



# TARC NEWSLETTER

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

**April 2010**

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## Keep our Dreams Alive

*These comments were delivered at the Developmental Disabilities Awareness Day rally in Oklahoma City on March 25, 2010 by TARC Executive Director John F. Gajda*

The people who settled Oklahoma during the land run were pioneers who lead the way for others. They risked their lives, the lives of their loved ones and their futures to face the difficult challenges of the Oklahoma frontier. Why did they take this risk? They did it because they had a dream – a dream of a better life. Today their pioneer spirit is still alive. It is a force that energizes Oklahomans.

All of us here today are also pioneers. We are pioneers in the disability rights movement. There are also many fellow pioneers who I know could not be here today but are here with us in spirit. The frontier that challenges us today is not the vast land area that is Oklahoma but the old system of services for people with disabilities in our state and the old ways of thinking about people with disabilities. Like the pioneers who settled the State of Oklahoma during the land run, we are leading the way for all current and future Oklahomans with disabilities and their families. We continue to push the service system and the rights of people with disabilities forward by advocating for change.

We continue, despite the personal risks that confront us and the costs we must bear. Anyone who challenges the way things are done and advocates for changing the way we do things risks incurring resentment and hostility from others, risks being made fun of, risks being considered foolish and risks being rejected by others. Anyone who is willing to advocate and challenge the way things are done must be willing to invest time that perhaps we would rather spend on something else, sacrifice rest and recreations and be willing to move on and continue to advocate despite disappointment. Like our pioneer ancestors we continue to push forward despite these risks and costs because we have a dream of a better life for people with disabilities and their families.

As we gather here today we are at a critical point in our journey. Like the successful pioneers who settled Oklahoma during the land run, we have confronted challenges and overcome them. We have made progress in our efforts to change how services are provided, increased the number of people served and established

*Please see "Dreams" 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:

**2516 East 71st St., Suite A, Tulsa, Oklahoma 74136-5531**

www.ddadvocacy.net tarc@ddadvocacy.net 918-582-8272/800-688-8272 918-582-3628(Fax)

important rights for people with disabilities and their families. We have journeyed a long way from the days of isolation in institutions, lack of opportunity and little respect for individuals with disabilities.

But we are now facing a difficult road ahead. It is filled with pot holes, crumbling bridges and other obstacles that make further progress difficult. The road we must travel goes right through our State Capitol where we are gathered today. That is why we are here. We can not let progress for people with disabilities stall in this building. Meeting today with your legislators and educating them will help smooth the road for you and other people with disabilities and their families.

You will be told by legislators that times are tough, that there is nothing that can be done. Like our pioneer ancestors we cannot be discouraged by words like these that block our path and halt our journey forward. We need to remember that like other pioneers we have come this far because we had dreams – dreams for a better life for all people with disabilities and their families. And we still have dreams.

- We dream that all people with disabilities will live and work in our communities. This is where all services should be provided.
- We dream of increased material resources. More funding must be provided so that the more than 5,300 people on the DDS waiting list for services can get services now.
- We dream that all people with disabilities will have the same opportunities to receive services regardless of what diagnosis they have. The large gap in services for individuals in Oklahoma on the autism spectrum must be eliminated.
- We dream that all students with disabilities will be safe in public schools. Seclusion and restraints of children with disabilities in our schools must be eliminated.
- We dream that all people with disabilities will be respected. How we make people feel is just as important as what we provide for them. We must eliminate the “R” once and for all.
- We dream of quality direct support staff. Quality support is worth more than minimum wage and rates need to be increased so direct care staff can be paid a living wage.
- We dream of recognition by elected officials that people with disabilities are a group of voters whose needs cannot be ignored. All people with disabilities count.
- We dream of a service system that maintains safeguards that assure quality services. Even in tough economic times we should not lower our standards.
- We dream of flexibility that will give those receiving services more options. Self directed care should be available for all who want it.
- We dream of an informed legislature that understands the needs of people with disabilities, appreciates where the services system has been and where it is going, and acknowledges that support is vital for vulnerable Oklahomans. Through understanding, support for our dreams will grow.

