



TARC NEWSLETTER

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

January 2007

CONTENTS

Oklahoma Gains National Notoriety for Handling of Transplant Case 1, 2, 3

Respite Bill Becomes Law 3

FY 2007 Federal Appropriations and Budget .. 4

Couples Conference 4

Autism News Roundup 5

ASA and ARI Partner to Improve Lives of People Affected by Autism 6

Online Discussion Groups for People With Autism 6

State Approach to Serving Students with Autism 6

American Dream Unlikely for People with Disabilities 7

Calendar of Events 8

Oklahoma Gains National Notoriety for Handling of Transplant Case

by John F. Gajda, TARC Executive Director

Attention was focused on Oklahoma on December 22nd when National Public Radio featured a story during their afternoon news program *All Things Considered* about a 25 year old woman from Duncan, Oklahoma who was referred to the University of Oklahoma Medical Center in Oklahoma City by her physician for a kidney transplant. She was turned down by the transplant team and was not put on the waiting list for a kidney.

Oh, and she happens to be a person with a disability.

Misty Cargill's life illustrates the kind of success that we hope for people with disabilities. She lives in a nice group home in a quiet neighborhood, has a job in a manufacturing facility, has an active social life that includes participation in a bowling league, has friends including a boyfriend with whom she enjoys doing things, and is an active member of a church. Her mild intellectual disability has not prevented her from enjoying a good quality of life in the community.

Misty, however, was born with abnormally small kidneys and her doctors say she needs a kidney transplant. Now every single day she feels sick and she's tired. If she does not get a transplant she'll need to go on dialysis soon and could die.

Misty appears to meet the University of Oklahoma Medical Center criteria for a transplant. She is the right age and the right weight. Although she needs a kidney soon, she's in good health. She has insurance that will pay for the operation and the follow-up medications. After meeting with the members of the transplant team at the Medical Center, however, she was notified that she was not a candidate for transplant because the transplant team decided she was not able to give informed consent to the procedure. After an advocate for Misty complained an official said the transplant team might reconsider if a legal guardian was appointed to make medical decisions for Misty.

An official at the hospital said it was Cargill's own doctor who said she was mentally incompetent, but her personal physician denies ever saying that and feels that she is a good candidate for a transplant.

Please see Transplant Case, 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)

Transplant Case, from pg. 1

But even after Misty asked Adult Protective Services to be her legal guardian and officials there declined, saying she was competent to make her own decisions, the hospital refused to reconsider. In response to additional protests the hospital scheduled its own testing at the end of January to evaluate Misty's competence even though the state of Oklahoma considers her competent to make her own decisions.

Making decisions regarding who gets a transplant is difficult because there aren't enough donated kidneys for everyone who needs one. At OU Medical Center, only about 25 percent of those applying are put on the transplant list. A number of judgments are made in deciding who gets on a transplant list, and biases about people with disabilities are hard to keep out of the decision-making process.

Unfortunately, the University of Oklahoma Medical Center is not unique. Discrimination by transplant programs against people with disabilities is a national phenomenon that is a concern of national disability organizations such as The Arc of the United States. Transplant centers feel that they have an obligation to try to figure out who has the ability to be a successful transplant patient, and in a survey of nearly 100 transplant centers, about 60 percent said they would have serious reservations about giving a kidney to someone with mild to moderate intellectual disabilities.

But the actual experience does not support this viewpoint. Recently Steven Reiss, an expert on developmental disabilities at Ohio State University, published a study on 42 known cases of people with intellectual disabilities who were lucky enough to get kidney transplants. He concluded that when people with intellectual disabilities do get transplants, they have results that are just as good, or better, than anyone else's. In this group he studied they had a 100-percent survival rate after one year, and 90 percent after three years.

Reiss feels that this positive outcome is due in part to the fact that people with intellectual disabilities often live in group homes or other settings where staff provide support to the individual and facilitate needed follow-up care and

compliance with the medications that are needed to keep people from rejecting the organ.

Reiss says he sees a lot of discrimination, in general, against people with intellectual disabilities and as hard as transplant centers try to stay neutral, biases do creep in. "There's thinking out there that some people's lives are more valuable than others," Reiss said and "it's very hard to keep that thinking totally out of the transplant process."

The dispute with the University of Oklahoma Medical Center is taking a toll on Misty. She is being helped by a therapist. Lately she has been crying a lot and arguing with people over small things. She seems to think it's her fault and that if she were "normal", she could get a new kidney and then she wouldn't be sick anymore.

