



TARC NEWSLETTER

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

December 2009

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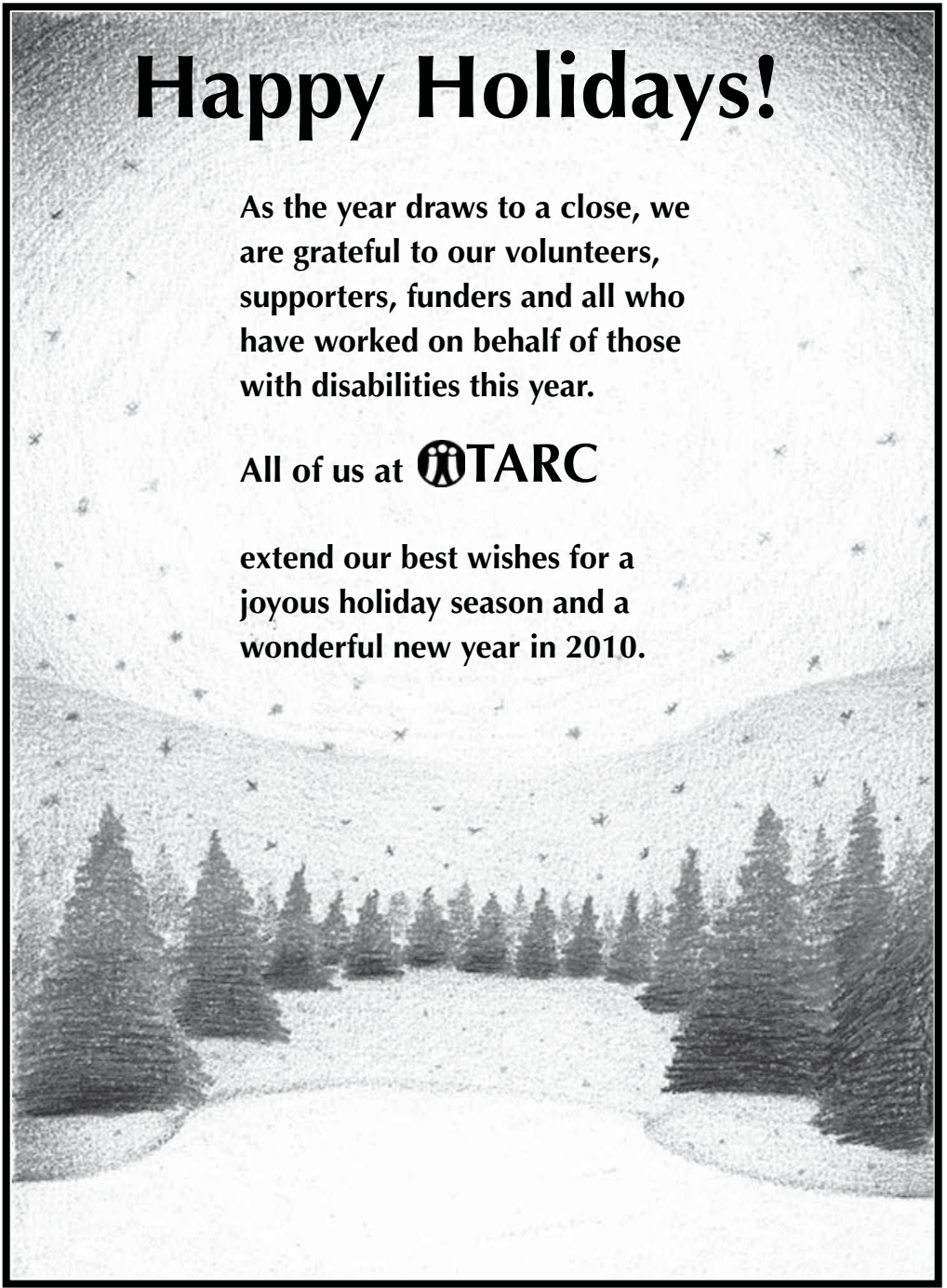
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Happy Holidays!

As the year draws to a close, we are grateful to our volunteers, supporters, funders and all who have worked on behalf of those with disabilities this year.

All of us at  TARC

extend our best wishes for a joyous holiday season and a wonderful new year in 2010.



Affiliated with
The Arc



Partner Agency

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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Joy to the World? Certainly Not in Oklahoma

By: John F. Gajda, TARC Executive Director

In this holidays season the midpoint of State Fiscal Year 2010 is nearly here and each week there seems to be more news about the gloomy fiscal climate that confronts the State of Oklahoma and the services provided by state agencies. It is certainly not a season of joy for those who depend on state-funded services. Each month it has been reported that state fiscal collections have fallen below the projected levels that were used to develop the budget for this fiscal year. Consequently all agencies have had to implement a series of cuts that are snowballing each month as we move through the fiscal year.

