



Family Connections

A Family Newsletter from OASIS
Oklahoma Areawide Services Information System



ON THE ROAD FAMILY PERSPECTIVE CONFERENCES

Next one will be Tuesday, September 26, 2006 in Idabel, OK

If your community would like to host a one day conference and want more information—Call Sally Selvidge at OASIS at 1-800-426-2747 or email her at Sally-Selvidge@ouhsc.edu

Volume 13

Summer 2006

OASIS Oklahoma Areawide Services Information System Where You Can Still Talk to a Person For Information and Help

OASIS has provided information and referral to families who have a child or family member with a disability or special health care needs since 1987. OASIS is operated and administered by the Department of Pediatrics at the University of Oklahoma Health Sciences Center, College of Medicine and is a member of the National Alliance of Information and Referral Systems (AIRS).

Talking to a “live” person and not a telephone menu of services is what makes OASIS unique in today’s world. You can search on the internet for information, but sometimes being able to talk to a person saves you many hours of frustration and stress. Oftentimes when people call the OASIS office they are not sure what they need. They may have called many numbers before reaching OASIS.

A trained information specialist will answer your call, talk with you about the services you need, provide you with specific information about service providers in your area, and tell you how to get the services they offer.

Families can access our phone line 24 hours a day, 7 days a week via a toll free 800 line or visit our website at <http://oasis.ouhsc.edu> to search our online directory to find information about the services and programs they are needing. The phones are answered by a trained information specialist Monday thru Friday 8 am to 6 pm, but anyone needing information can leave a message anytime and their call will be answered either the same business day or by the next business day.

Ongoing funding support for OASIS is provided through contracts with the Oklahoma Commission on Children and Youth, the Oklahoma State Department of Human Services and the Oklahoma State Department of Health.

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CALENDAR OF EVENTS



On Going Events:

Arthritis Community Education and Self Help Courses: Contact Marisa New, Oklahoma Arthritis Network for schedule - (405) 271-9444, ext. 56410 or by e-mail: marisan@health.state.ok.us

Oklahoma Respite Resource Network meets the first Tuesday of each month from 1:00 – 3:00 pm, usually in the Green Room at the Lincoln Plaza Office Complex, 4545 N. Lincoln in Oklahoma City. The ORRN is a collaboration of agencies, organizations and individuals working to increase the availability of respite care for families in Oklahoma. Anyone interested is welcome to attend. Meeting times and dates are subject to change, so check with OASIS at (800) 426-2747 to confirm.

Statewide Training and Regional Supports (STARS) The mission of STARS is to support the provision of individualized, comprehensive, multidisciplinary, family-centered, community-based programs and services for people with disabilities through a coordinated training system. Staff and contractors of the SoonerStart program, local public schools, and DDSD, as well as families accessing services from these agencies may attend STARS trainings at no charge. Others are welcome to register and attend STARS trainings on a “space available” basis for a charge of \$50.00 per person per workshop. A list of workshops and more information can be found at: http://www.ah.ouhsc.edu/tolbert/courses_workshops/

The Olmstead Strategic Planning Meetings. These meetings are held the first Thursday of each month at the Oklahoma State Capitol in Room 419C from 1:30 - 3:00 p.m. They open to the public and anyone interested in having input on how to implement the Olmstead Strategic Plan for people who have a disability to live in the community is welcome to attend. Please call Rose Ann Percival at (405) 522-0600 for more information.

Upcoming Events, Conferences and Workshops:

June 14 – July 19: Grandparents Raising Grandchildren Workshops. Series of 5 workshops that will help answer questions concerning issues and common challenges faced by “Grandfamilies”. Workshops will be held at the South Oklahoma City Chamber of Commerce Conference Room (701 SW 74th) 7:30 – 8:30 pm on Wednesday evenings beginning June 14th. For more information, please contact Dr. McCoy or Kendra Miller at Oklahoma City Community College Child Development Center & Lab School at (405) 682-7561.

October 25 -27: National Respite Conference. Doubletree Hotel Downtown. Omaha, Nebraska. For more information got to <http://archrespite.org/>

Medicare and Medicaid Important Information Changes

The proposed Medicare rule means Medicare will not be able to pay for low vision aids needed by beneficiaries who have severe vision loss. The proposed exclusion comes at a time when the population of people with blindness and low vision is growing dramatically. Today 45,000 Oklahomans age 40 and over are blind or significantly visually impaired. This population is expected to double by 2030.

For more information contact Jody Harlan at jhjones@drs.state.ok.us or at 405-951-3488.

