



TARC NEWSLETTER

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

June 2007

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A Spring Check-Up

by John F. Gajda, TARC Executive Director

As advocates for people with disabilities, one of our long-term overall goals is to improve services in Oklahoma. Living with the Oklahoma service system for people with disabilities from day-to-day, however, it is difficult to maintain an objective perspective on how we are doing. Evaluating the status of services, some of us will always see the glass as half full while others will perceive the same glass as half empty.

That is why I find it helpful to look at national studies that evaluate the same factors in all states and allow us to compare how our state is doing compared to other states. Two such studies were highlighted last month in the TARC Newsletter. Both examined state Medicaid systems, though each from a different perspective

The first was an updated report on inclusion published by United Cerebral Palsy. Titled "A Case for Inclusion," the report spotlights how state Medicaid programs are serving people with developmental disabilities.

Overall this report ranks the Oklahoma system 35th out of the 50 other states and the District of Columbia. According to this report, Oklahoma received its highest ranking for supporting meaningful work. The state is ranking first in this category for placing 71% of those receiving employment services in supportive or competitive employment.

The state does not rank as well in other rating categories. Oklahoma ranks 22nd in supporting individuals in the community and home-like settings. Only 75% of those served reside in settings with 1 - 3 residents.

Oklahoma ranks 28th in keeping families together through family support. This ranking is based on the fact that Oklahoma only serves 103 families with family support per 100,000 residents in the general population.

Oklahoma only ranks 31st in allocating resources to those in community (non-ICF-MR) programs with 67% of expenditures going to these programs.

please see "A Spring Check-Up" 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:

16 East 16th Street, Suite 405, Tulsa, Oklahoma 74119-4447

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

“A Spring Check-Up,” from pg. 1

Other categories that lower Oklahoma’s overall ranking in this report include: the size of the state’s waiting list; the percentage growth in the state’s funding for services that would be required to meet the needs of those on the waiting list; the spending on services relative to the state’s per capita income; the low level of funding for ICF-MR services; and the ratio of expected prevalence of disabilities based on state population relative to the number of individuals actually served.

The second report was published by Public Citizen, a national public interest organization. This report ranked the states on the extent to which they surpass the already low federal mandates and divided the scores into four categories: eligibility, scope of services, quality of care and provider reimbursement. Although Public Citizen and its report does not focus exclusively on people with disabilities, since people with disabilities depend to such a great extent on the state Medicaid system to meet their needs for care, the information included in the report has important implications for people with disabilities.

Overall, the report ranks Oklahoma’s Medicaid system 47th out of 50 states and the District of Columbia. Eligibility is where Oklahoma does best, earning 55.2 percent of the total maximum points and ranking 21st. Oklahoma has opted to cover more persons while providing them fewer services. While Oklahoma excludes those who are poor due to high medical expenses, the medically needy, and parents of children who are covered by the State Children’s Health Insurance Program (SCHIP), it has more inclusive Federal Poverty Level thresholds than are legally required, thus expanding the pool of beneficiaries.

In scope of services, however, Oklahoma fails abysmally, ranking 50th with only 35.9 percent of the total possible points. It is particularly deficient in services by type and/or target population (e.g., hospice care, private duty nursing services), rehabilitation services, and devices and equipment. This poor showing in scope of services means

that, even if people qualify for the program, they may not have access to many services provided to Medicaid recipients in states with a broader benefits package.

Similarly, Oklahoma ranks near the bottom in quality of care, earning a rank of 50th. The state is one of two in this category whose total score has a negative sign. This is the result of inadequate staffing and monitoring of nursing home care, and poor performance in outcomes associated with child health.

Oklahoma pays its Medicaid providers less than the national average and less than Medicare providers receive for providing the same service, thereby earning only 30.2 percent of the value assigned to the reimbursement category. It ranks 42nd in this area. Even if people are eligible for Medicaid and the services they need are covered, the stingy reimbursement policy makes it less likely that all patients will be able to get these services.