It is difficult to trust the hospital's motives in demanding that Misty submit to their own competency test. In Oklahoma determining if someone is competent and appointing a guardian is a legal process. Professionals who regularly deal with individuals who might need a guardian have already screened Misty and determined she does not need an appointed guardian. It seems unfair to take away Misty's legal right to make decisions about her own well-being as a condition to being put on the transplant list when this is not necessary. The medical professionals on the transplant team need to go back to practicing medicine rather than law.

The whole issue of competency appears to be nothing more than a smoke screen for the real issue behind this decision – discrimination against people with disabilities. While I would not want to be accused of operating outside of my area of expertise by interfering with the medical decisions of the transplant team, I feel secure in demanding that the University of Oklahoma Medical Center operate according to a higher standard of care. As stated in the Policy Statement on Health Care jointly issued by The Arc of the United States and the American Association on Intellectual and Developmental Disabilities, "Disability must not be a factor in the decision to provide ... or receive organ transplants. The person's medical condition and welfare must be the basis for the decision." The hospital should adopt and follow these guidelines.

Long held negative attitudes about the value of

Please see Transplant Case, pg. 3

Transplant Case, from pg. 2

people with disabilities die hard in the health care profession. In studies of health care providers, Special Olympics found rampant negligence in the care of people with intellectual disabilities. Some doctors even report that they don't want people with intellectual disabilities sitting in their waiting rooms. One confided that when care is given, it's usually "quick and dirty." These attitudes appear to still be flourishing at the University of Oklahoma Medical Center.

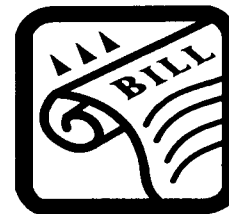
Writing on December 25th to the Washington Post in response to the public radio story featuring Misty Cargill, Timothy Shriver, the Chairman of Special Olympics, challenged everyone, particularly those of us in Oklahoma, to rise above the negative stereotypes illustrated by Misty's situation.

He commented, "During this season when we're confronted with the world's injustices, we're challenged to muster the willpower to make a difference for those who suffer from inequalities. But what about when the problem is not an absence of willpower but the presence of won't power? What about when we are the innkeepers — confronted by too little space and finding ourselves uttering the terrifying words to those who we decide matter less: "There is no room for you." What about when we ourselves construct the edifice on which the shocking and outrageous devaluing of human dignity rests?"

He further wrote that "on Christmas, we might remember that no matter how many restrictions and rules we create, the enigma of humanity remains our inability to follow the mystery of love all the way to its awe-filled conclusion: Every human life matters. There are no exceptions. There is no hierarchy. The presence of the divine can be seen in the tiniest and most vulnerable just as it can be seen in the strong and powerful. But it can be seen especially among those who are demeaned, reduced to a stable, having no room at the inn."

These are thoughts for all of us committed to advocating for people with disabilities to ponder as we move into a new year filled with new challenge. Let's work to keep Oklahoma out of this type of spotlight.

President Signs Respite Bill for Family Caregivers



President Bush signed *The Lifespan Respite Care Act of 2006 (HR 3248)* into law in December. The bill was introduced and championed in the US House of Representatives by Rep. Mike Ferguson (R-NJ) and James Langevin (D-RI). A companion bill in the Senate was cosponsored by Senator Hillary Clinton (D-NY) and Senator John Warner (R-VA). The Lifespan Respite Task Force includes a diverse group of national and state organizations: state respite and crisis care coalitions; health and community social services; disability, mental health, education, faith, family caregiving and support groups; groups from the child advocacy and the aging community; and abuse and neglect prevention groups.

The new law would authorize \$289 million over five years for state grants to develop Lifespan Respite Programs to help families access quality, affordable respite care. Lifespan respite programs are defined in the Act "as coordinated systems of accessible, community-based respite care services for family caregivers of children and adults with special needs." Specifically, the law authorizes funds for:

- development of state and local lifespan respite programs;
- planned or emergency respite care services;
- training and recruitment of respite care workers and volunteers; and
- caregiver training.

When the bill passed the House, Rep. Ferguson, whose own father was a caregiver for his ill mother for 6 years said, "Today's action by the House of Representatives represents not only an important victory for family caregivers nationwide, but it also sends America's caregivers a clear message: Your selfless sacrifice is appreciated, and help is on the way."

Family caregivers provide 80% of long-term care in the US, a level of care valued at \$306 billion a year, more than what is spent on nursing home and paid home care

Please see Respite Bill, pg. 4

Respite Bill, from pg. 3

combined. Even though most families take great joy in providing care to their loved ones so that they can remain at home, the physical, emotional and financial consequences can be overwhelming without some support, such as respite. Respite provides the much needed temporary break from the often exhausting challenges imposed by constant caregiving.

