



# TARC NEWSLETTER

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

## September 2009

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## Help TARC Honor the Best

*by John F. Gajda TARC Executive Director*

Advocacy is an activity that many of us like to lay claim to. Throughout the year many organizations and individuals (myself included!) call on people to advocate for one cause or issue or another.

Most of us take pride in being self-advocates or advocates for people with disabilities, but are we really advocates or just fair weather warriors? There are many who will carry the torch of advocacy as long as there is something in it for them personally. That's OK. But, how many will continue the fight when it is not fun, pleasant or self-rewarding in some way? There are also those who make a feeble attempt at advocacy, but the minute they run into a challenge, difficulty or disappointment they give up and say "I've done my share and now I want to take it easy and let others do the work."

In December, for the 19th year, TARC will be presenting the TARC Advocacy Awards to recognize outstanding advocates for people with disabilities. The process to select the 2009 winners begins this month.

Each year when the members of TARC select individuals to honor with Advocacy Awards we search for individuals who work not just for their own self-satisfaction but unselfishly advocate for the good of others. These individuals can be counted on no matter how disheartening the work or small the task. They are the true advocates who are willing to work for the benefit of all people with disabilities and not recognition or praise for themselves.

These awards shine the spotlight on these outstanding, often unrecognized, individuals who each, in their own way, are essential to the ongoing process of creating and maintaining an effective community-based service system in Oklahoma that meets the needs of people with disabilities.

TARC believes that the power of advocacy can make a difference in the lives of individuals in Oklahoma. This organization is committed to promoting the power of advocacy and encouraging and supporting the ongoing advocacy activities on behalf of people with developmental disabilities in Oklahoma.

So I am asking each of you to help us find the champions in communities throughout Oklahoma whose advocacy for people with disabilities makes a difference. In this edition of the TARC Newsletter, printed on green paper, is the nomination form for the 2009 TARC Advocacy Awards. Return the form and nominate them for the recognition they deserve.

Affiliated with  
**The Arc**



TARC is committed to ensuring a high quality of life for Oklahomans with developmental disabilities through education, empowerment, support and advocacy. For additional information about TARC or to volunteer, contact us at:

**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)

# Impairing Education: Corporal Punishment of Students with Disabilities in US Schools

Students with disabilities face corporal punishment in public schools at disproportionately high rates, says a report released today by the American Civil Liberties Union and Human Rights Watch. The physical discipline, which often includes beatings, can worsen these students' medical conditions and undermine their education, says the report, which calls for an immediate moratorium on corporal punishment in US public schools.

"Students with disabilities already face extra challenges, and being hit by teachers only makes it worse," said Alice Farmer, Aryeh Neier fellow with the ACLU and Human Rights Watch and author of the report. "Corporal punishment is abuse, any way you look at it, and it violates students' rights to a decent education."

In the 70-page report, "Impairing Education: Corporal Punishment of Students with Disabilities in US Public Schools," the ACLU and Human Rights Watch found that students with disabilities made up 18.8 percent of students who suffered corporal punishment at school during the 2006-2007 school year, although they constituted just 13.7 percent of the total nationwide student population. At least 41,972 students with disabilities were subjected to corporal punishment in US schools during that year. These numbers probably undercount the actual rate of physical discipline, since not all instances are reported or recorded.

Corporal punishment, legal in 20 states, typically takes the form of "paddling," during which an administrator or teacher hits a child repeatedly on the buttocks with a long wooden board. Interviews found that students with disabilities also suffered many other forms of corporal punishment, including beatings, spanking, slapping, pinching, being dragged across the room, and being thrown to the floor.

The report found that some students were physically abused for conduct related to their disabilities, including students with Tourette syndrome being punished for exhibiting involuntary tics and students with autism being punished for repetitive behaviors such as rocking. In some cases, corporal punishment against students

with disabilities led to a worsening of their conditions. For instance, some parents reported that students with autism became violent toward themselves or others following corporal punishment.

"Corporal punishment can leave students feeling helpless, humiliated, and reluctant to return to school," said Farmer. "Physical force is ineffective, violates children's rights, and is especially egregious when used to punish students for their disabilities. More effective discipline, including positive behavioral supports, creates safe classrooms where children are able to learn."