The findings in these two reports give disability advocates in Oklahoma a different perspective on the state of the service system. Although we continue to make progress, it reminds us of how far we have to go relative to the efforts in other states to provide services for people with disabilities. Many of the factors contributing to our state’s low ranking in both reports can only be addressed by an increased commitment by the state to the service system. The comments in the report by Public Citizen, although not disability specific, remind us of the interdependent nature of the Medicaid program and service for people with disabilities. The comments about a stingy reimbursement policy certainly help us understand why many people have difficulty finding providers who accept Medicaid.

We cannot talk about improving the quality of life in Oklahoma without considering the needs of people with disabilities. These reports help identify factors that need to be considered in the discussion.

TARC Tracking List

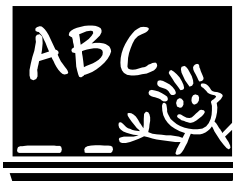
2007 Legislative Session Wraps Up

As required, the Oklahoma Legislature officially adjourned on May 25th, having completed work on the budget for next fiscal year that begins July 1st. Many bills were left dormant in the process, with some not making the final dash through a joint conference committee before the session ended, and were left on the table for possible revival during the second session of this legislature next year.

Several bills being monitored in the tracking list published in this newsletter ultimately made it through the process, receiving approval from the governor. Those are noted below. A full review of the implications of this session for people with disabilities will be included in the July edition.

Bill	Principal Authors	Status	Last Status Change	Description
HB1084	Wesselhoft, Paul (H) & Wilcoxson, Kathleen (S)	Governor Action-Signed	5/07/07	“Office of Handicapped Concerns” becomes “Office of Disability Concerns”
HB1695	Enns, John (H) & Anderson, Patrick (S)	Governor Action-Signed	5/31/07	Provides services to agricultural workers with disabilities.
HB1926	McDaniel, Jeannie (H) & Riley, Nancy (S)	Governor Action-Signed	5/31/07	Establishes system of reimbursement review for DHS providers
HB1933	Steele, Kris (H) & Johnson, Constance (S)	Governor Action-Signed	6/04/07	Addresses the operation of the Olmstead Strategic Planning Committee and creates an Office of Ombudsman for Persons with Disabilities

The Condition of Education 2007



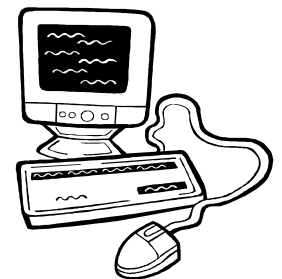
The Condition of Education is a congressionally mandated report that provides an annual statistical portrait of education in the United States. There are 48 indicators in the report, which cover all aspects of education. The following indicator is of special interest to the special education field:

- Indicator 7: Children With Disabilities in Public Schools – and can be viewed at: <http://nces.ed.gov/programs/coe/2007/section1/indicator07.asp>

To view the entire report, visit <http://nces.ed.gov/programs/coe/>

Source: Institute of Education Sciences, USDE

Check Out the New Riot Website!



A note from the editors of The Riot:

The Riot!, an e-newsletter for self-advocates, has a new website! It has a sharper look and is easier to use.

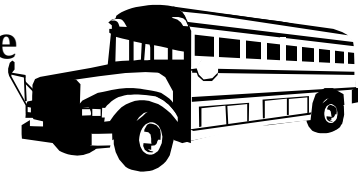
On the site, you can easily find your way around. Look at the current issue, find old issues, write Cubby for love advice, get a *Riot!* t-shirt, or send us your ideas or comments!

Check it out—it’s a regular *Riot!* The next issue of *The Riot!* will be ready in July 2007.

To view the site, go to: www.theriotrocks.org.

-The Riot Staff

IDEA Training Course Available Online



A new on-line training course on IDEA 2004, *Meetings of the IEP Team*, produced by the National Dissemination Center for Children with Disabilities (NICHCY) is now available.

