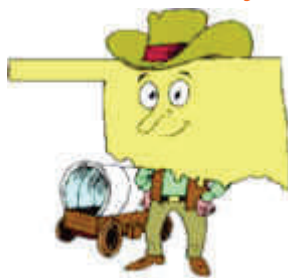


WILL'S CORNER, OKLAHOMA



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(Serving the Disability Community of Oklahoma)

If You Need Long-Term Care

Individuals need long-term care when a chronic condition, trauma, or illness limits their ability to carry out basic self-care tasks or activities such as meal preparation or managing money. In 2000 roughly 10 million Americans needed long-term care. Many of this population are individuals with disabilities who are not elderly.

Some people will receive long-term care in their own home or the home of a loved one. Oklahoma has a Medicaid waiver known as the Advantage Program to provide the supports for people to remain in their own home. Some Oklahomans will require the care offered in one of the many nursing homes

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Easter Seals Fights Autism

Autism is a bio-neurological disability that generally appears before the age of three. Autism impacts the normal development of the brain in the areas of social interaction, communication skills, and cognitive function. Individuals with autism typically have difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities.

Individuals with autism often suffer from numerous physical ailments which may include: allergies, asthma, epilepsy, digestive disorders, persistent viral infections, feeding disorders, sensory integration dysfunction, sleeping disorders, and more.

Autism is diagnosed four times more often in boys than girls. Its prevalence is not affected by race, region, or socio-economic status. Since autism was first diagnosed in the U.S. the occurrence has climbed to an alarming one in 150 people across the country.

Easter Seals Oklahoma is presently tailoring a program of intensive intervention for young children ages two through five. Paula Porter, president and CEO of Oklahoma Easter Seals declares, "Autism is nothing to mess around with. There is a window of time in the early years where we can really make a difference in the life this child will have."

Wayne Rohde is the Program Director for Easter Seals Oklahoma, which includes the autism initiatives. Rohde's dedication and inspiration in working on the many autism initiatives at Easter Seals is due to his son, Nicholas, who was diagnosed six years ago. He personally understands the struggles families face when searching for resources for their loved ones.

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**ODC web site:
www.odc.ok.gov**

Easter Seals Fights Autism (continued)

He reports that initially, his wife did a great deal of research on autism and found that early, aggressive interventions could have profound effects on their child's future. Applied Behavioral Analysis (ABA) is effective in both the treatment and recovery from some, if not all, autistic symptoms. ABA is endorsed by the U.S. Department of Education, the U.S. Surgeon General and the National Science Foundation.

ABA is just one of several interventions that hold promise in alleviating, if not reversing, the symptoms of autism. Speech, occupational and physical therapies, as well as biomedical and dietary interventions, are often extremely effective.

Pulling all these different approaches together, Wayne Rohde has designed a day program at Oklahoma Easter Seals to address the needs of young children with autism. His plans are impressive.

First, he insists on the importance of aggressive, one-on-one interventions which involve a highly-skilled staff tutor for each child in the program for the entire day. Each child is to have their individual work area, and the room is designed with safety of the child with autism in mind.

Easter Seals collaborates with other organizations and various groups in Oklahoma who are knowledgeable about autism. Therapy is to be consistent and intensive; both in the actual day-to-day environment and at home with participation from everyone in the family. The purpose is to mitigate the devastating effects of autism before a child reaches school age so the child can be mainstreamed into a typical classroom setting.

Plans are to select ten to twelve applications from all the applications received sometime after the July 4 holiday. In order to assure no bias in the selection process, a lottery system will be used to randomly select the applicants. Easter Seals Oklahoma aggressively plans for the Therapeutic Day School doors to open Monday, September 8, 2008. The program will last 48 weeks and upon comple-



Wayne Rohde is
the Program
Director for Easter
Seals Oklahoma

tion some children will go on to a second year program as new applicants are enrolled.

A service plan will be developed for each child with collaboration between Easter Seals staff and parents. The child's progress in meeting their goals and objectives will be reported monthly and modifications will be made to the service plans as goals and objectives are met or as the needs of the child change.

