



Family Connections

A Family Newsletter from OASIS
Oklahoma Areawide Services Information System



Oklahoma Family Perspective Conference. Friday, September 16, 2005. Sheraton Hotel, Downtown, Oklahoma City. This conference is being held in conjunction with the National Respite Conference. Friday, Sept. 16, 2005 and is devoted to Oklahoma Families. It is free to attend and lunch is included. For more information ,call Sally Selvidge at OASIS at 1-800-426-2747 go to <http://oasis.ouhsc.edu>

Volume 11

Summer 2005

What does Senate Bill 1015 the Oklahoma Self-Directed Care Act mean for your family?

Senate Bill 1015, the Oklahoma Self-Directed Care Act, was passed by the Senate and House on May 27, 2005 and signed into law by Governor Henry on June 7, 2005. This bill is a major victory for people with disabilities in Oklahoma. The bill contains the following measures:

- It extends the Oklahoma Olmstead Strategic Planning Committee until January 2007.
- It establishes a self-directed services pilot in the Department of Human Services for people with disabilities who receive waived services through the Developmental Disabilities Services Division and the Advantage Waiver through the Aging Services Division.
- It establishes a self-directed services pilot in the Medicaid State Plan Personal Care Services.
- It instructs the Department of Human Services (OKDHS) to appoint an advisory committee of consumers, family members, advocates, providers and the Center for Learning and Leadership to assist OKDHS in the development of policies and procedures for self-directed services and a functional needs assessment tool.
- It provides for a feasibility study on the future design and implementation of expanding home and community based waiver services to the unserved and under serviced populations, such as, Traumatic Brain Injury, Spinal Cord Injury and other developmental disabilities without a diagnosis of mental retardation.
- It provides for Medicaid money to follow the person whether he/she is moving from an institutional placement into the community or from the community into an institutional placement.

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CALENDAR OF EVENTS



Ongoing:

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.

OKTASH Teleconference is held on the third Thursday of every month at 6pm. Meetings are generally held at Rose State College LRC and Tulsa Community College West Campus. Please check the OKTASH website at <http://committed.to/oktash> for changes to the location or schedule or contact oktash-owner@yahoo.com.



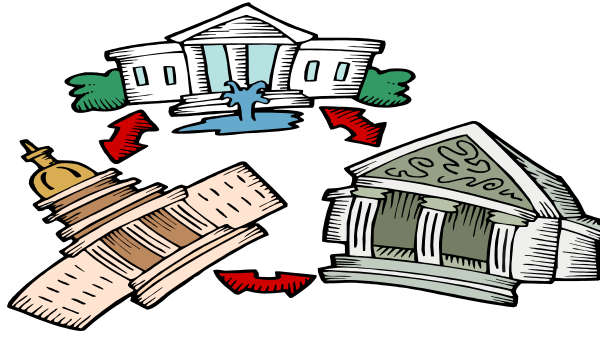
Upcoming:

August 26, 2005: Oklahoma Parent Center Fall Conference. OSU/OKC, 900 N. Portland, OKC, OK. For more information call Kim at (405) 619-0500 or (877) -553-4332.

September 12 – 13, 2005: Grandparents Raising Grandchildren annual conference. New Covenant Christian Church 120th & N. Rockwell, Oklahoma City, OK. More information to come.

September 14 – 16, 2005: Annual Respite and Crisis Care Conference. This national conference is being held in Oklahoma City this year, hosted and co-sponsored by the Oklahoma Respite Resource Network. It will be at the Sheraton Hotel, One N. Broadway. Information and conference brochures will be available at OASIS (800-426-2747).

September 28-30: The 13th Annual Oklahoma Conference on Child Abuse and Neglect and Healthy Families 2005 National Center for Employee Development (Postal Training Center) Norman, OK Contact: Jessica Shatley at (405) 271-8858, or jessica-shatley@ouhsc.edu



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Senate Bill 1015-Oklahoma Self-Directed Care Act

The Oklahoma Self-Directed Care Act would allow a consumer or a representative to do the following through a fiscal agent:

- Hire and fire staff that would provide support services in the home of the consumer;
- Purchase basic services
 - » Getting in and out of bed, wheelchair or motor vehicle
 - » Assistance with bathing, grooming, personal hygiene, dressing and eating.
 - » Assistance in acquiring ,retaining ,and improving self-help, socialization and adaptive skills.
 - »Respite Services and
 - »Health maintenance activities.
- Purchase ancillary services
 - »Includes housekeeping chores which are essential to the health and welfare of the consumer.
 - » Transportation services to enable the consumer to gain access to waiver services and other community services, activities ,and resources.
 - » Set the rate of pay for staff in the home for personal care attendants and Habilitation Training Specialists within the established Medicaid rates.
 - » Purchase medical supplies, incontinence supplies, and adaptive equipment at the most cost effective location.
 - » Purchase day care and respite care from an adult day care center.
 - » Purchase home modifications and assistive devices.