The bill is based on model state lifespan respite programs that have successfully addressed all of these barriers. Three states have enacted legislation to implement Lifespan Respite Programs (OR, NE, WI), which establish state and local infrastructures for developing, providing, coordinating and improving access to respite for all caregivers, regardless of age, disability or family situation. Oklahoma has also implemented a successful Lifespan Respite program. The *Lifespan Respite Care Act of 2006* will help establish respite as a national priority and provide the assistance states and localities need to move forward.

Source: National Respite Coalition

Fiscal Year 2007 Federal Appropriations and Budget



The incoming House and Senate Appropriations Committee Chairs for the 110th Congress, Representative David Obey (D-WI) and Senator Robert Byrd (D-WV), announced that they would extend the Continuing Resolution (CR) for the remainder of Fiscal Year 2007 when Congress convenes in January.

Rep. Obey and Senator Byrd also served notice that they would exclude all earmarks in the CR. The CR will stay within the unofficial budget ceiling of \$873 billion, giving appropriators about \$7 billion to make "limited adjustments" to increase priority spending for discretionary programs. They also released a report criticizing the outgoing Republican leadership for leaving behind a "fiscal disaster." Obey said, "It is going to take us years to get back on track" for the billions of dollars of tax cuts handed to the wealthy, while "shortchanging our national priorities."

Source: Capitol Insider, Volume 11, Issue 50, published by the Disability Policy Collaboration

UN General Assembly Adopts Convention on the Rights of Persons With Disabilities

International law now recognizes the full rights of persons with disabilities to enjoy the same economic, social, political, cultural and human rights as enjoyed by all other citizens.

The Convention on the Rights of Persons With Disabilities includes and protects the rights of people who cannot always speak for themselves and acknowledges the fundamental and often life-long role that families play in supporting their family members who have a disability. This Convention will be a tool for governments and civil society groups to work together toward the realization of human rights for all the world's people.

Four provisions in the Convention are particularly important to people with intellectual disabilities and their families:

- 1.) The right to live in the community, not in sub-human conditions or institutions, *is secured in Article 19*
- 2.) The right to be included in education along with other children *is secured in Article 24*
- 3.) The right to make one's own decisions *is secured in Article 12*
- 4.) The preamble recognizes the role of families in the achievement of human rights for their members with disabilities.

Source: Inclusion International

Couples Conference for Parents of Children or Adults With Special Needs



The Oklahoma Marriage Initiative (OMI) will present the 2nd Annual Couples Conference for parents/caregivers of children or adults with special needs January 26-27 at the Embassy Suites Hotel in Oklahoma City. The conference is free of charge, but pre-registration is required.

W.C. and Catherine Hoecke of Family Connections in Columbia, South Carolina are featured presenters.

Couples may register online at www.registernow123.com or by calling 1-877-435-8033. There are limited respite monies available to assist families with child care.

Source: OMI

Autism News Roundup

President Bush Signs *Combating Autism Act of 2006*

New Legislation Enhances Research, Surveillance, and Education Regarding Autism Spectrum Disorders

On December 19, President George W. Bush signed the *Combating Autism Act of 2006*. The legislation authorizes expanded activities related to autism research, prevention, and treatment through FY 2011.

Upon signing the legislation, President Bush said "By creating a national education program for doctors and the public about autism, this legislation will help more people recognize the symptoms of autism. This will lead to early identification and intervention, which is critical for children with autism. I am proud to sign this bill into law and confident that it will serve as an important foundation for our Nation's efforts to find a cure for autism." There are more than 1.5 million cases of autism in the United States.

The Act Authorizes Research Under NIH To Address The Entire Scope Of Autism Spectrum Disorder (ASD). Autism, sometimes called "classical autism," is the most common condition in a group of developmental disorders known as the autism spectrum disorders (ASDs). Other ASDs include Asperger's syndrome, Rett syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (usually referred to as PDD-NOS).

The legislation also authorizes Regional Centers Of Excellence For Autism Spectrum Disorder Research And Epidemiology. These centers collect and analyze information on the number, incidence, correlates, and causes of ASD and other developmental disabilities. The Act also authorizes grants to States for collection, analysis, and dissemination of data related to autism.