The training module explains what is new, the same, or different in IDEA 2004 with respect to meetings of IEP Teams.

To date, the following seven modules on critical IDEA topics are available and an additional 12 will be available by summer 2007: *Disproportionality and Overrepresentation, Early Intervening Services and Response to Intervention, Introduction to Evaluation, Initial Evaluation and Reevaluation, Identification of Children with Specific Learning Disabilities, The IEP Team: Who is a Member?*, and *Meetings of the IEP Team*.

The modules are available for download at:
<http://www.nichcy.org/training/contents.asp>

Source: NICHCY

Advocates Concerned About Erosion of ADA in Wal-Mart Case



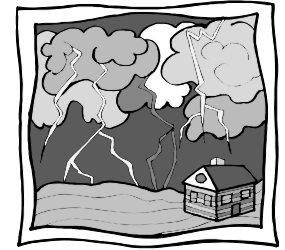
On May 11, the 11th Circuit Court of Appeals found in *Littleton v. Wal-Mart Stores, Inc.* that a man with mental retardation/intellectual disability is not disabled under the Americans with Disabilities Act.

The Court supported the District Court's finding that "Wal-Mart is entitled to judgment as a matter of law here because there is no evidence to support Littleton's necessary contention that his retardation substantially limits him in one or more major life activities."

This decision represents further erosion of the protections of the ADA for people with disabilities in employment matters. It is not known whether Charles Littleton will appeal the decision.

Source: Monday Morning in Washington

Disaster Preparedness for People with Disabilities



The American Red Cross has published a guide to help people with disabilities prepare for disasters.

The guide discusses all the points that people with disabilities should consider in preparing for disasters, from the more obvious measures such as first aid kits to the not so obvious, such as prescription drugs, adaptive equipment, items for service animals, etc.

The guide also emphasizes the importance of establishing emergency contacts who can provide important information about the individual such as family contact information, medical history, and special equipment the individual requires to rescue or health care workers who may respond to a disaster.

To view the guide, visit: <http://www.redcross.org/services/disaster/beprepared/disability.pdf>

Source: UCP of Oklahoma

Hectic Month for the House and Senate Appropriations Committees.

Both houses expect to pass several FY 2008 appropriations bills before the Independence Day recess, meaning the next few weeks will be very busy for House appropriators.

The so-called 302 (b) allocations will be made in the first week of June. These allocations set the amounts available to spend by each of the twelve appropriations subcommittees. Four FY 2008 appropriations bills are scheduled for votes by the full Appropriations Committee, and four others, including the bill that will fund the Departments of Labor, Health and Human Services and Education (L-HHS-ED) will be marked up in Subcommittee. The Senate, meanwhile, expects to start FY 2008 appropriations subcommittee markups during the second week in June.

Federal Agencies Work to Protect People with Disabilities from Harm During Emergencies and Disasters



The U.S. Department of Health and Human Services (HHS) Office on Disability and the Assistant Secretary of Preparedness and Response (ASPR) are in the process of finalizing an Emergency Preparedness Toolkit for State and Local Planners to meet the health and human services challenges of people with disabilities in emergency preparedness.

The toolkit consists primarily of web based training targeting State and local emergency response managers, but will also be available in written and audio formats. The toolkit will address planning considerations and best-practice research for functional limitations in a number of disability categories and will address planning considerations for each phase of emergency management.

Other relevant resources from the Department of Health and Human Services include:

- **The Administration on Aging's (AoA)** "Emergency Assistance Guide" is a preparedness and planning guide to assist the National Aging Network and others in planning for and responding to the special needs of older persons in the event of a disaster. See: http://www.aoa.gov/PRESS/preparedness/pdf/Attachment_1357.pdf

- **The Agency for Healthcare Research and Quality's (AHRQ)** "Disaster Response Tools and Resources," an online information site that can be used during emergency events and natural disasters to assist in response and recovery efforts for people with disabilities. See: <http://www.ahrq.gov/path/katrina.htm>

- **The HHS Office on Disability** has developed the "Emergency Preparedness for Persons with Disabilities" webpage and added the "Response for People with Disabilities and Dealing with Disabilities: Tips for First Responders." See: <http://www.hhs.gov/od/emergencypreparedness.html>.