The Olmstead Strategic Planning Committee understands that making these changes in a service delivery system will take a year to eighteen months. Approval will be needed from the Centers of Medicare and Medicaid (CMS) on any waiver amendment or if a new waiver is written for self-directed services. This bill makes it clear that this will be a pilot program.

Taken from the Third Annual Report of the Olmstead Strategic Planning Committee, June 1, 2005 Draft.

Everyone is welcome to attend the Children's Oral Health Coalition Meetings.

Held the 2nd Wednesday of each month at the Oklahoma Dental Association, 317 NE 13th St., OKC, OK 73104. 10-12 p.m.

For more information or questions , call Sally Selvidge at 1-800-426-2747 or email her at Sally-Selvidge@ouhsc.edu



Coping in New Territory. The Handbook of Children of Aging Parents. By Suzanne Roberts. Cheltenham Press. \$13.95.

Building Communities From the Inside Out. John P Kretzmann. John L. McKnight. ACTA Publications. \$20.00.

Animals in Translation : Using the Mysteries of Autism to Decode Animal Behavior. By Temple Grandin, Catherine Johnson. Scribner. \$25.00

Think in Pictures: and Other Reports From My Life with Autism. By Temple Grandin. First Edition Books. \$12.95.

A NEW MEDICAID PROGRAM CALLED TEFRA -134 TAX EQUITY AND FISCAL RESPONSIBILITY ACT OF 1982

Under section 134 of the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA), states are able to make Medicaid benefits available to certain children with severe disabilities who ordinarily would not be eligible for Supplemental Security Income (SSI) because of their parents' income or resources.

The important difference between this program and regular Medicaid is that only the child's income and resources— not the parents' - are counted toward eligibility.

To be eligible for the new program, a child must meet all of the following requirements:

- Be under the age of 19
- Be a United States citizen or qualified alien
- Be an Oklahoma resident
- Have a social Security number
- Meet the Social Security definition of disability(medically determinable physical or mental impairment which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months).
- Have a gross monthly income at or below \$1,737.00 and countable resources at or below \$2,000.00 (only the child's income and resources are counted).
- Meet an institutional level of care, which means that the child requires a level of care that is normally provided in an institution. These three levels of care are: intermediate care facility for persons with mental retardation (ICF-MR), nursing home facility, or hospital. To meet this level of care it doesn't mean a child must be institutionalized.
- The estimated cost of caring for the child outside the institution must not exceed the estimated cost of caring for the child in the institution.
- It must be appropriate to care for the child at home.

Under TEFRA, children will be eligible to receive the full scope of medically necessary Medicaid services which include, but are not limited to:

- Inpatient and outpatient treatment
- Pharmacy
- Emergency and non-emergency transportation
- Medical equipment
- Medically necessary services allowable under the provisions of the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Program.

Some of the services that NOT available through TEFRA include:

- Respite care
- Environmental accessibility adaptations
- Architectural modifications
- Habilitation Services
- Supported Employment
- Diapers
- Formula
- Services not covered by Oklahoma's Medicaid State Plan

There is no waiting list for TEFRA. If a child is eligible for TEFRA, he or she can still apply for, or remain on, the DDS Home and Community Based Services Waiver waiting list. A child on the waiting list for waiver services may use the TEFRA program and remain on the list until their name comes up for the waiver.

When the program begins, applications for TEFRA will be taken at each county Department of Human Services (DHS) offices. Once determined eligible, the child may be certified for TEFRA for 12 months. A re-determination will be made at that time.

The actual start date for this program will depend on the availability of the tobacco tax revenues from the newly enacted tobacco tax. The program is projected to be available this fall. For more information call Dan Alcorn at 405/522-7211 at the Oklahoma Health Care Authority.

Reprinted from Family Voices May-June 2005 Newsletter



What is a Medical Home?

<http://www.medicalhomeinfo.org/>



A medical home is not a building, house, or hospital, but rather an approach to providing comprehensive primary care. A medical home is defined as primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective.

In a medical home, a pediatric clinician works in partnership with the family/patient to assure that all of the medical and non-medical needs of the patient are met. Through this partnership, the pediatric clinician can help the family/patient access and coordinate specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the child/youth and family.

The National Center of Medical Home Initiatives for Children with Special Needs provides support to physicians, families, and other medical and non-medical providers who care for children with special needs so that they have access to a medical home.



SMILE

A smile costs nothing, but gives much.

It enriches those who receive without making poorer those who give.

It takes but a moment, but the memory of it can last forever.

*None is so rich and mighty that he can get along without it,
and none is so poor but that he can be made rich by it.*

*A smile creates happiness in the home, fosters good will in business,
and is the countersign of friendship.*

*It brings rest to the weary, cheer to the discouraged,
sunshine to the sad, and is nature's best antidote for trouble.*

Yet it cannot be bought, begged, borrowed or stolen.

For it is something that is of no value to anyone until given away.