In addition, the Act authorizes activities to increase public awareness of Autism, improve the ability of health care providers to use evidence-

based interventions, and increase early screening for Autism. The Act authorizes the Secretary of Health and Human Services to:

- Provide information and education on ASD and other developmental disabilities to increase public awareness of developmental milestones;
- Promote research into the development and validation of reliable screening tools for ASD and other developmental disabilities and disseminate information regarding those screening tools;
- Promote early screening of individuals at higher risk for ASD and other developmental disabilities as early as practicable;
- Increase the number of individuals who are able to confirm or rule out a diagnosis of ASD and other developmental disabilities;
- Increase the number of individuals able to provide evidence-based interventions for individuals diagnosed with ASD or other developmental disabilities; and
- Promote the use of evidence-based interventions for individuals at higher risk for ASD and other developmental disabilities as early as practicable.

This legislation also calls on the Interagency Autism Coordinating Committee (IACC) to enhance information sharing. The IACC provides a forum to facilitate the efficient and effective exchange of information about autism activities, programs, policies, and research among the Federal government, several non-profit groups, and the public. The Combating Autism Act requires the IACC to provide information and recommendations on ASD-related programs, and to continue its work to develop and update annually a strategic plan for ASD research.

Source: www.whitehouse.gov

"This legislation will help more people recognize the symptoms of autism, which will lead to early identification and intervention, which is critical for children with autism."

Autism Society of America and Autism Research Institute Announce Partnership To Address Epidemic

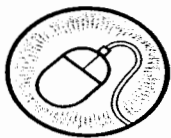
The Autism Society of America (ASA) and the Autism Research Institute (ARI) today announced a strategic partnership to collaborate on conferences, publications and services that will improve the lives of all those affected by autism in the United States. By joining forces, ASA and ARI aim to continue the important stewardship of their founder, Dr. Bernard Rimland. A pioneer in the area of autism diagnosis and treatment, Dr. Rimland transformed the prevailing pessimistic view of autism in the medical and scientific community and built the largest parent support organization in the United States.

A major purpose of the ASA/ARI partnership is to promote awareness that autism must be treated as a whole body condition. Projects in 2007 will include biomarker conferences, distribution of scientific journals and collaborative efforts to serve over 100,000 members and supporters of these two organizations.

ASA is the largest parent-based, autism organization in the U.S., with over 100,000 members and supporters and 200 local chapters. ARI, with over 70,000 supporters nationwide, has pioneered the study of medical problems of individuals with autism and effective treatments.

For more information on autism or ASA, visit www.autism-society.org or call 1-800-3AUTISM. For more information about the Autism Research Institute, visit www.autismwebsite.com/ari/index.htm.

Source: ASA/ARI



Online Discussion Groups Help People With Autism Find a Voice

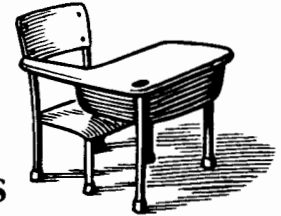
A new study of 39 people with autism and Asperger's syndrome using online discussion groups over time to communicate with each other reveals how the Internet helps people living with these conditions communicate with each other and discuss their lives and identities in an online environment. The study, titled "Constructing an Autistic Identity: AS Voices Online" was published in the October 2006 issue of the Journal Mental Retardation. Based on a careful study of the

messages exchanged during several online sessions, the study focuses on determining who "the experts" are in such forums—researchers or people living with the condition?

The authors conclude that while online environments have limitations, conducting research in such a manner can provide a rich pool of data and give a voice to an otherwise marginalized group. To read the study, visit: http://www.aamr.org/Reading_Room/pdf/ASVoicesOnline_MR_October2006.pdf

Source: AAMR/AAIDD

State Approaches to Serving Students with Autism Spectrum Disorders



An in-brief policy analysis has been created by Project Forum to clarify terminology and report findings gathered from a survey of state special education staff. Findings are reported in the following areas: state-level staff time and responsibilities; specific services for Part C eligible children; specific services for students with Asperger Syndrome; types of professional development activities offered; task force roles; how states measure outcomes; barriers to providing services to this population; and more. The most mentioned barrier to serving this growing population was the lack of educational professionals with ASD expertise. The policy analysis is available at <http://www.projectforum.org/docs/StateApproachesToServingStudentswithAutismSpectrumDisorders.pdf>.

Source: Project Forum, 12/31/06

STARS Training Schedule Online



The 2007 STARS (Statewide Training And Regional Supports) training schedule is now available online. As in the past, parents who have a child with special needs or developmental delay can attend for free.