Also contact Mark Richert, Public Policy Director, at the American Foundation for the Blind mrichert@afb.net. Or visit the website of the Department of Rehabilitation Services at : <http://www.okrehab.org>

The Oklahoma Legislature just passed on Friday, May 26, 2006 **The Oklahoma Medicaid Reform Act of 2006**. It makes many changes to the current Medicaid system in Oklahoma. To get more information and read the bill go to <http://www.captc.org/public-policy.asp> or the legislative service page of the Oklahoma State Legislator at <http://www.lsb.state.ok.us/> . It now goes to the Governor for his signature.

<http://www.cms.hhs.gov/medicaid/stateplans/map.asp>— Website for Center for Medicare and Medicaid state plans including Oklahoma.



OASIS

Continued from page 1



SAVE THE DATE

Children and Youth with
Special Health Care Needs
Oral Health Forum

Friday, August 25, 2006

Moore/Norman Technology
Center
13301 So. Penn
Moore, OK

For more information or questions, call
Sally Selvidge at (800) 426-2747 or email
her at Sally-Selvidge@ouhsc.edu

OASIS provides free statewide information, referrals, and one-on-one assistance to help people locate available services in Oklahoma. Some Special Programs include:

- **SoonerStart**, Oklahoma's Early Intervention program for children 0-3 with a developmental delay.
- **Children with Special Health Care Needs** can provide information about Supplemental Security Income (SSI), Dependent Children's Program (DCP), TEFRA-Tax Equity and Fiscal Responsibility Act of 1982), Developmental Disabilities Services Division(DDSD), and other programs.
- **Grandparents Raising Grandchildren** who have a grandchild with a developmental disability.
- **Women, Infants, Children and Adolescents** in finding a variety of health-care services such as: family planning, genetic counseling, prenatal care, nutrition services/WIC, well-baby and child check-ups, child guidance services, immunizations, and car seat programs.
- **OASIS Parent Contact System** which helps link parents who have children with similar conditions or disabilities through a special Parent Contact System. This is an informal parent matching that helps provide emotional support by linking parents with other parents who have a child with a similar condition or disability.
- **OASIS Family Connections Newsletter** which is free and helps connect families with each other while providing information on upcoming events, conferences, trainings and new programs that might help make their lives a little better.
- **OASIS also houses the Oklahoma Respite Resource Network** a public and private collaborative of agencies working together to improve support for families and caregivers by increasing the availability of respite care. Respite care is temporary relief for individuals who are caring for a family member with a special need or disability. One can call OASIS to get more information on applying for respite services.

Call 800-426-2747 or visit us on the internet at: <http://oasis.ouhsc.edu> for your window to information and referral in Oklahoma.



Family Pictures: Life with a brother with Autism.

Starring: Anjelica Huston, Sam Neill, Kyra Sedgwick, Jamie Harrold . DVD at www.suncoast.com for \$9.98. Based on book Family Pictures : A Novel (Paperback) by Sue Miller. \$11.66.

The Sibling Slam Book: What It's Really Like To Have A Brother Or Sister With Special Needs (Paperback)

by Don Meyer (Editor), David Gallagher . Woodbine Publishers. \$10.37.

Thinking In Pictures : and Other Reports from My Life with Autism (Vintage) (Paperback) by Temple Grandin. \$8.29.

OASIS/OUHSC does not endorse the information from these Publications. It is provided as a convenience to our readers and is for informational purposes only.



TEFRA For Children Overview

Taken from Ok Health Care Authority: www.okhca.org

Care for children with disabilities

TEFRA (Tax Equity and Fiscal Responsibility Act of 1982) gives states the option to make Medicaid benefits available to children with physical or mental disabilities who would not ordinarily be eligible for Supplemental Security Income (SSI) benefits because of their parent's income or resources. This option allows children who are eligible for institutional services to be cared for in their homes.

Eligibility

To be eligible, a child must meet the following requirements:

- Be under age 19;
- Meet the Social Security definition of disability;
- Have qualifying income and resources;
- Meet an institutional level of care. The three levels are: intermediate care for the mentally retarded, nursing facility, or hospital;
- It must be appropriate to care for the child at home;
- The estimated cost of caring for the child at home cannot exceed the estimated cost of caring for the child in the institution.

Services

Depending upon the person's needs, services may include:

- child health/EPSDT
- dental care
- emergency and non-emergency transportation
- inpatient and outpatient treatment
- medical equipment
- occupational therapy
- pharmacy
- physical therapy
- vision

How to apply

- Complete application for benefits
- Assessment form for OKDHS and the TEFRA-1 for families)
- Letter of denial from Social Security Administration must be included with TEFRA 1 form.
- Tips for completing application can be found at the Oklahoma Health Care Authority's website at <http://www.okhca.org/client/programs/tefra/tefra.asp>

Overview taken from Okla. Health Care Authority:
<http://www.okhca.org/client/programs/tefra/tefra.asp>

Tips to Parents for Completing the TEFRA Application

Once financial eligibility for TEFRA has been established, the TEFRA application will be reviewed to evaluate whether the criteria for disability, institutional level of care, cost effectiveness, and safety and appropriateness have been met.