Currently there is a great deal of interest in autism at Easter Seals across the country. Much of the planning of Easter Seals Oklahoma's autism Pilot Program is modeled after the Chicago, Illinois Easter Seals program.

Because 80% of individuals with autism are under the age of 16, and because we never stop learning, another expansion of the pilot as it demonstrates success is to serve older children and adults. Rohde has devoted his energies to meeting the needs of children who experience great challenges in life—children much like his own son, Nicholas, who is 10 years old.

If you would like to know more about the pilot program for children with autism at the Easter Seals in Oklahoma City, call Wayne Rohde at 405-239-2525, ext. 26. Or you may email him at wrohde@eastersealsoklahoma.org.

Go online to Easter Seals Oklahoma www.eastersealsoklahoma.org to learn how you can be of help to children with autism. Autism is treatable, but we need to act.

29th Annual International Conference on Developmental and Learning Disabilities

YAI/National Institute for People with Disabilities is a private, non-profit agency with 4000 employees serving 20,000 people with disabilities in a region around New York City. They sponsored a conference May 5-9, 2008 at the Crowne Plaza Hotel attended by over 3000 people with disabilities and professionals. This article is based on some of the information presented at that conference.

Dr. Temple Grandin from Colorado State University was the keynote speaker on May 6. As a person on the autism spectrum, she held the audience captive as she shared her personal story.

Temple Grandin grew up in the 1940's and 1950's when autism had only first been identified in professional journals. She did not speak until she was three and a half years old. There was no hope that she would be able to lead a life with any kind of normalcy.

And yet with a mother who insisted she observe social conventions even when she did not understand why and a teacher who took special interest in her with hours of one-on-one intervention, she was able to manage the symptoms of autism which imprisoned her mind and prevented her functioning in the world we have all come to know.

Temple Grandin says that she learns differently from other people. She learns through visual imagery. Verbal skills come with difficulty. She draws upon her acute visual skills to provide insight into the world of animals. She states that animals think in sounds and pictures much like the thinking of people with autism.

Dr. Grandin is one of the most well-known adults with autism in the world. From her unique perspective as a person with autism, she has written *Animals in Translation* to decode how animals think and feel. She has appeared on the "Today Show" and "20/20" as well as *Time* magazine and *U.S. News and World Report*.

Dr. Grandin tells us to look at ability before we see disability. She advises family and teachers to discover the strengths of people with disabilities and use those strengths to reach into the world that person lives in.

She shocks her audience by saying that most of the people who have given us computers and the internet are probably functioning somewhere on the autism spectrum. The unique insights of these "geeks" can bring good into all our lives.

Autism is a condition in which a person may be completely non-verbal or develop verbal skills with great difficulty. It is marked in severity from complete isolation of the person through its milder form known as Asperger's Syndrome.

Because a person on the autism spectrum is isolated from others, they do not develop the social skills which permit successful interaction with other children. Learning to take their place in line or to say "please" and "thank you" is difficult.

Early intervention is very important in assisting the person with autism to live in a world configured

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At pilot's training back in the Air Corps, one person proudly states they were taught, "Always try to keep the number of landings you make equal to the number of take offs you make."

29th Annual International Conference on Developmental and Learning Disabilities (continued)

much differently than their own. It was the early intervention of her mother and a teacher who believed in her which permitted Temple Grandin to know the successes she has known as an author and speaker.

Another breakout session at the YAI conference was called "Childhood Epidemics." Kenneth Bock, M.D. from Rheinbeck, New Jersey was presenter. He spoke of the explosion of children with Attention Deficit Disorder (ADHD), autism, and asthma.

One in sixteen children has a diagnosis of ADHD. One in eleven children has a diagnosis of asthma, and one in one hundred and fifty has been diagnosed with some form of autism. Truly these developmental disabilities have become a childhood epidemic.

Do we just have better reporting of these disabilities or are the actual numbers greater than recent history? It is true that we have better reporting, but it may also be true that numbers of these disabilities are growing in our population.

Is the mercury from childhood vaccinations actually causing some of these disabilities? Is it unsafe to vaccinate our children? Of course not, and by the way, the mercury from childhood vaccinations has been removed. The vaccinations are good for our kids, but we need to make sure that those same vaccinations are completely safe.