"Impairing Education" calls for a complete prohibition on the use of corporal punishment against all students in US public schools and offers recommendations for implementing a moratorium on corporal punishment against students with disabilities until a full prohibition is achieved.

Michelle R., whose son with Tourette syndrome, which causes involuntary physical tics, was punished for his condition at his public elementary school in Mississippi:

*"One of his tics was balling up his fists ... that was seen as aggression and he would get in trouble with it.... He would try to explain that it was a tic, and he couldn't control it, but they see that as him escalating it.... They had a closet and he would go in there, and that's where he was hit."*

The use of corporal punishment is a violation of international human rights law, under which physical force may only be used against students when it is absolutely necessary to protect a child or others. In July, the US signed the UN Convention on the Rights of Persons with Disabilities (CRPD), the most comprehensive international treaty on the rights of persons with disabilities in history.

"We hope that, by signing the CRPD, the Obama administration has signaled its willingness to take the next steps to bring the US in line with international human rights standards - including immediately banning corporal punishment against students with disabilities," Farmer said.

The press release can be found at:

<http://www.hrw.org/node/84970>

And the report can be found at: <http://www.hrw.org/node/84950>

# The World Mourns the Passing of Eunice Kennedy Shriver

Eunice Kennedy Shriver was instrumental over the past decades in bringing public attention to the status of children and adults with intellectual disabilities in our society. The entire world mourns her death which occurred on August 11th. She worked often with the U. S. Congress to secure services, supports, benefits and rights for people with intellectual disabilities and their families.

In 1961, Mrs. Shriver persuaded her brother, then-President Kennedy, to include in his first health message to Congress the proposal for an NIH institute focusing on child health and human development research. After the bill that would establish the new institute was introduced, Mrs. Shriver testified in support of that bill and worked to persuade members of Congress to approve it. The institute that now bears her name, by act of Congress, is a tribute to her vision and commitment.

Research that the Eunice Kennedy Shriver National Institute of Child Health and Human Development has sponsored has led to the near-elimination in the developed world of once common causes of intellectual disability. For example, as recently as the 1980s, Haemophilus influenzae Type B (Hib) meningitis was the leading cause of acquired mental retardation in the United States. A vaccine against the disease, developed in the NICHD's laboratories, has been so effective that today the disease is nearly eliminated.

Children with the metabolic disorder phenylketonuria, or PKU, develop severe intellectual disability soon after birth. In the 1960s, a blood test for PKU was developed and children with the disorder were identified at birth. NICHD research documented that a diet low in the amino acid phenylalanine spared them from brain damage and allowed normal functioning. Another newborn blood test developed through NICHD research for a disorder caused by failure to produce sufficient amounts of thyroid hormone allowed diagnosis and treatment before any brain damage could occur. Other NICHD research documented the benefits and feasibility of mainstreaming children and adults with intellectual and physical disabilities into schools and communities, a practice that is now routine.

In the early 1960's Mrs. Shriver also organized a summer camp in her own backyard, which has now grown into the internationally recognized Special Olympics

program serving 3.1 million people in 170 nations. Through Special Olympics International the world has learned that people with significant disabilities are capable of enjoying, participating and competing in sport and competition. Today, under the continued leadership of her son Tim Shriver, Special Olympics International has brought much joy to many athletes from every corner of the globe.

She was also instrumental in creating the Kennedy Foundation Public Policy Fellows program that brought many future leaders in our field to Washington to learn about national public policy. Along with this she was very influential in 1962, creating what eventually became the President's Committee for People with Intellectual Disabilities (ACF/HHS), and served on that Committee from 1966-1968 and from 1977-1980. That Panel delivered 95 recommendations calling for downsizing our institutional facilities and significantly expanding community services and opportunities. This was the beginning of the modern era of political activism, united advocacy, and the legal right to treatment movement in the U.S.



The entire world owes a debt to Eunice Kennedy Shriver for her foresight in calling for an institute at the National Institutes of Health to study the myriad aspects of human development, both as it unfolds without problems and when medical and environmental factors prevent it from doing so. She will be greatly missed.

Source: : The ARC of the United States, National Institutes of Health and AAIDD



*Help TARC  
by becoming a  
member today.*

**TARC**  
*helps families*

Call 1-800-688-TARC or visit  
[www.ddadvocacy.net](http://www.ddadvocacy.net)  
to become a member of TARC.