To avoid unnecessary delays in processing your application, please make sure that both you and your child's physician have completed all sections of the TEFRA-1 assessment form.

In addition, we will need supplemental documentation to support information provided on the TEFRA-1 document, as follows:

Disability – Include a current (within the past 12 months) physician's history and physical examination, as well as any hospital discharge summaries, psychological evaluations, or other information that will help us verify the disability. Even if SSA has established disability, we will also need this information to help us establish eligibility for institutional level of care.

Institutional Level of Care (ICF/MR, Nursing Facility, acute medical Hospital) – the criteria for institutional level of care is complex, but the following provides a general overview of eligibility and document requirements:

- **ICF/MR** – Must be at least 3 years of age. Must have a diagnosis of mental retardation or other developmental disability. Must be in need of active treatment as evidenced by a full-scale functional assessment indicating an age equivalency composite score of less than 50% of the child's chronological age. A psychological evaluation completed within the past 12 months by a licensed clinical psychologist is required for all ICF/MR determinations.
- **Nursing Facility** – Must have a verified medical condition that requires 24 hour professional nursing supervision. Medical condition must require the care and treatment services normally provided in a nursing facility. Application must include the necessary documentation to support this need.
- **Hospital** – Must have a documented medical condition that requires 24 hour supervision by a medical physician. Medical condition must require the care and treatment services normally provided in an acute medical hospital. Application must include the necessary documentation to support this need.

Make sure your child's physician has checked the Level of Care recommended on the TEFRA-1 Assessment form.

Cost Effectiveness – Before submitting your TEFRA application, please make sure you fully document all cost information requested as follows:

- If your child has private insurance coverage that you intend to maintain in addition to any TEFRA eligibility, please document only your actual costs per month for the services listed. If the service is not covered by the insurance provider, or you will not have third party insurance coverage, indicate the full cost of each service provided.
- The TEFRA-1 application asks you to list the child's current medications, however, space was not provided on the form to indicate prescription costs. Please itemize the child's prescription drug costs on a separate page and attach to the application.

Taken from: Oklahoma Health Care Authority Website link below: <http://www.okhca.org/client/programs/tefra/tips.asp>



How I Became An Information Specialist

By Janice Winters



On December 11, 1983, my daughter, Caryn was born. My life became that of a parent of a child with a developmental disability. Cheryl, my older child had never been sick... a couple of broken arms, a stitch in her ear, but nothing that had cause for constant doctor visits searching for answers. In April 1988, the girls and I moved to Oklahoma City to be close to family and Children's Hospital. It was at Children's Hospital where we finally found doctors who diagnosed Caryn with Tuberous Sclerosis. She was having seizures and delays in several areas. In May of that year, my journey as an Information Specialists at OASIS— Oklahoma Areawide Services Information System began.

Talking has never been a problem for me, so trying to help other parents try to find services is something I really enjoy doing. Sometimes it is very easy to help someone. Other times it may take several minutes, hours or days of searching to locate a service to help a family. The hardest days are when there is no service, no financial aid, no answer but NO. I hate those times!

Listening is often all the client needs for me to do. Just being able to say out loud some of the terrible things we as "special parents" think is often a comfort to people. I don't always tell our callers that I am a parent of a child with special needs, but there are some who find it easier to express their needs when they learn I really do know how they feel. They really feel able to express themselves! If I think that I have helped another parent get through a difficult time, no matter how long it may take a few minutes to an hour or more I have done my job. Having a parent tell me I have been a help makes my day!

Working with others who care is important Everyone here at OASIS are caring people and helping others is MOST important to all of us. Many of us here at OASIS have children with special needs or have had a family member young or old whom we have been the primary caregiver for days, years or a lifetime.

Our only hope is that we can help you find what service, program or supports you are looking for and that we never have to answer you with NO.

Janice is a Certified Information and Referral Specialist (CIRS) from the Association of Information and Referral Systems (AIRS), and has been with OASIS for over 15 years.
<http://oasis.ouhsc.edu> or call toll free at 1-800-426-2747 (800-42-OASIS)

Focus On: Tuberous Sclerosis <http://www.tsalliance.org>

Tuberous sclerosis complex (TSC) is a genetic disorder that causes tumors to form in many different organs, primarily in the brain, eyes, heart, kidney, skin and lungs. You will see it referred to both as tuberous sclerosis (TS) and tuberous sclerosis complex (TSC). The term TSC is used in scientific literature to distinguish tuberous sclerosis from Tourette's syndrome.