The Oklahoma Department of Human Services (OKDHS) in general and the Developmental Disabilities Services Division (DDSD) specifically are immersed in the doom and gloom and have had to make adjustments. DDSD is offering 162 voluntary buy-outs for positions at the two resource centers – NORC and SORC. This is part of the wider goal to reduce these facilities by a total of 259 positions by the end of SFY '10.

At its September meeting, the Commission for Human Services reduced the state-funded sheltered workshops by \$700,000 and the state-funded community integrated employment by \$450,000. Classroom training contracts with East Central University, Oklahoma State, and the University of Oklahoma were reduced by \$900,000. The web-based College of Direct Support is being used to replace general classroom lecture courses in Foundation Training.

Jim Nicholson, DDSD Administrator, reports that the long range funding picture for DDSD is murky. To keep all of state government funding for FY-10, the Oklahoma Legislature moved base funding from OKDHS and Oklahoma Health Care Authority (HCA) to areas of state government that didn't qualify for funds under the federal stimulus program. That loss was replaced with federal stimulus dollars including the revenue increase due to the stimulus' higher Medicaid matching rate. This base funding will have to be replaced when the stimulus ends on December 21, 2010. For DDSD, he estimates the loss of the higher matching rate will require \$27 million state dollars in the waivers alone just to maintain the current level of services.

Another issue that may impact services is whether providers can continue to deliver services at present prices without rate increases.

As the New Year begins, disability advocates are still waiting for some type of action to deal with the Oklahoma budget shortfalls. This fiscal climate will test the willingness of the state's leaders to consider prioritizing the human services needs of the state. Let's hope for some joy in 2010.

OK Policy Forecasts Give Extended Picture of State's Budget Crisis

The impact of the current recession will be long and deep in Oklahoma, and state services will continue to deteriorate, according to a report released by the Oklahoma Policy Institute. The issue brief explores the past, present and future of Oklahoma's revenue shortfalls and recommends improving revenue forecasting and budget planning. As the first publicly-released forecast for Oklahoma, the brief predicts the long-term effects

of the current economic downturn and recommends actions to address the shortfall.

"This shortfall is creating real hardship for the many Oklahomans who rely on state services," said David Blatt, director of Policy for Oklahoma Policy Institute, a state policy organization that analyzes state fiscal issues. "Our work shows a quick rebound is not likely, so we need to turn our attention to how we can preserve essential public services."

Revenues likely will not return to 2008 levels until 2012 or later, and the impact on public services will be both profound and long-lived, the report shows. OK

"Budget continued on pg 3"

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Policy's forecasts are based on six different forecasts using four methods of forecasting, including trend and regression analysis. They reveal that, according to mid-line estimates, even using the maximum available Rainy Day Fund allotment would result in 6 percent budget shortfalls in FY '10. Extending the forecasts out for three more years indicates that revenue may begin to rebound in FY '11, but will not return to FY '08 levels until FY '13, at which point inflation will have reduced the value by 15-20 percent.

To address the current recession and prepare for future downturns, Oklahoma Policy Institute recommends immediate and long-term action. In the short term, state officials should implement quarterly forecasting that is made public. The report also recommends that the Legislature hold public hearings for agency officials and citizens to discuss the effects of cuts in services. Finally, state leaders should define and announce their plan to use the Rainy Day Fund to limit further budget cuts.

According to Oklahoma Policy Institute executive director Matt Guillory, "We have to deal with falling revenues using the tools we have in place today. These give us some options, but are not enough to prevent hardship on Oklahoma families. What we can and should do, though, is be upfront with the public about what to expect through the recovery and make every effort we can now to design tools that will make the next downturn less disruptive to Oklahoma and its families and businesses."

Source: OK Policy Institute

Intellectual Disability Terminology

On November 24th, Senators Barbara Mikulski (D-MD) and Michael Enzi (R-WY) introduced "Rosa's Law" (S. 2781) a bipartisan bill to substitute outdated, stigmatizing terms in federal health, education and labor laws. The terms "mental retardation" and "mentally retarded" would be substituted with the terms "intellectual disability" and "individual with an intellectual disability." The change in terminology would in no way alter the eligibility requirements for services and supports.

The following is a portion Senator Mikulski's state-

ment regarding the bill delivered on the Senate floor: "Today I rise to introduce legislation that I'm calling Rosa's Law. This bill began ... when a mother told me a compelling story about her own daughter, her family's efforts to give her daughter (Rosa) an opportunity for an education and to be treated with respect and with dignity. And at the same time, it began with the advocacy of ... her entire family....

"That's why I stand on the Senate floor today to introduce, at the request of the family, a law on behalf of this little girl and on behalf of all of the children of the United States of America who are labeled, stigmatized and bear a burden the rest of their lives because of the language we use in the law books.