## Back to School Tips



- 1) Learn what you can about your child's new teacher(s) and other professionals and classroom. Check the school's website to learn about the class, curriculum, and staff, talk to other parents, make contact with the case manager.
- 2) Try to arrange an informal visit with the key staff people prior to or shortly after school starts. Alert them to any important developments with your child that occurred over the summer.
- 3) If your child has trouble with transitions, it may be helpful to arrange a visit with the new teacher before school starts. If your child has not attended the school before, set up a chance for them to take a tour of the school before school starts. One strategy is to work with the teacher to devise a treasure hunt type activity, where your child has the chance to find different key places in the building (classroom, lunchroom, locker, bathroom, library).
- 4) Prepare a one page summary of your child's strengths, learning style, needs and key IEP provisions and share it with the school staff. Check to make sure that they have copies of the IEP or attach it to the one page summary.
- 5) Identify key friendly faces at school for your child and for you. It is always helpful to have people that your child is more familiar with and trusts that they can greet, seek out if needed and will be "keeping an eye on them." As this may not be part of the IEP, you may need to arrange this informally, though at times a mentor or "go to" person can be written into the IEP or 504 plan.
- 6) Check out the curriculum for your child's grade level. Make sure you know what materials are required. If the District is using a computerized system for accessing homework assignments and the like, make sure you are aware of how it works and are monitoring it.
- 7) If your child has complex medical or learning issues, is using specialized methodologies or technologies, or has other more unusual needs, try to determine, in a non-threatening way, whether the staff has experience and training in relation to these issues. It doesn't help your child to have a sophisticated reading program or hi-tech computer system if the staff are unfamiliar with how to use it.

8) If your child has learning, communication, health or behavioral issues that respond well to strategies you have developed over time, offer to share these with school staff, including providing demonstrations of techniques you have found successful.

9) If your child has complex health or behavioral issues that require that all supports be operational day one, try to work this out in advance wherever possible. Unfortunately, most schools have a several week period where things are still being organized after school starts. If this puts your child at risk, work (collaboratively) to try to assure that the preparation for your child's special needs occurs in advance. Similarly, if your child has high risk needs, seek to have back up plans in place with the school, including identifying additional staff that will be available and trained if the primary staff are absent. On the other hand, if your child is not at high risk, give the school some slack in the first week or two as they get organized. It is likely to trigger a very defensive reaction if you are pushing for perfection in the first weeks of school. This may happen at any point, but the more time that has passed, the more cause you have to raise issues about the program not being in place.

10) Monitor how things are going for your child during the first 4-8 weeks of school. Give things a chance to settle in, but if there are any concerns, seek information from the staff. Try to communicate in a flexible and non-accusatory way,

but keep notes of all communication (email is a good way to do this, but make copies). Try to build relationships with the school staff, but don't assume that silence is golden. If problems are developing, reach out to the staff to try to work them out in a positive way that helps everyone, but be aware of whether the needed solutions are being implemented. Get involved in the school, via being a classroom volunteer, lunch monitor, booster club helper, tutor, or through the PTA. The more positive involvement you can have and the more connections to the school, the more you will be able to build relationships.



Source: Special Education News From Monahan & Cohen Vol 19 Issue

# 19th Annual Advocacy Awards



TARC is accepting nominations for the 19th Annual Advocacy Awards, to be held **December 7** in Tulsa. Anyone can nominate advocates for recognition by following these simple steps:

- Complete both sides of the nomination form and mail or fax to TARC.
- Return nominations to TARC by 5:00 p.m. on **Friday, October 9**.
- Nominations are reviewed by a selection committee, which slates at least three nominees in each category, based on quality of advocacy described in the nomination.
- The selection committee reserves the right to withhold an award in any category in which an insufficient number of nominations are submitted.
- Award recipients are selected through a vote of the TARC membership. Ballots will be mailed to all members in good standing (dues paid) as of October 16, 2009.
- The selection committee reserves the right to withhold an award in any category in which an insufficient number of nominations are submitted



2009 TARC Advocacy Award Nomination Form Due October 9!

# 2009 TARC Advocacy Awards Nomination Form

## Advocacy Award Categories

### *Advocate - Board Member:*

Recognizes a member of the board of directors of any non-profit, community-based service provider who has gone beyond the interest of his or her agency to become an advocate for all people with disabilities. *Sue Freeman was the 2008 recipient.*