Dr. Bock says, "We live in a chemical soup with over 87,000 chemicals in our everyday environment. Could some of these environmental factors explain the epidemics of ADHD, autism and asthma? We don't have a smoking gun right now although it is easy to blame these environmental factors.

Certainly autism is related to an impaired ability to neutralize toxins. Inflammation of the gut and esophagus frequently presents with autism. Inflammation of the bronchi in the lungs presents in asthma. Is there some connection between the auto-immune system and these developmental disabilities? Perhaps.

Is there a genetic component for autism, asthma and ADHD? Dr. Bock suggests we look not to a specific gene which in itself causes the appearance of these various developmental disabilities. However, there may be a gene which predisposes a child to develop one of these developmental disabilities if the right environmental factors are also present.

These are highlights from a small part of the 29th Annual International YAI Conference on Developmental and Learning Disabilities. You may want to google YAI/National Institute for People with Disabilities to browse several websites relating to the mission of the organization, career opportunities and events. YAI is a private, non-profit organization located in New York City.

Some symptoms of inner peace:

- Frequent attacks of smiling
- An increasing tendency to let things happen rather than make them happen
- An increased susceptibility to the love extended by others as well as the uncontrollable urge to extend it



Tips for Traveling with Grandma

Many of us will be traveling with a person who is older or a person who has a disability this summer. I received an email recently providing tips on traveling with older adults. Some of these same tips work for younger persons who have a disability.

Summer vacations for some families include traveling with grandparents. When traveling with older adults, senior health experts urge families to do some extra planning.

“I think it’s important for seniors to plan and prepare for travel,” said Dr. Bob Salinas of OU Physicians Family Medicine.

He added the first step is to check with the person’s physician and other health care providers to get their recommendations for safe travel. Most concerns can be properly addressed with a little help from the family physician.

Specifically ask if there are any contraindications for certain medications the person is taking, especially if flying or if there will be sun exposure, or if any types of travel or activities are restricted. Check to see if certain immunizations or prescriptions for motion or altitude sickness might be needed.

“For example, if they are going to be traveling for a few weeks away from home, I think it’s important for them to take all of their medications as well as a list of medications and medical conditions they may have,” he said.

Dr. Salinas suggested that families consider completing a pre-travel checklist. He said for seniors that list would include such items as:

- making sure they have all of the medications they take in adequate supply and carry them onboard with you if flying
- bringing along a list of those medications, with dosages, and the number for the pharmacy

where they were filled just in case the medications are lost

- taking a list of the person’s medical conditions and health history, including allergies
- packing reading glasses, hearing aides and any special supplies the person uses
- bringing along their physician’s phone number and instructions on how to reach him or her should there be a true medical emergency away from home

Angela Bradway, RN, the director of nursing at Grace Living Centers—El Reno, adds that it’s best to keep the medications in the original bottles when going through airport security; then put them into a medication planner case after arriving at your destination.

She adds that copies of documents regarding medical care such as an Advanced Directive, Power of Attorney and DNR orders should be brought too in case the person requires treatment while traveling.

Taking along a wheelchair, a cane or a walker to use while sightseeing may be helpful to the elderly or health-challenged person. Also bring a hat and sunscreen, and clothing for both warm days and cool indoors or nights as the person may be more sensitive to temperature changes.

“Remember to keep the person well hydrated with water, not with drinks that are sugary or high in sodium,” said Bradway. “The same goes for snacks, keep them healthy like soft pretzels or trail mix.”

Bradway says to pace the trip and activities so no one gets overheated or too tired. In addition, she suggests planning out rest stops on the trip route so regular breaks are taken for stretching and bathroom stops.

“It’s important to move around when traveling so a blood clot doesn’t form from sitting too long,” said Bradway. “Wearing elastic circulation stockings can also help with this.”

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If You Need Long-Term Care (continued)

across the state.

Selecting a nursing home for your own care or that of a friend or family member is a big decision. It is both a one-time decision and an ongoing process because the quality of care you receive and the proper maintenance of the facility can change over time and under different administration.

In the selection of a nursing home, "shopping" is a good thing. Taking time and visiting several facilities is more than worth the effort in the long run.