All these dreams are not about the status quo that keeps things the way they are. Our dreams break the mold. For them to come true there must be change. But changes threaten some people because they challenge the way things have been done. We need to encourage people to follow us forward rather than being stuck on the way things have always been done.

Because our dreams are important they are what we advocate for. Our dreams are what we need to talk to our legislators about today and every other time we have an opportunity to meet with them. The need for our advocacy is everlasting. We should not and cannot stop just because we are bogged down and stalled in one place. Like our pioneer ancestors we must forge forward and smooth the road ahead.

As the funder of services and the creator of our laws, the Oklahoma Legislature may be the guardian of our dreams but we are the keepers of our hope. The Oklahoma Legislature may deny our dreams by refusing to fund services or failing to pass the laws we advocate for, but unless we let them, they cannot destroy the hope that we all have that our dreams will come true. It is our hope for a better life that keeps our dreams alive. Don't let our dreams die. Continue to hope. Keep up the fight. And keep our dreams alive.

# Legislative Session Reaches Half-Way Point

Moving into April, the 2010 session of the Oklahoma Legislature is more than half way through the planned meeting days. The critical early April deadlines (the 8th in the House and the 1st in the Senate) for legislation to be reported out of the committee in the opposite house further weeded out bills that do not have a chance of being approved this session from those that do.

Only 11 of the original 32 bills of interest originally identified by the TARC Newsletter remain active. Two of these have already been signed by the Governor.

An additional carryover bill of interest from the 2009 session not previously identified has come back to life. HB 1512 that would exempt schools from meeting certain standards for providing services to children receiving special education services has seen additional action this session. Updates on these 12 remaining bills that are still being considered follow.

The issue of greatest concern remains the budget for the coming state fiscal year that begins on July 1st. Rumors about the level of cuts that will be made range from 7 – 25%. There is also an ongoing debate over how cuts are to be applied – across the board equally to all agencies or selectively, targeting some agencies for greater cuts than others. For individuals with disabilities and their families the potential of cuts that can result in rate reductions for existing services is a gloomy option that looms over the future of the service system. For those on the growing waiting list for community based services any hope of actually receiving services is fast becoming a seemingly unattainable dream.

Bill	Principal Authors	Status	Description
HB 1512	Blackwell, Gus (H)	House Amendments-Read 3/24/2010	Exempts certain schools meeting certain standards from liability for not providing necessary services to a “child receiving special education.” It removes related duties of the school in providing education services to children with special needs. It states that the school is to be the sole determiner of the methodology in which to provide services for the child, as long as the child is receiving some education benefit.
HB 2281	Wright, John A. (H)	Governor Action-Signed 4/02/2010	Recreates the Electronic and Information Technology Accessibility Advisory Council until July 1, 2014.
HB 2282	Wright, John A. (H)	Governor Action-Signed 4/02/2010	Recreates until July 1, 2014, the Group Home for Persons with Developmental or Physical Disabilities Advisory Board.
HB 2567	Wesselhoft, Paul (H)	General Order- Senate 3/29/2010	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)	Senate Amendments-Read 4/07/2010	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.