### *Advocate - Case Manager:*

Recognizes the OKDHS/DDSD case manager who has surpassed job requirements to advocate for his or her clients. *Angela King was the 2008 recipient*

### *Advocate - Direct Care Provider:*

Recognizes the direct contact staff person working for a community provider, who has gone beyond job requirements to advocate for people with disabilities. *Tiffany Williams was the 2008 Direct Care Provider recipient.*

### *Advocate - Educator:*

Recognizes a public school educator who has promoted the inclusion of children with disabilities in regular school

settings. *Kem Morrow was the 2008 Educator recipient*

### *Advocate - Professional Provider:*

Recognizes any professional such as a therapist or physician who advocates for people with disabilities beyond their professional responsibilities. *Dr. Marciale Ledbetter was the 2008 recipient.*

### *Advocate - Volunteer:*

Recognizes the volunteer or group of volunteers who, in a program serving people with developmental disabilities, has gone beyond the call of duty to advocate. *Irene Williams was the 2008 Volunteer recipient.*

### *Elected Official:*

Recognizes an elected official who has effectively promoted better understanding and integration of people with disabilities in employment, education, and the community. *Senator Jay Paul Gumm was the 2008 recipient.*

### *Media Advocate:*

Recognizes the media profes-

sional who has effectively promoted better understanding and integration of people with disabilities living in the community. *There was no recipient of this award in 2008.*

### *Parent Advocate:*

Recognizes the parent(s) of a person with developmental disabilities who has been a voice for all people with disabilities. *Joyce and Bobby House were the 2008 Parent recipients.*

### *Self-Advocate:*

Recognizes the self-advocate who has spoken out for all people with disabilities. *Michele Disario was the 2008 Self-advocate recipient.*

### *Special Achievement in Advocacy:*

Recognizes the individual, business, or organization not included in other categories, which through a significant advocacy effort has improved the lives of people with disabilities. *Cindy Jennings was the 2008 recipient.*

Nomination forms must be received by 5:00 p.m. on **Friday, October 9, 2009.**

Mail the completed 2-page form to TARC, 16 E. 16th St. Ste. 405,  
Tulsa, OK 74119-4447, or fax to 918-582-3628.

# 2009 TARC Advocacy Awards Nomination Form

Please make duplicate copies of this form for each nomination and/or category. If you need extra space to answer these questions, please limit additional pages to two typed sheets. You may include a maximum of three letters of support for your nominee(s) and up to four other applicable attachments such as newspaper clippings, programs, etc., per nominee.

*Select Category of Nominee* (For definitions, see "Advocacy Award Categories" on p. 2)

Individuals may not **win** an Advocacy Award in the same category more than once. Please do not nominate a past winner in a category they have previously won. Individuals **may be re-nominated** in a given category multiple times, so long as they have never won in that category. Individuals may win advocacy awards in more than one category, but no one person may win the same category more than once.

- |   |  |
|---|--|
| <input type="checkbox"/> Advocate - Board Member          | <input type="checkbox"/> Elected Official                |
| <input type="checkbox"/> Advocate - Case Manager          | <input type="checkbox"/> Media Advocate                  |
| <input type="checkbox"/> Advocate - Direct Care Provider  | <input type="checkbox"/> Parent Advocate                 |
| <input type="checkbox"/> Advocate - Educator              | <input type="checkbox"/> Self-Advocate                   |
| <input type="checkbox"/> Advocate - Professional Provider | <input type="checkbox"/> Special Achievement in Advocacy |
| <input type="checkbox"/> Advocate - Volunteer             |  |

## 1. What is the name, title, address, and telephone number of the nominee?

*(It is very important that this information is correct, especially the spelling of the nominee's name. If the nominee is an organization, please provide the name of the primary contact at that organization.)*

Nominee Name: \_\_\_\_\_

Title (if applicable): \_\_\_\_\_

Address: \_\_\_\_\_  
city state zip

Telephone Number: \_\_\_\_\_  
area code

## 2. Describe the projects or activities in which the nominee participated in on behalf of individuals with developmental disabilities.