- **The Substance Abuse and Mental Health Services Administration's (SAMHSA)** National Mental Health Center has developed a guide called "Developing Cultural Competence in Disaster Mental Health Programs: Guiding Principles and Recommendations." See: <http://>

mentalhealth.samhsa.gov/publications/allpubs/SMA03-3828/default.asp

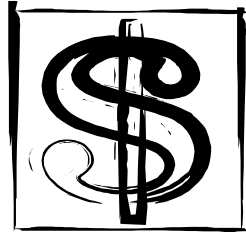
- **The Durable Medical Goods Stockpile.** A number of efforts are taking place to address the "warehousing" of durable medical goods for disasters. Both the Departments of Health and Human Services (DHS) and Homeland Security (HHS) have efforts underway. DHS, for example, has teamed up with the Adventist Community Service (ACS) Disaster Response to address warehousing of durable medical goods following a disaster, modeled on the past successes of ACS.

- **The U.S. Department of Homeland Security (DHS)** has hired a Disability Coordinator, a position that was hard fought for by The Arc and United Cerebral Palsy as well as the rest of the disability community during the last Congress. The Disability Coordinator position was mandated with passage of the Post-Katrina Emergency Management Reform Act of 2006. Expected to be on board by June, the Disability Coordinator will be located in the Office of Equal Rights (OER) at the Federal Emergency Management Agency (FEMA) and will be responsible for ensuring that the needs of individuals with disabilities are being properly addressed in emergency preparedness and disaster response, recovery and mitigation. In addition, the Coordinator will help establish policies, procedures and standards for emergency personnel nationwide.

- **The Federal Emergency Management Agency (FEMA)** has also developed an online independent study program, "Special Needs Planning Considerations for Service and Support Providers." The primary purpose of the course is to provide representatives of the service and support community with the basic information and tools to develop their own emergency plans. The course is particularly designed for people who work with the elderly and people with disabilities, and teaches how to partner with local emergency management to better prepare for all phases of an emergency. To access the course go to: <http://training.fema.gov/EMIWeb/IS/IS197SP.asp>

Source: Washington Watch, Vol. 5, Issue 3

Developing a Financial Strategy for Your Child with Special Needs



By Chris Sullivan, Vice President of Special Needs Financial Services Group within Merrill Lynch

As you're busy making decisions about everything from healthcare to daily care for your child with special needs, preserving your child's lifelong financial security may seem like a distant priority. Yet, early planning in this area can make a meaningful difference in your child's life. To help you avoid costly mistakes down the road and help ensure a financially secure future, consider the following key steps.

Step 1: Build your "special needs team."

Alongside physicians, social service representatives and counselors with expertise in your child's area of disability, consider adding an attorney who specializes in disability law and a financial advisor with the experience and resources necessary to address special needs financial concerns.

Step 2: Put your financial "house" in order.

With the help of a knowledgeable advisor, review your family's overall financial situation and make sure that goals like education and retirement savings are on track – and that there is adequate insurance to protect the family in the event that something happens to either parent.

Step 3: Draft a "Letter of Intent" or Life Plan

that details your child's health, abilities and challenges, hobbies and interests and future care needs. Your social service representative can help you develop this important document, which will serve as a roadmap for you and for future caregivers.

Step 4: Learn about public benefits. Generally, it's best to plan for the possibility of needing public benefits such as Supplemental Security Income (SSI), which offers a monthly stipend as well as access to Medicaid and other critical benefits. To

ensure your child's eligibility, you'll need to limit the assets he or she owns to \$2,000.

Step 5: Calculate the need for "supplemental" funds to help preserve your child's quality of life by supplementing SSI income. Using a specialized formula, your financial advisor can help you obtain a realistic estimate of what your child will need. You'll want to recalculate this "goal" periodically to adjust for changes in your financial situation or your child's anticipated needs.

