



# TARC NEWSLETTER

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

## January 2009

### CONTENTS

Oklahoma's Waiting List  
Crisis..... 1- 4  
Views of our new H.H.S.  
Secretary.....4  
The 2008 Election Results on  
the Disability Policy.....5 - 7  
Submit Social Security Forms  
Online .....7  
Oklahoma Down Syndrome  
Conference Dates ..... 8  
Women with Disabilities at  
Risk ..... 8  
TARC Newsletter  
Survey .....9 &10  
Autism News Roundup..... 11  
Calendar of Events..... 12

## OK Geraldo, What About Oklahoma's Waiting List?

by John F. Gajda, TARC Executive Director

Geraldo Rivera is now the host of *Geraldo at Large* on the FOX News Channel. He began developing his national reputation as an investigative reporter in 1972 when he garnered national attention and won an Emmy Award for his report on the neglect and abuse of patients at Willowbrook State School at Staten Island, New York. Video clips of his reports are still used today to orient new staff and demonstrate how bad life was in this and many similar institutions. Over the years, his award winning reports on institutional life continued and drew much attention from political leaders, celebrities and many ordinary citizens. They not only led to the eventual closing of Willowbrook and similar facilities, but also created a focus nationwide on the need to provide community based services for people with disabilities.

On Saturday, December 27, 2008 the *Geraldo at Large* broadcast featured a program titled "The Waiting List: America's Health Care Crisis" that reviewed the progress made since the original investigative reports in the 1970's and showed examples of the many excellent community based programs that are now providing care for people with disabilities. The program also focused on the plight of the many families who can not access these excellent programs and are facing difficult obstacles in finding any appropriate support services to meet the needs of their sons and daughters with intellectual and developmental disabilities. These thousands of families are languishing on state waiting lists for services for up to ten years and are struggling to care for their children with disabilities.

In November 2008, Geraldo Rivera was keynote speaker at The Arc's national convention in Albuquerque, NM where he discussed his groundbreaking expose of the Willowbrook State School for people with disabilities. He was inspired to produce this recent episode of his television program by families, self-advocates and others at this meeting who told Geraldo about the waiting lists most states have for services, the adverse impact budget-cutbacks are having on the availability of services and about the stubborn efforts of some states to bring back the discredited institutions. They also gave testimony about the current impact that lack of services are having on the lives of people with disabilities and their families.

*please see "Waiting" 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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## **Waiting, from pg 1**

Today, the numbers of qualified families waiting for necessary services has reached critical levels. Many states are experiencing alarming increases in the number and rate of deserving individuals being placed on waiting lists. Oklahoma is one of those states that has a growing waiting list.

Currently:

- There are over 300,000 people with disabilities in the U.S. who are on waiting lists for the appropriate services.
- The average wait to receive services is between 5 - 10 years depending upon the state and the type of service needed. During this time period people with disabilities and their families often receive no in-home support, help obtaining a job, or a secure home in which to live.
- Government statistics report an 11% increase from 2006 to 2007 in the number of people reported by states to be on waiting lists.
- The waiting lists could be much longer. Of the 2.8 million individuals with disabilities living with a family caregiver, over 700,000 individuals are being cared for by someone over 60-years-old. Many of them have not applied for services and are not on waiting lists.
- Elderly parents who are on a waiting list are told the only way service would become available to their child is if they were to die. And even then, that adult child could face the prospect of being put in an institution due to the lack of available community services.
- The Medicaid program, that is the major funding source for community based services, has a long standing bias in favor of funding institutional rather than less expensive community-based services. Individuals with disabilities have an entitlement and can get access to institutions such as ICF/MR facilities and nursing homes but must wait to receive community-based services provided through a waiver even though the community-based services are more cost effective and allow the individual to participate in and contribute to society, rather than be put in seclusion.
- In Oklahoma as of 12/22/08 there were 4,407 individuals on the waiting list for community-based waived services. Applications that were being processed were originally filed four years and eight months prior, meaning that Oklahoma has an almost five year wait for services. During the month of November 2008 104 new individuals were added to the waiting list and 16 were removed. This trend has been true for some time in Oklahoma as the waiting list has been growing rather than decreasing.