The true prevalence of TSC is unknown, but its incidence has recently been estimated to be 1 in 6,000 live births. This means approximately 50,000 individuals in the United States and more than 1 million worldwide have TSC. It occurs in both sexes and in all races and ethnic groups.

Because TSC is a genetic disorder, it is not contagious. It is the result of a genetic mutation over which a parent has no control. It is often first recognized in children who have two neurological symptoms—epileptic seizures and/or varying degrees of mental handicap. However, the clinical symptoms of TSC vary greatly and may often not appear until later in life. There are presently no cures and there is no way to predict how severely or mildly an individual may be affected by TSC. (Taken from National Tuberous Sclerosis Alliance webpage: <http://www.tsalliance.org>)

Introduction to the Oklahoma Department of Rehabilitation Services (DRS)

By Jody Harlan Public Information Administrator

<http://www.okrehab.org>

Contact Information

Last year, nearly 150,000 Oklahomans with disabilities and their families turned to the Oklahoma Department of Rehabilitation Services (DRS) for help with disability-related problems. For more information about vocational rehabilitation, employment, education, independent living programs or the agency's role in determining medical eligibility for Social Security benefits, please keep reading. If you visit "DRS Online" at <http://www.okrehab.org>, please check out the 950-page "Disability Resource Guide" section which offers a wide range information about local, state, and national disability programs and social services. DRS has offices located throughout the state. To find the Division of Vocational Rehabilitation or Division of Visual Services office nearest to you, phone/TTY our toll free hotline at 1-800-487-4042, or TTY the DRS State Office toll free at 1-800-845-8476.

Employer Services

Oklahoma's smartest employers save time and money by hiring capable employees qualified to meet specific their job requirements at no charge through DRS's Business and Employment Services Team (BEST).

The agency's job development and placement experts offer free recruitment and placement assistance, pre-employment testing, job-related training, on-site job analysis, information about special technology and training on how to use it, as well as information about tax credits and deductions available to employers who hire workers with disabilities.

For more information about BEST, phone the Employer Hotline at 1-877-739-4319.

Employment Programs

DRS's divisions of Vocational Rehabilitation and Visual Services help Oklahomans with disabilities get jobs in careers of their choice. The Division of Vocational Rehabilitation serves Oklahomans with all types of disabilities, except persons with visual disabilities who are served by the Division of Visual Services. Counselors provide or coordinate services, such as vocational, medical or psychological assessments; career counseling and guidance; physical and mental restoration to improve employment opportunities; rehabilitation equipment and devices; supported employment; vocational training; college education; on-the-job training, job placement assistance; and specialized services for people who are blind, deaf, hard of hearing or deaf blind, and those with speech impairments. These services are provided to eligible individuals with disabilities by community-based organizations under contract to the agency.

A person is eligible for vocational rehabilitation (VR) services if he or she has a physical or mental disability, which results in a substantial barrier to employment. The individual must be able to benefit from VR services. Individuals with disabilities may share the cost of some services, depending on their incomes.

To reach the Vocational Rehabilitation or Visual Services office nearest to you, phone 1-800-487-4042 toll free. If you are blind or have a visual impairment, press "1" for the Division of Visual Services. If you have another disability, press "2" for the Division of Vocational Rehabilitation. Then enter your five-digit zip code when asked to do so. Your call will be transferred to the nearest office.

Transition from High School to Work

High school-age students with disabilities can get a head-start on job training and work experience through Transition School to Work Programs available free of charge by Vocational Rehabilitation and Visual Services.

Students may receive services, such as vocational counseling and guidance, vocational assessment, work adjustment training, work study, on-the-job training, supported employment and job placement assistance, that boost their confidence, help them discover their strengths and improve the skills needed to succeed on the job.

Vocational Rehabilitation and Visual Services have cooperative agreements with many high schools in Oklahoma that help students work in the community or at school while they get pre-employment skills, work experience and high school credits.

Both divisions offer summer programs with limited enrollment for students participating in the Transition program during the school year. Vocational Rehabilitation offers a one-week Transition Camp that provides intensive job readiness training as well as social activities. Visual Services is expanding their five-week Brighter Futures in Transition (BFIT) program, which combines a week of job readiness training with four weeks of paid employment.

Part I— To Be Continued Fall Newsletter 2006.....



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Email Sally-Selvidge@ouhsc.edu or fax this form to 405-271-6305
Or mail to OASIS/OUHSC, PO BOX 26901, OKC, OK 73190

NAME _____

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CITY _____ STATE _____ ZIP CODE _____

PHONE _____

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