



TARC NEWSLETTER

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

October 2007

CONTENTS

The Facts About Fetal Alcohol Syndrome 1 & 2

Postsecondary Resources for Students with Intellectual Disabilities 3

Disability Programs Not Keeping Up With Societal Changes 4

Information for Women with Disabilities 4

Health and Wellness Programs for People with Disabilities ... 5

October Designated National Disability Employment Awareness Month..... 5

TARC Disabilities Month Speaker Series 6

Autism News Roundup 7

Calendar of Events 8

The Facts About Fetal Alcohol Syndrome

September 9 marked International Fetal Alcohol Syndrome Awareness Day in countries around the world, including the U.S. The ninth day of the ninth month of the year (September 9 or 9/9) was designated Fetal Alcohol Syndrome Awareness Day as a reminder of the nine months of pregnancy during which women should abstain from drinking alcohol. Given that fetal alcohol syndrome is known to cause mental retardation, low birth weight, learning disabilities, behavioral disorders and developmental delays, it is important to remind all advocates that this is one of the few causes of developmental disabilities that can be prevented.

The information below comes from a fact sheet on Fetal Alcohol Syndrome (FAS) published by The Arc:

What is FAS?

FAS refers to a group of physical, behavioral, and cognitive abnormalities that can occur to unborn babies when pregnant women drink alcohol and pass the alcohol along to their unborn babies through the blood stream. FAS is identified by abnormal facial features, central nervous system problems and a slowness of growth. FAS can cause physical and mental disabilities of varying levels of severity (including mental retardation). Alcohol-related neurodevelopmental disorder (ARND) is also caused by prenatal alcohol use. Children with ARND do not have full FAS, but may demonstrate learning and behavioral problems. Another term commonly used to describe children affected by prenatal alcohol use who do not have all the symptoms of FAS is fetal alcohol effects (FAE).

The prevalence of FAS is not known. CDC (Centers for Disease Control & Prevention) studies have documented FAS prevalence rates ranging from 2 to 15 cases per 10,000 live births. Other prenatal alcohol-related conditions, such as ARND, are believed to occur approximately 3 times as often as FAS.

Children with FAS or ARND can have serious lifelong disabilities other than mental retardation, such as learning disabilities and serious behavioral problems. The good news is FAS is not hereditary and only occurs if a woman

please see "FAS" 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)

FAS, from page 1

drinks alcohol during her pregnancy. In other words, **FAS and ARND are 100% preventable.**

How is FAS diagnosed?

FAS is diagnosed by 4 criteria:

1. Growth deficiency in height and/or weight either prenatally or postnatally.
2. Specific pattern of facial anomalies: short eye slits, smooth or indistinct philtrum (the ridges running vertically between the nose and lips) and a thin upper lip.
3. Some brain damage to the central nervous system demonstrated through microcephaly (small size of the brain), tremors, hyperactivity, fine or gross motor problems, attentional deficits, learning disabilities, intellectual impairments and possible mental retardation.
4. Evidence of alcohol use by the birth mother during pregnancy (however, some diagnoses are made without this criteria) (Streissguth, 1997).

How does alcohol affect the unborn child?

Alcohol in the mother's blood passes through the placenta and enters the embryo or fetus through the umbilical cord. Through a number of biological means, alcohol affects the size, shape, and function of the cells that form the brain, the heart, the kidneys, and all other body organs and systems. Effects of these organs and systems can occur as a result of drinking any time during pregnancy.

What treatment is recommended for individuals with FAS?

There is no cure for this condition and it does not appear to get better with age. The damage of FAS caused by a mother's drinking during pregnancy is permanent. However, with early identification and diagnosis, children with FAS can receive services that can help maximize their potential. They will benefit from early intervention services and an individualized education program in school that includes preparation for transition from school to work and possible further education.

Many people with FAS benefit from one-on-one counseling support. In addition, they often require

intensive service coordination if they do not have someone who can coordinate the many services they need (such as on-going individual therapy, job coaching, housing, and transportation).

What services are available to families of children with FAS?

There are programs offering income assistance, health care and related services, education, help with basic needs such as food programs and social services and child welfare services. Specific services may include Head Start, early intervention, special education, and vocational services.