## **How Did We Get to Where We are Now?**

Up until the 1960's people with developmental disabilities received services in large institutions or their family provided care with little in the way of government support. On the Federal level Medicaid was created in 1965 to provide care for this population and others. Today Medicaid is the largest funder of services for people with disabilities. Public outcry over the conditions in some institutions, which began in the 60's and in the 70's, was further fueled by exposés such as Geraldo Rivera's reports on Willowbrook. In 1972, the Medicaid program added a new benefit called Intermediate Care Facilities (ICF/MR) to expand funding for people with intellectual disabilities with the thought that this would help increase the quality of care. Most ICF/MRs are large congregate care facilities focused on intensive medical or behavioral intervention, and they are both public and privately operated.

Class action law suits and intense scrutiny of the horrifying conditions in institutions led initially to attempts to improve these conditions but ultimately resulted in pressure and court orders to close them.

In the 1980's states were given the option of applying for a waiver of the ICF/MR and nursing home requirements that enabled states to provide services in the community using Medicaid money as an alternative to institutions for limited numbers of people. Unlike regular Medicaid services such as nursing homes and ICF/MRs, these waived services are not an entitlement and do not have to be available to everyone who qualifies for Medicaid. These so-called waiver programs have grown in popularity and are now the service desired by most people with disabilities and their families. Because waived services are not an entitlement in Oklahoma and almost all other states, states are not required to provide funds to fully meet the needs of all those who apply. When we talk about people waiting for services, they are on lists waiting for these waived services provided in the community.

The Americans With Disabilities Act of 1990 contained an 'integration mandate' that requires public agencies to provide services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities" and reinforced the movement to Medicaid funded waived services in the community. In 1999, the Olmstead decision of the Supreme Court upheld the ADA's integration mandate when the state of Georgia appealed to attempt to enforce institutionalization of individuals as the only service option offered.

To further complicate the issue the Medicaid program allows states, within limits, to shape the package of services they offer and manage eligibility in their state. This has resulted in a lack of portability of waived services from one state to another, and even in some states, one county to another, putting further pressure on families who have received services not to move. Portability of services across states and counties is important so that families can, during these difficult times, move to another state and continue to receive services if they had them before. Right now, if a family who is receiving services moves, they are placed at the bottom of the new state's waiting list and can wait additional years for services.

### **What is the Impact on Those Waiting?**

Few families can afford to pay out-of-pocket for these services that are provided by a waiver. Many parents have already had to leave careers to care for their children and have been paying for large medical bills. As a result:

- People with developmental disabilities who are no longer eligible for special education services sit at home with their parents with nothing to do and nowhere to go. Most often one of their parents, if they have been able to maintain employment, must then leave their job to stay at home to take care of them.
- As parents age, their children with disabilities also age. We know there are many parents in their 70s and 80s needing care themselves who continue to care-give for their sons and daughters with disabilities. There are many cases where parents pass away before they can qualify for an alternative residential option for their child, leaving their adult child facing a sudden and traumatic transition.
- In cases where parents have found their adult children cannot be managed at home because of severe behavioral issues or physical problems, the families struggle to cope, essentially hoping they receive services before disaster strikes.
- Even families who have been lucky enough to receive services are unable to move to other states to accept better jobs because the price they will pay for doing so would be that their family member with a disability would lose all of their services and go to the end of the line in their new home state.

For many families we have essentially regressed back to the 1960s, when parents and families had no support in taking care of their loved ones with developmental disabilities in the community.

### **What are Some Proposed Resolutions?**

Simply stated, additional money would be the remedy to these problems. However, the source of this money poses a complex issue. Most states, including Oklahoma, say they are now cash-strapped although even in better economic times states did not fully fund services, allowing waiting lists to continued to grow. Each year the Oklahoma Department of Human Services, Developmental Disabilities Service Division (OKDHS/DDSD) has requested additional funding to serve some of those on the DDSD waiting list but such requests have never been one of top priorities for OKDHS and the Oklahoma Legislature has failed to provide even the limited funds requested for several years. This year the request for additional funds to provide services to 600 persons on the waiting list is the 73rd priority in the OKDHS Fiscal Year 2010 budget request submitted to the Governor. The OKDHS Medicaid waiver program that serves the elderly, the ADvantage program, does not have a waiting list and in this same budget request funds to expand this program is the 23rd priority.