*Continued on pg. 4*

HB 2710	Wallace, Collins (H)	General Order-Senate 3/23/2010	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)	General Order-Senate 3/31/2010	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 3170	Hickman, Jeff (H)	General Order-Senate 3/29/2010	Directs the State Board of Education to develop a funding mechanism for the disbursement of federal funds to reimburse local education agencies for the excessive costs of high-need students. It states that the mechanism is to divide the available federal funds evenly between funding for out-of-state residential placements for students with special needs who have an individual education program that calls for out-of-state residential placement and other high-need students with excessive costs to the local education agency that are three times the average per-pupil expenditure with a total excess cost of all high-need students that is at least 10 percent of the flow-through allocation for the local education agency.
HB 3393	Nelson, Jason (H)	General Order-Senate 3/31/2010	Clarifies that the Oklahoma Health Care Authority and the Department of Human Services are to operate the Self-Directed Care Option. It removes language allowing the consumer's self-directed care budget allowance to be used for home modifications and assistive devices that may increase the consumer's independence or make it possible to avoid institutional placement. It allows consumers to choose providers of services, including the home- and community-based self-directed services in conjunction with the Scholarships for Students with Disabilities Program created in the bill. It allows a child to be transferred upon submission of a written request by a parent and subject to the approval of a receiving district. The program allows school districts beginning with the 2010-2011 school year to comply with the Individuals with Disabilities Education Act by providing scholarships at the request of a parent for a student with an individualized education program to attend a private institution. The bill directs private schools wishing to participate in the program to notify the Department of Education of its intent by May 1.
SB 1280	Anderson, Patrick (S)	General Order-House 4/01/2010	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)	General Order-House 3/23/2010	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)	General Order-House 4/08/2010	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.

## Bridging the Budget Gap: Revenue Options for a Balanced Approach

Oklahoma is facing a severe and prolonged fiscal crisis. While budget cuts enacted this year are already corroding the public services upon which Oklahomans rely, the outlook for the coming year is even worse. Without additional revenues, next year's budget gap is equivalent to an additional 11 to 12 percent cuts to every agency of state government on top of the cuts already enacted.

### SPECIAL POINTS OF INTEREST

- Without additional revenues, next year's budget will require cuts of up to 12 percent across all state agencies on top of the cuts already enacted.
- Cuts of this magnitude would seriously damage core public services.
- Policymakers should choose a balanced approach to bridging the budget gap, one that includes new revenues in addition to budget cuts, efficiencies, and using reserves.
- Sensible revenue options include: eliminating the deduction for state income taxes; revising the vendor discount; enhancing collections of taxes on remote sales; and controlling runaway tax credits.

Cuts of this magnitude would inflict serious and lasting damage to our ability to provide education and public safety, meet the growing needs for social services, and maintain needed investment in physical infrastructure. To avoid this outcome, policymakers can choose a balanced approach, one that includes new revenue sources along with budget cuts, efficiencies, and using reserves. OK Policy believes the following revenue proposals represent sound and feasible policy ideas to help bridge the budget gap:

#### 1. *Eliminating the State Deduction for State Income Taxes*

Oklahoma is one of only five states that allow taxpayers who claim itemized deductions to also deduct state income taxes on their state returns. Closing this loophole would yield the state nearly \$120 million and affect only those who itemize their deductions.

#### 2. *Revisiting the Vendor Sales Tax Discount*

The rebates Oklahoma pays to vendors for helping collect the sales tax were set long ago when compliance costs were higher. The state could lower the discount rate and lower the monthly cap.

#### 3. *Enhancing Tax Collections of Online Sales*

The constraints the state faces in collecting sales tax owed on many online purchases deprives state and local government of needed revenue and puts Main Street retailers at a competitive disadvantage. The state should broaden its definition of "nexus" to collect taxes that are already owed.

#### 4. *Controlling Runaway Tax Credits*

The cost of certain tax credits has exploded in recent years. Some credits should be eliminated, while others could be suspended or capped until revenues recover.

For the full-length issue brief, go to: <http://okpolicy.org/fy-10-fy-11budget-information>.

Source: Oklahoma Policy Institute

## Race to the Top for Education

Education Secretary Arne Duncan announced the finalists among states for the \$4 billion Race to the Top competition to improve our nation's schools. This competition is extremely important to financially struggling school systems, including those where special education programs may be endangered. Fifteen states and the District of Columbia were selected as finalists from among the 41 states that submitted applications. Besides DC, the following states were selected: Colorado, Delaware, Florida, Georgia, Illinois, Kentucky, Louisiana, Massachusetts, New York, North Carolina, Ohio, Pennsylvania, Rhode Island, South Carolina and Tennessee. The Department is expected to announce the winning states in April. For more information, see: <http://www2.ed.gov/news/speeches/2010/03/03042010.html>.