As advocates for people with developmental disabilities, it is inherent that we also be advocates in the fight to prevent Fetal Alcohol Syndrome. Educating women and expectant mothers is the key to preventing FAS. We have a rare opportunity in our approach to FAS in that it is 100% preventable. If you need more information about FAS or if you would like FAS brochures for an upcoming meeting or presentation, contact TARC at 918-582-8272.

Quick Facts About Fetal Alcohol Syndrome

Link to Mental Retardation: Approximately 25% of people with FAS also have mental retardation

Who it Affects: Children of some women who drink alcohol during pregnancy

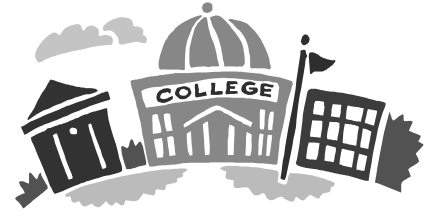
Symptoms: Growth retardation, facial abnormalities, central nervous system dysfunction, behavioral problems, hyperactivity, learning disabilities, low IQ and other possible abnormalities

Incidence: Not known. Some studies show a range from 2 to 15 cases per 10,000 live births. ARND may occur approximately three times as often

Cause: Drinking alcohol during pregnancy; FAS is not hereditary and is 100% preventable by not drinking during pregnancy

Treatment: There is no cure for FAS. However, early intervention, individualized education programs, transition supports from school to adult life, intensive service coordination and one-on-one counseling can help improve the lives of individuals affected by FAS

Postsecondary Resources for Students with Intellectual Disabilities



College Options for Students with Intellectual Disabilities

The Postsecondary Education Research Center Project, coordinated by TransCen, has launched a web site that provides information and resources on college options for students with intellectual disabilities. The site provides answers to frequently asked questions related to developing or expanding services for students with intellectual disabilities in college settings. It also provides access to a free online evaluation tool, the PERC Self-Assessment Tool, which allows users to evaluate aspects of programs or services for students with intellectual disabilities on college campuses. This self-assessment tool provides a snapshot of the quality of existing services and provides users with a concise evaluation report. It also provides users with the opportunity to create an itemized action plan that can be used to address areas in need of improvement. For more information, visit <http://www.transitiontocollege.net>.

Individual Supports to Increase Access to an Inclusive College Experience for Students with Intellectual Disabilities

This online training module provides guidance on developing an Individual Support Model (ISM) to increase access to inclusive college experiences and to improve chances for the success of students with intellectual disabilities. An ISM approach provides students with individualized services and supports (e.g., educational coach, tutor, technology, natural supports) in college courses, certificate programs, internships, and/or degree programs. Offered by the On-Campus Outreach project at the University of Maryland; funded by the U.S. Office of Special Education Programs. For more information, visit http://www.education.umd.edu/oco/training/oco_training_modules/IndividualSupports/start.html.

Transition Services for Students with Significant Disabilities in College and Community Settings: Strategies for Planning, Implementation and Evaluation

This resource is recommended for professionals responsible for designing or implementing transition services for students with autism, developmental, multiple, or other significant disabilities. The book guides readers through each phase of developing, implementing, and evaluating effective and appropriate transitions services for students with significant disabilities. For purchasing information, go to: www.proedinc.com.

Source: Monday Morning in Washington

Emergency Response

Assessment



Emergency

A newly developed assessment tool is now online for state disability services officials nationwide to determine the extent to which their agency's emergency preparedness plans address issues critical to the support and protection of persons with intellectual and developmental disabilities during disaster or crisis.

While designed primarily for state agencies, it may also be useful to community service providers and others. A demonstration version can be found online, as well as more information about the tool. For more information, visit: <http://rtc.umn.edu/erp>.

Source: Monday Morning in Washington

American Academy of Pediatrics Publishes Toolkits for Professionals



The American Academy of Pediatrics (AAP) has posted several toolkits designed to aid healthcare providers, medical professionals and medical staff in their work with children with disabilities and their families to its website.

To view and download the toolkits, visit: <http://www.medicalhomeinfo.org/tools/Toolkits.html>.

Source: AAP



Largest Federal Disability Programs Have Not Kept Up with Societal Changes in the U.S.

The U.S. Government Accountability Office (GAO) gathered advocacy groups, academia, federal agencies, and researchers for a forum to discuss what's working well in over 200 federal disability programs in the United States, what needs to be improved, and how to strengthen partnerships and modernize programs.