Some national advocacy groups are proposing the federal government fully fund the Medicaid waiver program as part of the next Economic Stimulus Package to provide health care and services for individuals with disabilities and the elderly. This could be considered an increased federal match so that states are not put into an impossible situation. It is also being suggested that at the same time that portability of services across states and counties be mandated.

If the Medicaid waiver program were fully funded it would not only end decades-long waiting lists for people with developmental disabilities, but would also have a positive impact on the economy. It would create small businesses and jobs because more service providers would be needed. Furthermore, parents who have had to stay home to be caregivers could go back to work, and people with developmental disabilities would also be able to go to work because they would have employment supports to do so. By making funding available in all states, portability across and within states could be addressed.

### **What Should We Do?**

The Geraldo News Special on FOX News shined light on the waiting list issue. Those of us in Oklahoma and throughout the nation now have the opportunity and challenge to bring a more detailed focus on this critical issue. We need to educate and inform a wide audience to build awareness of the waiting list crisis in Oklahoma.

## Views of Our New H.H.S. Secretary



President-elect Barack Obama has nominated former Senator Tom Daschle to be Secretary of the U.S. Department of Health and Human Services. His book “CRITICAL - What We Can Do About the Health-Care Crisis,” is quite important for advocates of the disability and elderly communities. Below are some relevant portions of the book.

The book starts out with the following quote: “Millions of our citizens do not now have a full measure of opportunity to achieve and enjoy good health. Millions do not now have protection or security against the economic effects of sickness. The time has arrived for action to help them attain that opportunity and that protection.”

Whom did he quote? Clinton? No. President Harry Truman, 1945. Daschle writes that both Truman in 1945 and Clinton in 1993 “underestimated the strength of the forces arrayed against them. Special-interests lobbyists...” He asks “Why have we failed to solve a problem that is such a high priority for so many citizens?... the limitations of our political system, and the power of the interest groups...”

Here’s what he writes about “long-term care,” which he recognizes as a “troubling area - and the only one in which we spend less compared to peer nations.” Medicaid “is fundamentally geared toward institutional care, even though most elderly people prefer to receive care at home or in more personalized community settings.”

“I believe that our health-care system must cover these vital services [i.e., long-term care].... We should promote home-based care, which most people prefer, instead of the institutional care that we emphasize now.”

Will Daschle and Obama have both the will and fortitude to stand up to the “power of the interest groups” that have forced people with disabilities and elderly Americans to go into nursing facilities instead of receiving care at home? Will he take the initiative and make sure Medicaid provides every elderly and disabled American the choice of where they wish to receive long-term care? Let’s see if he will walk-the-walk, and not just talk-the-talk.

Source: Information Bulletin # 273 (12/08), by Steve Gold

- Each of the over four thousand families on the waiting list, their extended family members (aunts, grandfathers, etc.), and friends needs to meet with the members of the Oklahoma Legislature and tell them why the services they could receive if they received waived services are important to their family.
- We need to contact our federal legislators and convince them that the current patchwork of state waiver programs is in need of an overhaul and encourage them to support making full funding for Medicaid waiver services a part of the next economic stimulus package. We should also urge them to address these needs in any healthcare reform measure considered by Congress.
- Each family on the waiting list needs to reach out to their local media by telling the story of their family needs in order to generate widespread public support, including writing letters to the editor of all of our local newspapers.
- Each calendar quarter the Director of OKDHS holds a listening session for families on the waiting list. These meetings are held during working hours in Oklahoma City and are thus inconvenient for those families who work and live a distance from Oklahoma City. But more of the over 4,000 families waiting for services need to attend these meetings to convince OKDHS to give a higher priority to expanding services.
- Now is also a good time to educate the public and policy makers about changes we need to make in Oklahoma’s waiver to expand it to cover individuals not currently eligible such as people with Autism Spectrum Disorders.
- The current Medicaid waivers that provide services to people with disabilities in Oklahoma are not perfect because of gaps in the groups served. But, let’s all band together, regardless of disability or diagnosis, to use this opportunity to bring awareness to the long wait for people with disabilities and the need for expanded community support in Oklahoma.

Geraldo alone won’t fix the waiting list problems in Oklahoma. They are a relatively small part of the health care crisis the entire national is facing. We need to do it ourselves. Let’s use the publicity he has generated for the issue to energize the advocacy in our state.