STARS also has a limited fund for parents who would like child care and/or travel stipends. All registrations and child care/travel funding is available on a first come, first serve basis. Workshop and registration details are available at: http://www.ah.ouhsc.edu/tolbert/courses_workshops/#top

Source: OU Health Sciences Center



The American Dream is Unlikely for People with Disabilities

Americans with disabilities make up the United States' third largest minority, and yet they are the least likely of any demographic within the nation to achieve the American dream, according to Frank Bowe, Hofstra University's Dr. Mervin Livingston Schloss distinguished professor for the Study of Disabilities.

A new study by Bowe finds that among adults with disabilities:

- Only a quarter have full-time employment
- Less than one fifth go to college
- Fewer than half have private health insurance

More than one in nine Americans, 32 million in all, have severe disabilities, according to the U.S. Bureau of the Census. Bowe's study, titled "Disability in America" found that among Americans with disabilities, one in four subsists on below-poverty income and more than 75 percent have an individual income of less than \$20,000. The 2002 mean income of Americans with severe disabilities was \$18,363, compared with \$32,870 among adults in that age range with no disabilities.

One major reason for the low employment and income numbers is that many adults with disabilities subsist on Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) for the health coverage they guarantee. Although the monthly funds received from those programs are barely livable wages, the benefit of Medicare and/or Medicaid is something this population cannot do without.

Only 13 percent of Americans with disabilities between the ages of 21 and 64 work year round, full time. Because it is so difficult for people with disabilities to find full-time, year-round careers — jobs which feasibly would provide them with the health coverage they need — they acquiesce to this life of poverty in order to have some peace of mind with their health care. Only 45 percent of adults with severe disabilities have private health coverage; another 46 percent are on Medicare and/or Medicaid; and the remaining 19 percent have no health insurance.

Bowe also examines education for Americans with disabilities. Bowe says that despite measures to level

the playing field, the reality is that educational opportunity for students with disabilities and those without is not parallel. Schools are only required to provide sufficient tools to help students with disabilities to keep up with their education. Many continue to struggle. While the typical 9-year-old would be in the 4th grade, a 9-year-old student with disabilities is more than half as likely (61 percent) to be in the third grade and another third are only in second grade. Among high school students, most 15-year-old students with disabilities are not with their same age peers in the 10th grade. The vast majority are in 9th grade and more than a quarter are in the 8th grade.

Bowe does not dispute that educational opportunities are better today for students with disabilities than they were years ago, but there is still progress to be made. In 2004 students with disabilities comprised 6.8 percent of all full-time college freshmen. Those who complete their degree are more likely to get the full-time year round jobs with the private health insurance and escape the trappings that would likely keep them dependent on public entitlement programs.

To read the study, visit: http://people.hofstra.edu/faculty/Frank_G_Bowe.

Source: Hofstra University

National Professional Development Center on Inclusion Launches Website



Although many preschool classrooms have at least one child with a disability or special need, early childhood teachers often have little or no training in educating and caring for these children.

The recently funded National Professional Development Center on Inclusion (NPDCI) will work with states to create a system of high quality, cross-agency professional development for early childhood personnel to support inclusion. NPDCI has recently launched a new Web site that provides an overview of the project and information about the state selection process. Visit www.fpg.unc.edu/~npdci for more information.

Source: FPG Child Development Institute



TULSA ADVOCATES FOR THE RIGHTS OF CITIZENS WITH DEVELOPMENTAL DISABILITIES

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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



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

Next Meeting: Monday, January 29
7:00 to 8:30 p.m.

Martin Regional Library, 2601 S. Garnett
For information, call:
Zaida Castro-Kepford, 918-582-8272

Day Makers

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



TULSA PEOPLE FIRST

Next Meeting
Tuesday, Jan. 9

Dinner-5:30 p.m.
Meeting-6:30 p.m.

For information,
call Amie
at 918-582-8272

Asperger's Syndrome S.O.S.

A project of Tulsa Public Schools
in conjunction with TARC

No Meeting in January,
but beginning in February, join us
on the 1st Thursday of each month
from 6:30-8:00 p.m.

Kendall Whittier Elementary

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.

To sign up, call Stephanie Orban at 746-8747. For more information, contact Sherilyn Walton at TARC, 918-582-8272.

Connections

Asperger's Group

Next Meeting:

Wednesday, Jan. 24 - 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 Walton, TARC family support coordinator, 918-582-8272 for information.

MOMS & DADS SUPPORT GROUP

Next Meeting:
Thursday, Jan. 25
7:00-9:00 p.m.

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

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.

MOMS & DADS SUPPORT GROUP – OWASSO

Next Meeting: Tuesday, January 16
7:00 - 8:30 p.m.

First Baptist Church of Owasso, 13307 E. 96th Street North, Room 700
For more information, contact Sherilyn Walton at 918-582-8272.