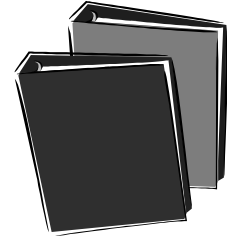
A new report titled *Modernizing Federal Disability Policy* published by GAO articulates the key concerns expressed in this forum. The report found that "social and legal changes have promoted the goal of greater inclusion of persons with disabilities in the mainstream of society, including adults at work." For example, the Americans with Disabilities Act (ADA) supports the full participation of persons with disabilities in society and fosters the expectation that persons with disabilities can work and have the right to work.

However, GAO's reviews of the largest federal disability programs indicate that such programs have not evolved in line with these larger societal changes and, therefore, are poorly positioned to provide meaningful and timely support for persons with disabilities. The report further cites the looming crises in the slowdown in the nation's labor force and the low rate of return to work for individuals with disabilities receiving cash and medical benefits

Some of the steps identified to enhance federal programs include talking with people receiving disability services to find out what additional services they need to succeed; developing a definition of disability and standard language that could be used across programs; and providing services to youth. The report can be viewed at: <http://www.gao.gov/new.items/d07934sp.pdf>.

Source: AAIDD FYI-September 2007, Vol. 7 No. 9

New International Handbook Provides Basic Information for Women with Disabilities



A new handbook with examples and illustrations drawn from across the world, serves as a basic guide to health and wellness for women living with a physical or mental disability.

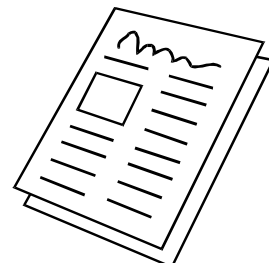
Women with disabilities across the world often find it difficult to get the health care they need, when they need it. *A Health Handbook for Women with Disabilities* by the Hesperian Foundation provides basic and essential information on issues such as understanding your body, sexuality, pregnancy, preventing abuse, taking care of assistive devices, information on common medications, and more.

To download the book by chapter, visit http://www.hesperian.org/publications_download_wwd.php.

Source: AAIDD FYI-September 2007, Vol. 7 No. 9

 Visit us on the web at: www.ddadvocacy.net

Online Publication Tracks Efforts to Uphold Rights of People with Disabilities



The Disability Rights Section of the Civil Rights Division of the U.S. Department of Justice has recently posted the 18th edition of the *Disability Rights On-Line News*, a publication that gives readers some of the latest information surrounding efforts to uphold the rights of people with disabilities across the country.

The text is available in HTML and PDF formats, and you may also read back issues of the publication. Visit: <http://www.usdoj.gov/crt/ada/disabilitynews.htm>.

Source: U.S. Department of Justice

October is National Disability Employment Awareness Month; October 17th is Disability Mentoring Day



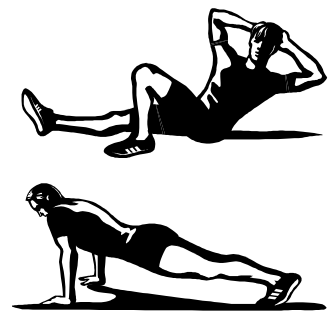
Congress designated each October as National Disability Employment Awareness Month (NDEAM). The Office of Disability Employment Policy has the lead in planning NDEAM activities and materials to increase the public's awareness of the contributions and skills of American workers with disabilities. Various programs carried out throughout the month also highlight the specific employment barriers that still need to be addressed and removed.

This effort to educate the American public about issues related to disability and employment actually began in 1945, when Congress enacted a law declaring the first week in October each year "National Employ the Physically Handicapped Week." In 1962, the word "physically" was removed to acknowledge the employment needs and contributions of individuals with all types of disabilities. In 1988, Congress expanded the week to a month and changed the name to "National Disability Employment Awareness Month."

Disability Mentoring Day (DMD) is a national program that promotes career development for students and job-seekers with disabilities through job shadowing and hands-on career exploration. If you would like to participate in Disability Mentoring Day 2007 on October 17 in your region of the country, as either a mentee or employer mentor, please visit <http://www.dmd-aapd.org/coordlist/coordlist.php> for more information.