# THE 2008 ELECTIONS RESULTS: WHAT DO THEY MEAN FOR FEDERAL DISABILITY POLICY?

The 2008 election results will bring significant changes to the Executive Branch and the Congress. Republicans lost the White House and had their minority status further eroded in the House and Senate. Moderates and incumbents were other high casualty groups, losing a number of important seats.

## What Might We Expect From the Obama Administration?

There are two official sources for what the disability community might expect from the Obama Administration. These include the 2008 Democratic Platform and the Obama-Biden Plan on Disability. The 2008 Democratic Platform lays out the priorities for the incoming Administration, including many disability specific programs. However, it is important to note that this platform was developed before the economic crisis became a national focal point. Attention to the increasing unemployment rate, the credit crunch, and industry bailouts can be expected to push much of the health and human service agenda laid out in the party platform to the back burner, at least temporarily.

Barack Obama and Joe Biden have a comprehensive agenda to empower individuals with disabilities in order to equalize opportunities for all Americans. In addition to reclaiming America's global leadership on this issue by becoming a signatory to -- and having the Senate ratify -- the UN Convention on the Rights of Persons with Disabilities, the plan has four parts, designed to provide lifelong support and resources to Americans with disabilities. These four parts include, first, providing Americans with disabilities with the educational opportunities they need to succeed by funding the Individuals with Disabilities Education Act. This Act includes, supporting early intervention for children with disabilities and universal screening, improving college opportunities for high school graduates with disabilities, and lastly, making college more affordable. Along with these, Obama and Biden will authorize a comprehensive study of students with disabilities and issues relating to the transition to work and higher education.

Second, they will end discrimination and promote equal opportunity by restoring the Americans with Disabilities Act, increasing funding for enforcement,

supporting the Genetic Information Nondiscrimination Act, ensuring affordable, accessible health care for all and improving mental health care.

Third, increase the employment rate of workers with disabilities by effectively implementing regulations that require the federal government and its contractors to employ people with disabilities, providing private-sector employers with resources to accommodate employees with disabilities, and encouraging those employers to use existing tax benefits to hire more workers with disabilities and supporting small businesses owned by people with disabilities.

And fourth, support independent, community-based living for Americans with disabilities by enforcing the Community Choice Act, which would allow Americans with significant disabilities the choice of living in their community rather than having to live in a nursing home or other institution. Thus creating a voluntary, budget-neutral national insurance program to help adults who have or develop functional disabilities to remain independent in their communities, and streamline the Social Security approval process.

If you would like to learn more about the Obama-Biden Plan on Disability you can visit the site online at [www.change.gov](http://www.change.gov).

## How Has the Obama Transition Team Been Developing its Agenda?

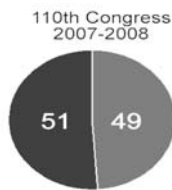
The transition team has been extremely active preparing formalized plans of action for the White House and each of the federal agencies. The team has been using a variety of mechanisms to solicit community input on all national issues. On December 10, the transition team rolled out a new feature that allows the public to ask questions on any issue of interest called "Open for Questions". This resource is a "crowd sourcing" tool which allows users to post and/or vote for questions. Votes determine which series of questions are answered by the transition team. Open for Questions received over 7,000 questions from over 11,000 people who cast over 600,000 votes for questions within its first 24 hours.

Fortunately, the transition team has also been gathering information that is specific to disability issues through meetings with disability organizations. The transition team has been conducting an ambitious series of meetings with national disability organizations. There have been two general kinds of meetings -- policy specific (e.g. education, civil rights) and federal agency

review (e.g. the Departments of Education and the National Council on Disability). The agency review meetings were completed in mid December. The transition team has also created a web page entitled, “The People, By the People,” where the public can submit stories, ideas, and opinions regarding disability issues.

### What Were the Party Results in the Senate Elections?

Democrats gained at least seven seats, bringing their total to at least 58. Only one seat is still in question. The Senate race between incumbent Norm Coleman (R-MN) and challenger Al Franken is still undecided.



Though Democrats gained as many as seven seats, they failed to reach 60. Having 60 votes in the Senate is extremely important. The only way to stop a filibuster (unlimited debate) is through a cloture vote (to limit debate), which requires 60 votes. However, Democrats may be able to recruit at least two Republicans in certain circumstances to reach 60.

### What Were the Party Results in the House Elections?

Democrats gained 24 seats in the House, giving them a 39 seat advantage. Republicans ended up with 178 Members.