Some people are too tired to give you a smile.

*Give them one of yours, as none needs a smile so much
as he who has no more to give.*

Unknown author

People seem to always ask... “Where are the Parents?”

Where Are the Parents?

by Sue Stuyvesant

Where are the parents?

They are on the phone to doctors and hospitals and fighting with insurance companies, wading through the red tape in order that their child's medical needs can be properly addressed. They are buried under a mountain of paperwork and medical bills, trying to make sense of a system that seems designed to confuse and intimidate all but the very savvy.

Where are the parents?

They are at home, diapering their 15-year-old son, or trying to lift their 100 lb. daughter onto the toilet. They are spending an hour at each meal to feed a child who cannot chew, or laboriously and carefully feeding their child through a g-tube. They are administering medications, changing catheters and switching oxygen tanks.

Where are the parents?

They are sitting, bleary eyed and exhausted, in hospital emergency rooms, waiting for tests results to come back and wondering: is this the time when my child doesn't pull through? They are sitting patiently, in hospital rooms as their child recovers from yet another surgery to lengthen hamstrings or straighten backs or repair a faulty internal organ. They are waiting in long lines in county clinics because no insurance company will touch their child.

Where are the parents?

They are sleeping in shifts because their child won't sleep more than 2 or 3 hours a night, and must constantly be watched, lest he do himself, or another member of the family, harm. They are sitting at home with their child because family and friends are either too intimidated or too unwilling to help with childcare and the state agencies that are designed to help are suffering cut backs of their own.

Where are the parents?

They are trying to spend time with their non-disabled children, as they try to make up for the extra time and effort that is critical to keeping their disabled child alive. They are struggling to keep a marriage together, because adversity does not always bring you closer. They are working 2 and sometimes 3 jobs in order to keep up with the extra expenses. And sometimes they are a single parent struggling to do it all by themselves.

Where are the parents?

They are trying to survive in a society that pays lip service to helping those in need, as long as it doesn't cost them anything.

They are trying to patch their broken dreams together so that they might have some sort of normal life for their children and their families.

They are busy, trying to survive!

Olmstead v. L.C.
What is Olmstead?
How Does it Affect People with Disabilities in Oklahoma?

When Olmstead Meets and How to get Involved?

The Olmstead Strategic Planning Committee meets the first Thursday of each month at the Oklahoma State Capitol, Rm. 419C at 1:30 p.m. **These meetings are open to everyone and anyone is welcome to attend!!!!** Whether you have a child with a disability that is an infant or elderly the actions of the Olmstead Strategic Planning Committee will affect the long-term care your family member receives long after you are gone. I encourage you or your family member with the disability to get involved in Olmstead. There are many ways, besides attending a meeting. You can be kept informed via email and newsletters like this one. For more information about Olmstead call RoseAnn Percival at 405-522-0600.

What is Olmstead?

Olmstead is a United States Supreme Court decision under the Americans with Disabilities Act that dealt specifically with issues related to community placement. Olmstead v. L.C. involved two Georgia women residing in a State mental health facility. Both plaintiffs had dual diagnoses of mental illness and mental retardation. Though both parties were eligible for community-based services through an existing state program, which had open slots to serve them, the women were denied community placement because of inadequate funding. In June 1999, the United States Supreme Court determined that “unjustified isolation is discrimination under the ADA and required that the women be served “in the most integrated setting appropriate to their needs.”

In implementing the Olmstead decision one must remember the Supreme Court was making an interpretation of an existing law. This decision is not a law into itself and the Court cannot enforce the law. However, the Court’s findings effect how the law can be applied or how the decision is implemented.

The Supreme Court said as a result of this ruling that each state was obliged to “make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modification would fundamentally alter the nature of the service, program or activity.” In other words confinement in an institution severely takes away the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.

The Supreme Court further stated that a State could show that it had met the “reasonable accommodation” standard by demonstrating that it has a:

- Comprehensive, effectively working plan for placing qualified persons with disabilities in the most integrated setting; and
- Waiting list that moves at a reasonable pace not controlled by a State’s objective of keeping its institutions fully populated.

Impact of Olmstead on Oklahoma

The Oklahoma Olmstead Strategic Planning Committee was created to improve community services for persons with disabilities. The formation of the committee has provided a rare opportunity for collaboration and coordination among individuals and groups with diverse interests. This group has identified and begun work on needed improvements in the systems of services with a long-term goal of ensuring that people have the choice to live in the community instead of an institution or nursing home.

The Oklahoma Olmstead Strategic Planning Committee includes representatives from state agencies, advocacy organizations, local service providers and individuals with disabilities and families of individuals with disabilities. This group is well positioned to work together to not only develop a plan for change, but also to assist in implementation and monitoring of that plan.

The Third Annual Report is due out July 15, 2005 and will contain position papers that will form the basis for action steps in the final plan due in 2007.



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

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I want to: _____ **be a Parent Contact**
_____ **receive the Newsletter**

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