"My law changes the phrase 'mentally retarded' to 'an individual with an intellectual disability' We did this in health, education and labor policy without in any way negatively impinging upon either the educational or other benefits that these children are entitled to.

"This is not the first time we've updated this terminology. Our laws once referred to boys and girls as 'feeble minded.' We thought we were being advanced when we changed it to 'mentally retarded' in the 1960s. Now, 40 years later, let's take another big step and change it to 'intellectual disability.'

"This bill makes language used in the federal government consistent. The President's Committee on Mental Retardation was changed by executive order so it is now the Committee on Individuals with Intellectual Disabilities. The CDC uses 'intellectual disability,' the World Health Organization uses 'intellectual disability,' so my law makes the language consistent within the federal government.

"I've always said that the best ideas come from the people. Rosa's Law is the perfect example of effective citizen advocacy. A family that pulled together for their own and in pulling together they're pulling us all along to a new way of thinking.

"This bill is driven by a passion for social justice and a compassion for the human condition. We've done a lot to come out of the dark ages of institutionalization and exclusion when it comes to people with intellectual disabilities. I urge my colleagues to join me in a step further. Help sponsor the legislation that I offer on a bipartisan basis. Help me pass the law and know that each and every one of us makes a difference. When we work together, we can make change."

New Professional Resource Establishes Ground-breaking Paradigm To Support People with Intellectual Disabilities

Society's labels have consequences. A bad credit score means you pay more for a loan. Careless driving that translates into several points on your license labels you a risky driver. But no label damages more than being called "mentally retarded."

Setting aside that label and establishing the means to integrate people with intellectual disabilities into society based on their abilities rather than their deficits are the fundamental objectives of a new resource for professionals working with people with intellectual disabilities. The new resource, the 11th edition of *Intellectual Disability: Definition, Classification and Systems of Supports*, known in the field as the "Definition Manual" is published by the American Association on Intellectual and Developmental Disabilities (AAIDD).

"We understand that people with intellectual disabilities face enough challenges every day that they don't need to deal with a pejorative label. And as medical, educational and legal professionals, we know that mental intellectual disability is far more complex than a low score on an IQ test," said AAIDD president Joanna Pierson, PhD, Executive Director of The Arc of Frederick County, MD. "The definition manual represents the most current thinking on how professionals should approach those with intellectual disabilities and offers tools and strategies to implement progressive services and strategies in various settings such as schools, provider agencies, and the policy world."

AAIDD is committed to setting aside labels and instead focus on creating and supporting the services people with intellectual disability need to function fully in our society. AAIDD is committed to including the people with intellectual disability within every aspect of our lives whether they ride the bus with us, work in the same offices or play with our children.

To this end, the 11th edition establishes an advanced paradigm that professionals will use when evaluating and delivering the support services that a person with intellectual disability needs at school, at home, in the physician's office or the courts, if the need arises. Rather than look at individual deficits, this model is based on evaluating the support services someone needs to

reduce the mismatch between a person's capabilities and skills so that they can participate fully in all aspects of daily life.

Uniform criteria are included in the 11th edition that should be used to diagnose intellectual disability, including a combination of age of onset, IQ, and adaptive behavior skills. Several states now use different standards, ranging from IQ scores to a combination of IQ and certain skills. The 11th edition also contains the latest thinking, tools and strategies to diagnose whether a person has intellectual disability or not. The 11th edition is designed to be an invaluable resource for many professionals, including:

- Physicians may consult the guidelines to more precisely diagnosis a child or adult, such as evaluating the role of IQ in making a diagnosis and assessing how the individual is adapting to life's challenges and opportunities.
- Teachers and school psychologists at both the secondary and post-secondary levels can refer to sections when determine eligibility for special education services and how the AAIDD paradigm and IDEA (Individuals with Disabilities Education Act) are related.
- University and college faculty and students in medicine, special education and psychology disciplines can use the manual as a key reference in developmental disability.
- Those involved in the civil and criminal justice system can use the 11th edition when considering how the court should handle criminal cases involving an individual with intellectual disability.



Written by a committee of 18 experts, the 11th edition is based on seven years of work to synthesize current information and best practices regarding intellectual disability; reviews and critiques of the previous edition and feedback from the field. To download an FAQ on the AAIDD Definition Manual go to <http://www.aaid.org/media/PDFs/11eFAQ.pdf>. To purchase the book go to, <https://bookstore.aaid.org/BookDetail.aspx?bid=97>.

Source: AAIDD

Autism News Roundup



Parent Training Complements Medication for Treating Behavioral Problems in Children with Pervasive Developmental Disorders

Treatment that includes medication plus a structured training program for parents reduces serious behavioral problems in children with autism (<http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders/index.shtml>) and related conditions, according to a study funded by the National Institute of Mental Health (NIMH). The study, which was part of the NIMH Research Units on Pediatric Psychopharmacology (RUPP) Autism Network, was published in the December 2009 issue of the *Journal of the American Academy of Child and Adolescent Psychiatry*.