Source: Office of Disability Employment Policy

Health, Fitness and Wellness and Programs for People with Disabilities



The Office on Disability (OD) of the U.S. Department of Health and Human Services has two programs underway that are important for children with disabilities, their families, and their physicians. One program is the implementation of the strategic plan of the Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities. Through the implementation of this document, the OD is working to improve healthcare access and health behaviors for persons with disabilities, including children, and make sure that all Americans know that good health means the same thing to everyone.

A second Office on Disability program, *I Can Do It, You Can Do It!*, is a physical fitness and nutrition mentoring program for youth with disabilities. The program is run through organizations in each community who match youth with disabilities with physically fit mentors. Together, the children and their individual mentors develop weekly physical fitness plans that are fun for the mentees and are tailored to their interests and abilities. The mentor then supports the mentee throughout the 6 week program in meeting physical activity and nutritional goals.

Visit the Office on Disability (OD), *Call to Action* www.surgeongeneral.gov/library/disabilities, and "I Can Do It, You Can Do It!" (www.hhs.gov/od/physicalfitness.html) websites to learn more about these programs and others. If you would like more information on what you can do to support or take part in these

Save these Dates!

In recognition of Disabilities Awareness Month, TARC will present the 5th annual Speaker Series. All lectures are presented free of charge and no reservations are required to attend. Locations, program dates and topics are as follows:

Disabilities Month

Speaker SERIES

October 11, 16, 24 & 30

Presented by



Estate Planning Essentials for Your Child with Special Needs

Thursday, October 11

Time: 6:30-8:00 p.m.

Location: Helmerich Library, 5131 E. 91st Street, Tulsa

An overview of estate planning tools currently available to provide for the long term needs of your child with disabilities, including special needs trusts, supplemental needs trusts, guardianships-pro & con, and related concerns. Presented by Curtis J. Shacklett of Barber & Bartz law firm.

The Autism Pilot and Self-Directed Services: What Lies Ahead?

Tuesday, October 16

Time: 6:30-8:00 p.m.

Location: Hardesty Regional Library-Pecan Room, 8316 E. 93rd Street, Tulsa

A summary of findings from Oklahoma's autism pilot to date, as well as an overview of information on self-directed services for individuals with developmental disabilities. Presented by James Nicholson, Director, Developmental Disabilities Services Division, Oklahoma Department of Human Services and Rene Daman, Project Director, Oklahoma Autism Network.

What Can We Learn From Children With Special Needs?

Wednesday, October 24

Time: 6:30-8:00 p.m.

Location: Kirk of the Hills Presbyterian Church-Sanctuary, 4102 E. 61st Street, Tulsa

The inspiring story of Zachary Moore and how his life enriched the lives of others. Zachary was one of just eleven children in the nation with Progeria, a rare and fatal disease that causes rapid aging. His parents recently published a book, *Old at Age 3*, about Zachary, which was released in September 2007. Presented by Keith and Molly Moore, Zachary's parents.

The Culture Factor: An Overview of Working with Hispanic Clients

Tuesday, October 30

Time: 11:30 a.m.-1:00 p.m.

Location: Hardesty Regional Library-Redbud Auditorium, 8316 E. 93rd Street, Tulsa

We all know that culture affects how people perceive and respond to services, and this presentation breaks it down in simple terms. From learning what "Hispanic" means, to a basic knowledge about government, social class, race, formalities and lifestyle in Spanish-speaking countries, participants will learn techniques to interact more effectively with Hispanic clients. Presented by Zaida Castro-Kepford, TARC Hispanic Outreach Specialist.

** All presentations have been submitted for approval for DHS training credit*

For more information: call 918-582-8272

Autism News Roundup

NIH Funds New Program to Investigate Causes and Treatment of Autism

The National Institutes of Health (NIH) will intensify its efforts to find the causes of autism and identify new treatments for the disorder, through a new research program.

The Autism Centers of Excellence (ACE) program represents a consolidation of two existing programs, the Studies to Advance Autism Research and Treatment (STAART) and Collaborative Programs of Excellence in Autism (CPEA) programs into a single research effort.

“The consolidation was needed to capitalize on the gains made by the NIH research effort in autism,” said Elias Zerhouni, M.D., Director of the National Institutes of Health. NIH autism program officials hope to expand on earlier discoveries made by research previously supported by NIH.