The Department of Education also announced that its Civil Rights Division would boost enforcement efforts this year. Letters are being sent out to most school districts and colleges focusing on seventeen areas of civil rights concerns, including their responsibilities to students with disabilities. The Department monitors civil rights implementation through compliance reviews. Thirty eight compliance reviews are scheduled to take place before October 1.

Source: Capitol Insider

## Enhanced Workforce Infrastructure Needed for People with Disabilities

To understand the important role national, state and local workforce infrastructure plays in the lives of Americans with disabilities, the National Council on Disability has released a report titled "Workforce Infrastructure in Support of People with Disabilities: Matching Human Resources to Service Needs." It includes information that you can use to better understand the supply and demand of the disability workforce, to influence the nature and content of workforce training and to develop the management capabilities for a sustainable, skilled disability workforce. To learn more, visit [www.ncd.gov](http://www.ncd.gov).

## Incidence of Cerebral Palsy on the Rise in the United States.

*Increase may be tied to common complication of premature birth*

Cerebral palsy (CP) has increased in infants born prematurely in the United States, according to data presented by researchers from Loyola University Health System (LUHS). These findings were reported at the 30th Annual Meeting of the Society for Maternal-Fetal Medicine in Chicago. They also were published in the latest issue of the American Journal of Obstetrics & Gynecology.

Researchers reported that CP is associated with inflammation of the connective tissue in the umbilical cord. This inflammation is more common in premature births from preterm labor and premature rupturing of the amniotic sac versus early deliveries due to preeclampsia. Premature births from preterm labor and rupturing of the amniotic sac also are often associated with infections while preeclampsia is not.



"These findings are valuable, as we continue to study the link between premature births and cerebral palsy," said John Gianopolous, MD, chair,

Mary Isabella Caestecker professor and chair, Department of Obstetrics & Gynecology, LUHS. "While further investigation is needed, managing inflammation may reduce the risk of certain complications in these infants."

CP is a disorder that impairs movement due to brain damage. This condition typically develops by age 2 or 3. More than 500,000 Americans have CP, and it is one of the most common causes of chronic childhood disability.



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to become a member of TARC.



### Autism Speaks Unveils 100 Day Kit Version 2.0

*An Update of the Signature Resource for Parents of Children Newly Diagnosed with Autism*

Autism Speaks announced on March 18th the launch of Version 2.0 of the 100 Day Kit, a personalized resource designed to assist families in getting through the critical time following an autism diagnosis. It has also created a separate Asperger Syndrome and High Functioning Autism Tool Kit.

The original 100 Day Kit includes information about autism and dealing with the news of a diagnosis. The personalized kit lists local service providers, support groups, recreational activities, sources of legal information, conferences, local autism organizations and information about the local chapter of Autism Speaks. It provides insight into getting services for a newly diagnosed child and explains various available treatment options. A week-by-week action plan helps walk a family through the steps they need to take to ensure that they are on the right track. The kit also includes a safety plan and a list of recommended books and informational websites.

Since its release in February of 2008, the 100 Day Kit has been downloaded tens of thousands of times and sent to more than 6,000 families of recently-diagnosed children in all 50 states, as well as the District of Columbia and Canada. Four months after receiving the kit, these families were invited to participate in a short survey to provide feedback based on their experiences with the kit. The response was overwhelmingly positive. It was evident through these responses that the kit was highly successful in serving its purpose of calming the fears and easing the stress of families of recently-diagnosed children.

The Autism Speaks Family Services staff, in conjunction with a professional advisory committee comprised of parents of children with autism and professionals, has produced Version 2.0 of the 100 Day Kit based on this feedback from families, new scientific information, and updated valuable resources.