Results from a previous RUPP study (<http://www.nimh.nih.gov/science-news/2002/nimh-study-finds-anti-psychotic-medication-useful-in-treating-serious-behavioral-problems-among-children-with-autism.shtml>) reported in 2002 showed that the antipsychotic medication risperidone (Risperdal) reduced such behavior problems as tantrums, aggression and self-injury in children with autism. However, most children's symptoms returned when the medication was discontinued. Although effective, risperidone is associated with adverse effects such as weight gain, which can lead to metabolic changes, obesity and related health problems.

"Medication alone has been shown to help with some symptoms of autism, but its potential is limited," said NIMH Director Thomas R. Insel. "This study shows promise of a more effective treatment protocol that could improve life for children with autism and their families."

In the study, the RUPP group tested the benefits of medication alone compared to medication plus a parent training program that actively involves parents in managing their children's severely disruptive and non-compliant behavior. Parents were taught to modify their children's behavior and learned to enhance their children's daily living skills.

The 24-week, three-site trial included 124 children

ages 4 to 13 with pervasive developmental disorders (PDD) such as autism, Asperger's or related disorders accompanied by tantrums, aggression and self-injury.

The children were randomized to a combination of risperidone and parent training, or to risperidone only. Parents in combination therapy received an average of 11 sessions of training over the course of the study.

Although both groups improved over the six-month trial, the group receiving combination therapy showed greater reduction in behavioral problems like irritability, tantrums and impulsiveness compared to the group receiving medication only. The combination therapy group also ended the trial taking an average dose of 1.98 milligrams (mg) per day of risperidone, compared to 2.26 mg/day in the medication-only group—a 14-percent lower dose. However, children in both groups gained weight, indicating "a need to learn more about the metabolic consequences of medications like risperidone," said the authors.

"The combination group was able to achieve its gains with a lower dose of medication. Plus, it appeared that the benefits of added behavioral treatment increased over time, a strong signal that actively including parents in the treatment of children with PDD could only benefit families," said lead author Michael Aman, Ph.D., of the Ohio State University.

"Future studies will evaluate whether the benefits of parent training endure over a long period of time," concluded the authors. The investigators also plan to apply the parent training to younger children with PDD to prevent the evolution of serious behavioral problems. Future studies may also look for ways in which the parent training program can be used in schools and community clinics.

Source: National Institute of Health

**To learn more about TARC
Visit us online at
www.ddadvocacy.net**

National Autism Center Releases New Autism Educator Manual

Schools today face the challenge of providing appropriate services to a diverse and increasingly numerous student population diagnosed with ASD. In order to achieve this goal, evidence-based practice is essential in the schools. To assist school professionals as they strive to help these students reach their potential, the National Autism Center has produced a comprehensive 245-page manual, Evidence-Based Practice and Autism in the Schools. The manual outlines relevant topics, including the current state of research findings, professional judgment and data-based clinical decision making, values and preferences of families, and capacity building. Each chapter sets a course for advancing the efforts of school systems to engage in evidence-based practice for their students on the autism spectrum.

The center has distributed 3,000 printed copies of this manual to school systems around the country. Due to high demand, they are now offering the manual on their website as a pdf, and making hard copies available for purchase. Go to <http://www.nationalautismcenter.org/learning/practitioner.php>



TARC
helps families

Learn more about TARC by visiting our website at www.ddadvocacy.net

**Not a member of TARC?
Join Today!**

Visit us online to find out how to become a member today!!
www.ddadvocacy.net

TARC is a network of programs advocating for Oklahomans with developmental disabilities. Your membership allows TARC to continue providing the vital programs that help ensure a high quality of life for people with developmental disabilities.

TARC CALENDAR OF EVENTS

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,
December 16th
6:30-7:45 p.m.

The next meeting will be held at
TARC's new office:
2516 East 71st St., Suite A
Tulsa, OK 74136-5531

Links is a support group for adults with Asperger's Syndrome. Contact Amie Farinella, 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
February 10th
6:30 p.m.

Contact Amie Farinella, 918-582-8272
For more information about the next meeting

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

Connections Asperger's Group

Please call TARC for information about the next Connections meeting

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, December 30th
7:00 to 8:30 p.m.

St. Thomas Moore Catholic Church,
2720 S. 129th E. Ave., Tulsa

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



MOMS & DADS
SUPPORT GROUP

Instead join us on
Thursday December 3rd
7:00 pm-9:00 p.m.

Kirk of the Hills,
4102 E. 61st St, Tulsa

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

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

1ST TULSA PEOPLE FIRST

Please contact
Amie Farinella
for information
about the next
Tulsa People First
Meeting
918-582-8272