### Why are Majority/Minority Ratios So Important?

Once all election results are final and the exact number of majority and minority party members are known, Congress determines how many of its members will be assigned to each committee and then makes its assignments based on those numbers for both the majority and minority parties. Though most returning Members of Congress keep their committee assignments, there is a fair amount of shifting as Members seek to move up the ladder by getting assigned to more prestigious committees or to fill the seat of committee chairpersons who have left to join other committees, retired, or were voted out of office. These committee ratios are extremely important because, the majority party, regardless of the size, has tremendous power as it decides what legislation to consider. The majority also determines when legislation is scheduled to be considered.

### Which Disability Bills Do We Expect To Be Reintroduced in the 111th Congress?

Class Act. This bill would create a national, broad-based long term services insurance system based on payroll contributions. People would be eligible for cash assistance if they meet the level of need. People would not have to impoverish themselves to qualify – there would be no means-testing.

Community Choice. This bill would establish a mandate in Medicaid that states must provide community-based personal assistance services and supports.

Direct Support Professionals. This bill provides a higher federal Medicaid match to states who choose to raise wages for targeted direct support professionals.

Disability Savings Accounts. This effort would amend the tax code to allow tax-free contributions to an account for a person with severe disabilities, similar to tax-free savings plans for college. The funds in the accounts would be exempt from income and resource limits of federal programs.

Expanding the Promise of Individuals with Autism. This bill provides funding to states to expand services and supports to adults with autism.

Javits, Wagner-O'Day (JWOD) Modernization. While the Act has a permanent authorization and does not need to be reauthorized, it is expected that bills will be introduced to modernize the program. Congress has not significantly changed the Act since the early 1970s.

No Child Left Behind (NCLB) Reauthorization. The Elementary and Secondary Education Act (ESEA) includes NCLB. The ESEA is scheduled to be reauthorized in the new Congress. How academic progress of students with disabilities is assessed is expected to be a major issue during reauthorization.

WIA/VR. The Vocational Rehabilitation Act is title IV of the Workforce Investment Act and the 110th is the third Congress that has failed to agree on reauthorizations of our general workforce bill and the vocational rehabilitation system.

### Why are Congressional Committees so Important?

Most Members of Congress spend over half of their time working in committees. Committees are where the most substantive work of the Congress gets done. Bills are drafted, revised, debated and marked up in committees. Congressional committees have several full time staff who have considerable expertise on the programs and issues for which the committee is responsible.

Source: Disability Policy Collaboration

## Which Committees are Most Important For Disability Issues?

House Committees	Disability Policy Oversight
Senate Appropriations Committee, Subcommittee on Labor, Health and Human Services and Education Appropriations	Funding for IDEA, employment, vocational rehabilitation, administrative funds for Social Security and many other programs
Senate Appropriations Committee, Subcommittee on Transportation, Housing and Urban Development, and Related Agencies	Funding for Housing and Urban Development (HUD) Section 8 and Section 811 housing programs and transportation programs
Senate Banking, Housing and Urban Affairs Committee	HUD programs, mass transit
Senate Finance Committee	Medicaid, Medicare, Social Security, Supplemental Security Income
Senate Health, Education, Labor and Pensions (HELP) Committee	IDEA, Vocational Rehabilitation, Development Disabilities Act programs, ADA, health care, and more
Senate Judiciary Committee	Civil rights
Senate Commerce, Science, and Transportation Committee	Transportation, aviation, regulation of consumer products
House Committee on Education and Labor	IDEA, Vocational Rehabilitation, employment, and other programs
House Committee on Energy and Commerce	Medicaid, Development Disabilities Act programs
House Committee on Financial Services	Housing and Urban Development programs
House Judiciary Committee, Subcommittee on the Constitution, Civil Rights, and Civil Liberties	ADA, hate crimes, and other civil rights issues
House Committee on Transportation and Infrastructure	Mass transit and other transportation programs, aviation
House Ways and Means Committee	Social Security, Supplemental Security Income, Medicare

## Census Bureau Reports Number of Americans with Disabilities

A new report by the U.S. Census Bureau says more than 54 million U.S. residents have some degree of disability, or about 19 percent of the total U.S. population. The survey found that only about 46 percent of adults aged 21 to 64 with a disability were employed, compared with 84 percent of adults without disabilities. Based on 2005 data, the report found a slight increase in the total number of Americans with disabilities compared with the 2002 survey, when 51.2 million people or 18 percent reported a disability. To view the report, visit <http://www.census.gov/prod/2008pubs/p70-117.pdf>.