In addition, based on the feedback from families, Version 2.0 of the 100 Day Kit includes more information for school-aged children, along with an expanded list of new resources, and suggested books and web-

sites. The Asperger Syndrome and High Functioning Autism Tool Kit will be sent out separately to families of children with this diagnosis. It contains information, tips, and resources specific to Asperger Syndrome and high functioning autism, and was created to more effectively inform and assist these families.

The 100 Day Kit Version 2.0 is available for download at [www.autismspeaks.org/community/family\\_services/100\\_day\\_kit.php](http://www.autismspeaks.org/community/family_services/100_day_kit.php).

A personalized version of the new kit can be sent to families of children who have been diagnosed in the past six months by calling the Autism Response Team at 888-AUTISM2 (888-288-4762). The hard copy of the kit consists of pertinent information for families, specific to the age and location of the child.

### Statement By Secretary Sebelius on National Autism Awareness Month

During National Autism Awareness Month, we reflect on an urgent public health challenge and re-dedicate ourselves to addressing the complex needs of people with autism and their families. Over the last decade, we've learned that autism is far more prevalent than we had previously believed, affecting one out of every 110 American children. While we still have a lot to learn about what causes autism and which treatments can help people with autism thrive, we're getting closer to finding answers thanks to a historic new investment in autism research. At the same time, we continue to improve lives by educating health care professionals about how to detect the disorder early, funding networks of providers and parents that spread information about the most promising autism treatments, and helping autistic children get the support they need in school.

We took another step forward last month when President Obama signed a health reform bill that will make it illegal for insurance companies to deny health insurance to people because they have autism. This month, we recognize the significant challenges that Americans with autism face and rededicate ourselves to these efforts to address them.

For more information on the Department's efforts regarding autism, please visit <http://www.hhs.gov/autism/>.

Source: Department of Health and Human Services

# Help TARC Glow Even Brighter!!



On Friday, May 7th, golfers will gather after sunset for a starlight scramble on a golf course illuminated only by the moon and glow-in-the-dark golf balls! The 15th annual *Shot In the Dark* golf tournament benefiting TARC, will once again be held at the LaFortune Championship Golf Course.

Golfer registration begins at 7:00 p.m., with tee off shortly after sunset (approximately 9:00 p.m.) in a four-player, shotgun start tournament format. The course is set as a Par 3, and golfers play nine holes. The top three teams will receive trophies and bragging rights as tournament champions.

Golfers are welcome to sign up in teams of four for \$300 or individually for \$100.

Sponsorships are still available and range from \$250 to \$10,000. Consider asking your employer to sponsor the event, or becoming a sponsor yourself!

Volunteers are needed as course monitors throughout the tournament. Volunteers will be needed on site from 6:30-11:45 p.m.

For more information on sponsorship opportunities or to volunteer, call Christina Merlo, TARC Director of Communications, at 918-582-8272 extension 223 or 1-800-688-8272 or email [cmerlo@ddadvocacy.net](mailto:cmerlo@ddadvocacy.net).

## TARC CALENDAR OF EVENTS



**Links Meets the 3rd  
Wednesday of each month:**

Apr. 21st	May 19th	June 16th
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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.



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

The next meeting will be:

May 12th
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Contact Amie Farinella,  
918-582-8272  
for more information about the next meeting.



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



**Connections meets the 4th  
Wednesday of each month:**

Apr. 28th	May 26th	June 23rd
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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.

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

Apr. 27th	May 25th	June 29th
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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.



**Moms and Dads meets the last  
Thursday of each month:**

Apr. 29th	May 27th	June 24th
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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



**Tulsa People First  
meets the 2nd Tues-  
day of each month:**

Apr. 13th	May 11th	June 8th
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**Dinner 5:30 p.m.**  
**Meeting 6:30 p.m.**

For more information call  
Amie Farinella at  
918-582-8272