Step 6: Fund your "special needs goal" such as purchasing a second-to-die life insurance policy payable to a Special Needs Trust (SNT). SNTs are designed to hold supplemental funds for the benefit of an individual who receives SSI. Together, your attorney and financial advisor can help you draft an SNT, consider who will serve as trustee, how trust assets will be invested, and how they will be disbursed to meet your child's needs.

Step 7: Choose an estate plan strategy that meets your objectives for both the child with disabilities and other intended heirs. Preserving public benefits eligibility will require changing beneficiary designations from your child to the SNT.

Study on Housing Affordability for People with Disabilities Released



The Technical Assistance Collaborative (TAC) and the Consortium for Citizens with Disabilities (CCD) Housing Task Force released *Priced Out in 2006* – a new study of the severe housing affordability problems of people with disabilities who must survive on incomes far below the federal poverty line.

The study compares the Supplemental Security Income (SSI) monthly income of people with serious and long-term disabilities to local U.S. Department of Housing and Urban Development (HUD) Fair Market Rents for modestly priced rental units in 2006.

Since the data is broken down by local area, *Priced Out* is a very useful tool for state and local advocates. To access the report go to: <http://www.tacinc.org/Docs/HH/PricedOut2006/POin2006.htm>

Source: TAC

Autism News Roundup

Expanding the Promise for Individuals With Autism Act of 2007

There is considerable Congressional interest in advancing research on autism. Late last year, President Bush signed into law the Combating Autism Act of 2006 (PL 109-416). The Act authorizes \$168 million for autism related activities in FY 2008, an increase of \$25 million over FY 2007. This funding increase would primarily benefit research on autism through the National Institutes of Health (NIH) and the Centers for Disease Control (CDC).

Building on the Combating Autism Act, advocates urged members of Congress to introduce legislation to address the service and support needs of individuals with autism and their families. In response, the bipartisan “Expanding the Promise for Individuals with Autism Act of 2007” (S. 937) was created. The bills amend the Public Health Services Act by providing additional funds to improve access to comprehensive treatments, interventions, and services for individuals with autism spectrum disorders and their families.

It is important to note that the term “autism” is defined in the bill as an autism spectrum disorder or a related developmental disability. The following is a brief summary of the bill.

▪ **Evaluation Task Force.** The bill authorizes the Secretary of Health and Human Services to convene a Treatments, Interventions, and Services Evaluation Task Force no later than 60 days following enactment of the bill to evaluate evidence-based biomedical and behavioral treatments and services.

▪ **Demonstration Grants for Coverage of Treatments, Interventions, and Services.**

Authorizes \$20 million per year over four years for the Secretary to establish a demonstration grant program awarding multiyear grants to enable selected states to provide evidence-based autism treatments, interventions, and services, as identified by the Evaluations Task Force.

▪ **Planning and Demonstration Grant for Services for Adults.** The bill authorizes \$5 million for the Secretary to establish a one-time, single year planning grant for selected states to expand autism services for adults; and a multiyear service provision demonstration grant program. The planning activities must be carried out in partnership with the state Developmental Disabilities Council and other organizations representing or serving individuals with autism.

▪ **Expanding Access to Post-diagnosis Care.**

Section 399KK authorizes \$10 million in FY 2009 for

grants to states to provide treatments, interventions, and services to children with autism with the main purpose of reducing the amount of time between diagnosis of autism and the point when children receive evidence-based treatment, interventions, and services.

▪ **National Training Initiatives on Autism.** Section 399LL authorizes \$13.4 million in FY 2008 for the Secretary to award supplemental grants to provide training, technical assistance, dissemination, and services, and address the unmet needs of individuals with autism and their families.