Source: Capitol Insider

## Representative Payees Can Now File Reports Online

The Social Security Administration appoints a relative, friend, institution or other interested party to receive benefits on behalf of more than seven million people who need help managing their money. These representative payees use the benefits on the person's behalf and are required to file a report each year showing how the funds were used.

Until recently, the form could only be submitted via mail, but representative payees may now submit their annual accounting reports online. Visit [www.socialsecurity.gov/payee](http://www.socialsecurity.gov/payee) to learn more.



## Oklahoma Down Syndrome Conference Planned

What educational strategies are being used to teach children with Down syndrome? How does the medical condition of a child with Down syndrome affect his/her development? What is the best way to support the families of a child with Down syndrome?

These topics and more will be on the agenda at the 1st Annual Statewide Conference on Down Syndrome: Down Syndrome – Reaching Across the Plains, to be held on Saturday, March 7, 2008 at the Moore Norman Technology Center, South Penn Campus in Oklahoma City. The conference will feature presentations on family and parenting issues, education, medical concerns, and therapies to help parents, educators and professionals provide the best care for those individuals who have Down syndrome.

Topics on the agenda include early intervention therapy, employment opportunities for teens & adults, workshops for new parents, inclusion, secondary transition, higher education, special needs trusts, health concerns, writing effective IEPs, sexuality, and homeschooling. One of the highlights is the choice of Jan Moss as the conference's keynote speaker. Moss is with the Center for Learning and Leadership at the OU Health Sciences Center and was chosen as Outstanding Woman of the Year in 2007. She is also the parent of two adult children with disabilities. Moss has a way of bringing humor into the day-to-day process of parenting a child with a disability.

The one-day conference is set to begin at 8:00 a.m. with registration and a continental breakfast for attendees. Registration fees are set at \$25 per person, \$40 per couple and include lunch and an afternoon snack. Financial assistance is available for a limited number of families. Certificates of attendance will be provided at the conference.

The conference brochure can be downloaded at [www.dsaco.org](http://www.dsaco.org). For more information call Juanita Killingsworth at (405) 330-5025 or by e-mail at [JuanitaKillingsworth@gmail.com](mailto:JuanitaKillingsworth@gmail.com)



## Women with Disabilities at Risk for Partner Abuse

A new study shows that women with a disability are far more likely to experience a physical assault by a spouse or other intimate partner than those without a disability.

To estimate disability prevalence and differences in intimate partner abuse among women with and without a disability, Dr. Brian Armor and his colleagues from the Centers for Disease Control and Prevention, analyzed data from the CDC's 2006 Behavioral Risk Factor Surveillance System -- a large annual telephone survey of Americans designed to monitor the prevalence of key health behaviors. They found that women with a disability were significantly more likely than women without a disability to report experiencing some form of intimate partner violence in their lifetime (37.3 percent versus 20.6 percent).

Women with a disability were more likely to report ever being threatened with violence, (28.5 percent vs 15.4 percent) hit, slapped, pushed, kicked or physically hurt (30.6 percent vs. 15.7 percent) by an intimate partner.

Women with a disability were also much more apt to report a history of unwanted sex by an intimate partner (19.7 percent vs 8.2 percent).

"Perhaps, women with disabilities are vulnerable to intimate partner violence because their disability might limit mobility and prevent escape; shelters might not be available or accessible to women with disabilities; the disability might adversely affect communication and thus the ability to alert others or the perpetrator might control or restrict the victim's ability to alert others to the problem." Fear is another possibility, Armor said. "That is, a catch-22, stemming from reliance on the perpetrator for caregiving needs that might go unmet or lead to some form of undesirable placement if they tell authorities."

He concluded, "Since intimate partner violence is a public help problem, we need to ensure that prevention strategies for people with disabilities are widely adopted."



Source: Down Syndrome Association of Central Oklahoma and Down Syndrome Association of Tulsa

Source: Monday Morning in Washington

# ***Tell Us What You Think!***

**We appreciate your comments and suggestions so that we can make this newsletter more useful to our readers.**

**Simply fill out the form on the back, fold this page into thirds, seal it with tape, add a stamp and drop it in the mail. It's as easy as that.**

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*(fold down second)*

Please place  
your own  
stamp here.  
Thank you  
very much!

