carol McLean at 918-333-1201. For more information visit www.marfan.org.



TULSA ADVOCATES FOR THE RIGHTS OF CITIZENS WITH DEVELOPMENTAL DISABILITIES

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TULSA, OKLAHOMA 74119-4447

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

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Advocacy Has the Power to Make a Difference

MOMS & DADS
SUPPORT GROUP




Next Meeting: Thurs.,
January 26, 2006
7:00 - 9:00 PM

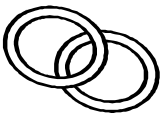
Kirk of the Hills Presbyterian Church, 4102 E. 61st St., Room B-8
Contact: Sherilyn Walton, 918-582-8272 • No childcare provided

Connections Asperger's Group

Next Meeting: Wed., January 25, 2006 – 4:30 p.m.
The "Connections" Asperger's Group is a social skills group for children and adolescents with Asperger Syndrome. The group meets monthly. Contact Sherilyn Walton, TARC family support coordinator, 918-582-8272 for information.



TULSA PEOPLE FIRST
Tuesday, February 14
Dinner @ 6:00 p.m.
Meeting @ 7:00 p.m.
For location or information, call Aaron Brown at 918-582-8272.

Couple's Conference:
"Reconnecting the I Do's"
for parents of children with disabilities



Saturday, January 28, 2006
8:30 a.m. to 3:30 p.m.
Location: Sheraton OKC, 1 N. Broadway
Cost: \$25 per couple, includes lunch and materials
Pre-registration Required
For more information, visit www.dsaco.org

Asperger's Syndrome S.O.S.
A project of Tulsa Public Schools in conjunction with TARC
Who: Parents and their children with Asperger's Syndrome
What: A social group for the kids; a support group for parents
Where: Remington Elementary School, 2524 W. 53rd Street
When: First Thursdays. Next Meeting: Thurs., Feb. 2, 2006 - 6:30 p.m.
S.O.S. is open to all students, not just those in Tulsa Public Schools.
To sign up, call Stephanie Orban or Lisa Rutledge at 746-8880.
For more information, contact Sherilyn Walton at TARC, 582-8272.


Hispanic Parents Support Group
El Grupo Hispano de Apoyo a Padres de Familia
Next Meeting: Monday, Jan. 16th • 7 to 8:30 p.m.
Martin Regional Library, 2601 S. Garnett
For information, call: Zaida Castro-Kepford, 918-582-8272