The NIH Institutes providing funding and expertise for the effort are the National Institute of Child Health and Human Development, the National Institute of Deafness and other Communication Disorders, the National Institute of Environmental Health Sciences, the National Institute of Mental Health and the National Institute of Neurological Disorders and Stroke.

Autism is a complex brain disorder involving communication and social difficulties as well as repetitive behavior or narrow interests. Autism is often be grouped with similar disorders, all of which may be referred to collectively as autism spectrum disorders (ASD). The underlying causes of ASD are unclear. Currently, there is no cure for the disorders and treatments are limited.

The ACE program will encompass research centers and research networks. The research centers will foster collaborations between teams of specialists, who share the same facility so that they can address a particular research problem in depth. For example, specialists in brain imaging might collaborate with behavior researchers to determine if a particular behavior is associated with a difference in brain structure. They might also consult with a team of genetics experts to find a hereditary basis for their observations.

ACE networks consist of researchers at many facilities in locations throughout the country, all of

whom work on a single research question.

Because networks encompass multiple sites, they can recruit large numbers of volunteers with a particular disorder.

Initially, five centers and one network will receive funding in 2007 to study ASD. Funding for a second set of ACE research programs will be announced in 2008.

All ACE award recipients will contribute their data to the National Database for Autism Research (NDAR). Housed at NIH, NDAR is a Web-based tool that autism researchers around the world can use to collect and share information on autism.

Topics to be researched by the 2007 ACE program award recipients are:

- Whether genetic factors, as well as brain chemicals and brain functions, could account for repetitive behaviors in people with ASD;
- Infants who have been referred by their physicians will be studied to identify brain or other physical differences that might predispose a child to autism.
- Researchers will seek to identify genes and other potential factors that may predispose an individual toward ASD, as well as factors that might protect against them. Researchers will also try to determine whether certain types of interactions between the parent and baby can decrease the chances for ASD.
- Brain imaging will be used to study how people with ASD learn and understand information, as well as how infants at risk for autism and toddlers diagnosed with the disorder place information into categories.
- In hopes of identifying brain differences in children who develop ASD, researchers will use brain imaging techniques to compile images of the brains of very young infants, to identify differences between children who develop autism and those who do not.
- By looking at genes, behavior, and brain structure and functioning, researchers will try to find clues to language-related communications problems, as well as how the disorder affects the mirror neurons.

Source: NIH



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!

Families in Transition

Families in Transition is a support group for parents of adult children with developmental disabilities. The group meets quarterly and covers topics of interest such as housing, guardianship, state services and residential care providers.

NEXT MEETING:
Wednesday, November 14
6:00-7:30 p.m.
Full Cup Cafe,
4634 E. 31st St. in Tulsa

RSVP to Amie Farinella, 918-582-8272

The group is for parents only-participants are asked not to bring their adult children to the support group.

Connections Asperger's Group


Next Meeting:
Wednesday, October 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 or Amie at 918-582-8272 for more information.

Day Makers

Activities group for adults with developmental disabilities

Thursdays • 1:00-2:30 p.m.
McClure Recreation Center
7440 E. 7th Street in Tulsa
Contact: Amie, 918-582-8272

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

Next Meeting: Monday, October 29 *For more information, call Zaida at 918-582-8272*
7:00 to 8:30 p.m.
Martin Regional Library, 2601 S. Garnett


MOMS & DADS SUPPORT GROUP

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

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

Contact: Sherilyn, 918-582-8272



TULSA PEOPLE FIRST

Next Meeting:
Tuesday, October 9

Ryan's Steakhouse
10934 E. 21st St.
Dinner-5:30 p.m.
Meeting-6:30 p.m.

MOMS & DADS SUPPORT GROUP – OWASSO

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

Due to low attendance, the Owasso Moms and Dads Support Group has been discontinued. Parents in the Owasso area are encouraged to attend the Tulsa Moms and Dads Support Group.

SAPULPA Support Group for Families of Children with Special Needs

Next Meeting: Tuesday, October 16, 6:15 p.m.
Creek County Literacy Center, 15 N. Poplar
Childcare is not provided, but please take advantage of Sapulpa's great Respite Care Program!

For more information, contact Mindy Littlefield, 378-5632

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