Questions? Call 800-688-8272 or 918-582-8272

- Form continues on back -

3. Describe the ways in which the nominee advocated for individuals with developmental disabilities.

4. Why is the nominee deserving of special recognition?

5. Use this space (or attach up to two pages) to make any additional comments.

6. Please provide your (nominator) contact information:

Name: \_\_\_\_\_

Address: \_\_\_\_\_ City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone Number: (        ) \_\_\_\_\_

*Questions? Call 800-688-8272 or 918-582-8272*

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*All nomination forms become the property of TARC and will be kept confidential.*

# Autism News Roundup

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## New Advocacy Group Focuses on Non-vaccine Related Autism Research

The Autism Science Foundation was launched in April of this year to support autism research by providing funding and other assistance to scientists and organizations conducting, facilitating, publicizing and disseminating autism research. The organization also provides information about autism to the general public and serves to increase awareness of autism spectrum disorders and the needs of individuals and families affected by autism. The organization claims it adheres to rigorous scientific standards and that every research dollar needs to count.

The Autism Science Foundation's mission is premised on the following facts and principles:

- Autism is known to have a strong genetic component. Research must aim to discover the mechanisms of action that trigger autism, as well as safe, effective and novel treatments to enhance the quality of life for children and adults currently affected.
- Early diagnosis and early intervention are critical to helping people with autism reach their potential, but educational, vocational and support services must be applied across the lifespan. Science has a critical role to play in creating evidence-based, effective lifespan interventions.
- Vaccines save lives; they do not cause autism. Numerous studies have failed to show a causal link between vaccines and autism. Vaccine safety research should continue to be conducted by the public health system in order to ensure vaccine safety and maintain confidence in our national vaccine program, but further investment of limited autism research dollars is not warranted at this time.

The organization is co-founded by Alison Singer, former executive vice president of Autism Speaks, and Karen London. London is the Director of the Autism Treatment Laboratory at the New York State Institute for Basic Research in Developmental Disabilities. He is also Chief Scientific Advisor of the New York State Autism Consortium and a member of the Autism Science Foundation's Scientific Advisory Board. He is the co-founder of the National Alliance for Autism Research (NAAR). Both Singer and London are parents of children with autism. Singer serves as president of the new organization.

Singer resigned from Autism Speaks, the country's biggest and best-known autism organizations, in January of this year, citing disagreement with the group's decision to continue to fund more vaccine research despite multiple scientific studies exonerating vaccines as a cause of autism. To learn more about the Autism Science Foundation, visit [www.autismsciencefoundation.org](http://www.autismsciencefoundation.org).

Sooner Success is holding a Free Training

### **"Raising a Child with Autism: The Practical Wit & Wisdom of Parents"**

Tuesday, September 29, 2009

Chisholm Trail Technology Center, Seminar Room

Hwy. 33, between Kingfisher and Watonga

Registration: 8:30 a.m.—9:00 a.m.

Workshop: 9:00 a.m.—2:30 p.m.

Lunch On Site: Provided by The Health Occupations Students of America, benefiting Autism Speaks.

Cost: \$7.00

REGISTER EARLY! SEATING IS LIMITED.

Please respond to the Sooner SUCCESS Coordinator in your county by September 22.



# TULSA ADVOCATES FOR THE RIGHTS OF CITIZENS WITH DEVELOPMENTAL DISABILITIES

16 EAST 16th STREET SUITE 405  
TULSA, OKLAHOMA 74119-4447

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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.

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# HELP TARC HELP FAMILIES-BECOME A MEMBER TODAY!

The Sapulpa Group has decided to discontinue their monthly support group but please take advantage of our other Mom's and Dads Group in Tulsa. If you have any questions please contact Sherilyn Walton, 582-8272

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

Next Meeting:  
Wednesday, Sept. 16th  
6:30-7:45 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 • 10:00-11:00 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

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

**iJUNTOS!**  
Support Group for Hispanic Families

Next Meeting: Monday, September 28th  
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.

*Families in Transition*

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

Next Meeting:  
Wednesday November 11th  
6:30 pm

Contact Amie Farinella, 918-582-8272  
For more information

**Connections Asperger's Group**

Next Meeting:  
Wednesday, Sept. 23rd 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.

**MOMS & DADS SUPPORT GROUP**

Next Meeting:  
Thursday, September 24th  
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

Next Meeting:  
Jason's Deli  
Cherry Street

September 8th  
Dinner 5:30  
Meeting 6:30

For more information please contact Amie Farinella  
918-582-8272