**TARC  
16 E. 16 St., Suite 405  
Tulsa, OK 74119-4447**

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*(fold up first)*

**Please add any additional comments about the *TARC Newsletter*:**

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**1. I am (check all that apply)**

- Person with a disability/Self Advocate
  - Family member of a person with a disability
  - Direct service provider/Agency staff
  - Professional working on behalf of persons with disabilities but not providing direct services
  - Teacher (e.g., special education, regular education, higher education)
  - Policy Maker (e.g., Legislator, Agency Head, Program Director)
  - Student
  - Other, please specify
- 

**2. How often do you read the TARC Newsletter?**

- Every Month
- Most Months
- Few Months
- Never

**3. Having read the TARC Newsletter, which of the following best reflects your level of satisfaction with the quality of this publication?**

- Highly satisfied
- Satisfied
- Satisfied somewhat
- Not at all satisfied

**5. After reading this newsletter do you know more about and better understand public policy that affects people with disabilities and their families?**

- YES  NO

**6. Features you like most about the TARC Newsletter (check all that apply)**

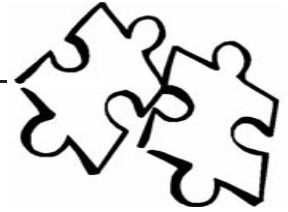
- Length of Newsletter
- Calendar of Events
- State Legislation/Policy information
- National Legislation/Policy information
- Information/current developments about specific disabilities
- Commentaries on Public Policy

**7. Features I would like to see added or dropped from the TARC Newsletter**

Added: \_\_\_\_\_

Dropped: \_\_\_\_\_

**Thank you for completing and returning this survey!**



## Online Reviews of Current Autism Treatments Now Available

Various aspects of the treatment of autism are discussed in three recent papers:

Mahatmya, Zobel and Valdovinos review behavioral and pharmacological approaches to the treatment of self-injurious behavior in autism in a paper in the *Journal of Early and Intensive Behavioral Intervention*, Volume 5, Issue 1, p. 106-118 (2008). **The journal is available online at <http://www.jeibi.net/Issues/JEIBI-5-1.pdf>.**

Levitas and Hurley review the history of the use, overuse, and misuse of antipsychotic medications in persons with intellectual disabilities in "Optimum Treatment of Problem Behaviors in Children with Autism Spectrum Disorders," published in *Mental Health Aspects of Developmental Disabilities*, Volume 10, Issue 1, p. 31-35 (2007). The abstract is available online at <http://www.mhaspectsofdd.com/abstracts/Vol10Num1/5.htm>.

Mohammadi and Akhondzadeh review drug therapies for autism spectrum disorders and conclude that pharmacological interventions may have a limited role to play in the overall therapy of children with autism, but that medications may be most helpful in reducing hyperactivity, impulsivity, and aggressive and obsessive behaviors. They note that for the development of everyday life skills, one-on-one behavioral therapy seems to be essential. "Autism Spectrum Disorders: Etiology and Pharmacotherapy," *Current Drug Therapy*, Volume 2, p. 97-103 (2007). The abstract is available online at <http://www.bentham.org/cdth/contabs/cdth2-2.htm#2>.

## Senator Honored for His Work on New Autism Legislation

Senator Jay Paul Gumm (D-Durant) was presented with the Advocate-Elected Official of the Year award at the 2008 TARC Advocacy Awards for his work to mandate that health insurance policies cover treatment for individuals with Autism spectrum disorders by authorizing Senate Bill 1537, known as *Nick's Law*.

"Senator Gumm is an outstanding advocate for the  
*TARC Newsletter*

needs of children with Autism and other developmental disabilities. People with disabilities and their families should be grateful for his persistent advocacy and dedication to meeting the needs of all Oklahomans with disabilities," said John F. Gajda, TARC executive director. Gajda added, "Senator Gumm joins a small group of legislators who have been honored in this category and his advocacy efforts are admirable and appreciated."