▪ **Expansion of University Centers for Excellence in Developmental Disabilities.** Part B of Section 399LL authorizes \$5 million to establish up to four new University Centers for Excellence in Developmental Disabilities with a primary focus on providing interdisciplinary training and services for individuals with autism and related developmental disabilities.

▪ **GAO Study on Service Provision and Financing.** The bill requires the Government Accounting Office to release a report after examining: the ways in which autism services and treatments are currently financed in the U.S.; current policies for public and private health insurance coverage of autism treatment, interventions, and services; geographic and regional disparities in provision of services across the life-span; levels of community-based versus institutional services, and coverage for such services; and ways in which to improve financing of autism treatment, interventions, and services, so as to ensure a minimum level of coverage.

▪ **Protection and Advocacy Systems.** \$8 million is authorized for grants to address the needs of individuals with autism and other emerging populations of individuals with disabilities. Services provided under this section may include the provision of information, referrals, and advice; individual and family advocacy; legal representation; and specific assistance in self-advocacy.

▪ **National Technical Assistance Center for Autism Treatment, Intervention, and Services.** The bill authorizes \$2 million for the establishment of a national technical assistance center.

Source: Washington Watch, Vol. 5, Issue 3



TULSA ADVOCATES FOR THE RIGHTS OF CITIZENS WITH DEVELOPMENTAL DISABILITIES

16 EAST 16th STREET SUITE 405
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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HELP TARC HELP FAMILIES – BECOME A MEMBER TODAY!

<p>Asperger's Syndrome S.O.S</p> <p>A project of Tulsa Public Schools in conjunction with TARC</p> <p>Next Meeting: September 2007-Date TBA 6:30-8:00 p.m. Kendall Whittier Elementary</p> <p><i>S.O.S. is a social group for kids with Asperger's Syndrome and a support group for their parents, both of which are open to all families – not just those in Tulsa Public Schools.</i></p> <p>To sign up, call Stephanie Orban at 746-8747. For more information, contact Sherilyn Walton at TARC, 918-582-8272.</p>	<p>Connections Asperger's Group</p> <p>Next Meeting: Wednesday, June 27 - 4:30 p.m. Hardesty Library, 8316 E. 93rd St.</p> <p>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.</p> <p>Day Makers</p> <p>Activities group for adults with developmental disabilities Thursdays • 1:00-2:30 p.m. McClure Recreation Center 7740 E. 7th Street in Tulsa Contact: Amie, 918-582-8272</p>	<p> Hispanic Parents Support Group El Grupo Hispano de Apoyo a Padres de Familia</p> <p>Next Meeting: Monday, June 25 <i>For more information, call Zaida at 918-582-8272</i> 7:00 to 8:30 p.m. Martin Regional Library, 2601 S. Garnett</p> <p>MOMS & DADS SUPPORT GROUP</p> <p>Next Meeting: Thursday, June 28 7:00-9:00 p.m.</p> <p>Kirk of the Hills Presbyterian Church, 4102 E. 61st St., Room B-8 • No child care provided</p> <p><i>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 joy of raising our children.</i> Contact: Sherilyn, 918-582-8272</p> <p> TULSA PEOPLE FIRST</p> <p>Next Meeting: Tuesday, June 12 <i>Dinner-5:30 p.m. Meeting-6:30 p.m.</i></p> <p>For more information, call Amie at 918-582-8272</p>
<p>MOMS & DADS SUPPORT GROUP – OWASSO</p> <p><i>For more information, contact Sherilyn, 918-582-8272. - No child care provided-</i></p>	<p>Next Meeting: Tuesday, June 19 7:00 - 8:30 p.m. First Baptist Church of Owasso, 13307 E. 96th Street North, Room 700</p>	<p>SAPULPA-New! Support Group for Families of Children with Special Needs</p> <p>Next Meeting: Tuesday, June 19, 6:15 p.m. Creek County Literacy Center, 15 N. Poplar <i>Childcare is not provided, but please take advantage of Sapulpa's great Respite Care Program!</i> For more information, contact Mindy Littlefield, 378-5632</p>