When *Nick's Law* was not favorably received by legislative committee chairs who objected to imposing mandates on insurance companies, Senator Gumm did not accept this as a defeat but fought on until the very end of the legislative session to achieve his goals by getting the language of SB 1537 included in another bill that was likely to be approved. Although he was not successful, he never gave up advocating for insurance coverage and became an outspoken advocate for this specific legislation goal as well as the overall needs of children with Autism spectrum disorders.

In the interim between legislative sessions, he has continued to advocate for insurance coverage with legislative study groups examining the issue, and has vowed to fight on by filing a similar bill to mandate coverage in 2009 and advocating for its passage when the legislature convenes.

## National Conference of State Legislatures' Autism Legislation Database

A new database providing information about autism legislation introduced in the 50 states and the District of Columbia from the 2008 legislative session to present is now available.

The database can be searched by state, topic, keyword, status, year, bill number, or primary sponsor. Topics include awareness, education, financing, health and human services, infrastructure, insurance, professional training, and screening. New legislation will be added to the database as it is introduced. The database is available at <http://www.ncsl.org/programs/health/autism.htm>.

Source: Monday Morning in Washington



# TULSA ADVOCATES FOR THE RIGHTS OF CITIZENS WITH DEVELOPMENTAL DISABILITIES

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## RETURN SERVICE REQUESTED

The TARC newsletter is published monthly by the Tulsa Advocates for the Rights of Citizens With Developmental Disabilities, Inc., to inform readers about issues and legislative action that affect adults and children with developmental disabilities, their families, and professionals working in the field of developmental disabilities. The contents do not necessarily represent the official position of TARC.

# HELP TARC HELP FAMILIES-BECOME A MEMBER TODAY!

*Families in Transition*

*Families in Transition* is a support group for parents of adult children with developmental disabilities.

**NEXT MEETING:**  
Wednesday, February 11th  
6:30-7:45 p.m.  
Goldie's Patio Grill  
4401 E. 31st St. in Tulsa

RSVP to Amie Farinella, 918-582-8272

**Connections Asperger's Group**

**Next Meeting:**  
Wednesday, January 28- 4:30 p.m.  
Hardesty Library, 8316 E. 93rd St.  
The "Connections" Asperger's Group is a social skills group for adolescents and young adults with Asperger's Syndrome. The group meets monthly. Contact Sherilyn or Amie at 918-582-8272 for more information.

**Hispanic Parents Support Group**  
El Grupo Hispano de Apoyo a Padres de Familia

**Next Meeting: Monday, January 26**  
7:00 to 8:30 p.m.  
St. Thomas Moore Catholic Church,  
2720 S. 129th E. Ave., Tulsa

*Contact Zaida at 918-582-8272 for more information.*



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

**Next Meeting:**  
Wednesday, January 21  
6:30-8:00 p.m.  
Brookside Library, 1207 E. 45th Pl.

Links is a support group for adults with Asperger's Syndrome. Contact Amie Farinella, 918-582-8272 for more information.

**Day Makers** Activities group for adults with developmental disabilities  
Contact: Amie, 918-582-8272

**Tuesdays • 10:00-11:30 a.m.**  
Gatesway Foundation-Mabee Gym  
1217 E. College in Broken Arrow

**Thursdays • 1:00-2:30 p.m.**  
McClure Recreation Center  
7440 E. 7th Street in Tulsa

**MOMS & DADS SUPPORT GROUP**

**Next Meeting:**  
Thursday, January 29  
7:00-9:00 p.m.

Kirk of the Hills Presbyterian Church  
4102 E. 61st St., Room B-8

*The mission of the Moms & Dads Support Group is to nurture and support families whose children have a developmental disability, to encourage positive strategies in dealing with challenges, and to share in the joys of raising our children.*

*For more information, contact Sherilyn, 918-582-8272*

**1<sup>ST</sup> TULSA PEOPLE FIRST**  
Tulsa People First  
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**Next Meeting:**  
Tuesday, January 13  
Diamond Jack's,  
7031 S. Zurich Ave.  
Dinner-5:30 p.m.  
Meeting-6:30 p.m.

For more information, contact Amie at 918-582-8272

**Support Group for Families of Children with Special Needs in Sapulpa**

**Next Meeting:**  
Tuesday, January 20, 6:15 p.m.  
CREOKS Behavioral Health, 23 E. Ross in Sapulpa  
*Childcare is not provided, but please take advantage of Sapulpa's great Respite Care Program*

*For more information, contact Mindy Littlefield, 378-5632*