The Centers for Medicare and Medicaid Services (CMS) operates a website at www.medicare.gov/NHCompare. Information about nursing homes nationwide is here. CMS will begin rating nursing homes from one to five stars beginning in December 2008.

The Oklahoma State Department of Health conducts regular surveys of all nursing homes in our state. Copies of recent surveys should be available when you visit any facility. It is OK to ask an administrator where that survey is and if you can look at it.

Surveys will address things such as health care, dietary and the physical condition of the building itself. This can be valuable information if you are actually considering living at this facility or if you are considering this as a residence of a family member or friend.

Dorya Huser is Chief of Long Term Care at the State Department of Health in Oklahoma City. She provides some tips to people considering residence at a long-term care facility.

- Visit the facility twice unannounced (once during a meal time).
- Notice if the facility is clean.
- Notice if staff are friendly.
- Observe the appearance of residents.
- Ask a resident what they think about the facility.

If you are satisfied with what you find in your spontaneous visits, make an appointment with an administrator for further information. Don't be intimidated by an administrator. They are there to answer your questions and provide you valuable information you will need to decide if this nursing home is the right place for you or your loved one.

Does the administrator provide you with a copy of their latest surveys from the Health Department without hesitation? Does the administrator welcome your questions and demonstrate an openness to your concerns?

You may have specific questions about nursing home policy. Are there any restrictions on visitors? If your loved one is used to a certain routine at home, will this same routine be possible in the nursing home? What special needs do you have which staff from the nursing home may or may not be able to provide?

What is the staff/resident ratio on the various work shifts at the nursing home? It is Oklahoma law that nursing home administrators check potential new staff and residents on the sex offender registry. You may ask if this has been done and if OSBI checks have been done on all staff.

We are concerned about the schools our children attend, and it is appropriate to do diligence in selecting a nursing home as well. Now, let's assume you have already selected a nursing home and you already have a loved one living there. What if you have a concern about someone's care?

Your first source of information is with the director of nurses and/or administrators in the nursing home itself. Give them an opportunity to address your concerns within a reasonable time frame.

If you continue to have a concern, you may call the toll-free number at the Oklahoma State Department of Health (800-747-8419) and register a complaint either verbally or in writing. This complaint will

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If You Need Long-Term Care (continued)

trigger the Health Department to do a survey focusing on the concerns you have raised.

Even though you remain anonymous, you can request a copy of the survey be sent to your home. The surveyor will prioritize their investigations based on what you tell them. If they feel the health and safety of a resident is in immediate jeopardy, they will investigate that complaint first.

If you feel an adult in Oklahoma has been either abused or neglected, call the Adult Abuse Hotline at 800-522-3511. An employee of Adult Protective Services of OKDHS will investigate your complaint, again prioritizing that investigation based on the immediacy of danger to health and safety of the individual.

The Oklahoma Department of Aging has volunteer long-term care ombudsmen. Call 800-211-2116 and ask to be connected to an ombudsman. When you get that person, you may register your complaint at this location as well as the other places already mentioned.

A Perfect Cause is a private, non-profit agency in Oklahoma City covering the whole state. A Perfect Cause is an advocacy agency for residents in long-term care. Browse their website at www.aperfectcause.org or call 405-228-0513.

When I spoke with her to gather information for this article, Dorya Huser at the State Department of Health who monitors nursing homes across the state made it a point to remind me of something. She reminded me that the population of Oklahomans in need of long-term care is the most vulnerable people in our state. They deserve to live in safety, and they deserve to have a life of dignity and respect.

The Centers for Medicare and Medicaid Services (CMS) operates a website at www.medicare.gov/NHCompare.

Information about nursing homes nationwide is here. CMS will begin rating nursing homes from one to five stars beginning in December 2008.

Tips for Traveling with Grandma (continued)

Just like the rest of us, an older adult can become bored if traveling a long distance without anything to do. So she suggests it is important to bring along DVDs or audio books, which can be rented from the library, to keep everyone entertained while in transit.

By taking a few steps to better prepare and by keeping everyone's needs in mind, you can have a comfortable vacation and set the stage for wonderful family memories.

For more information on this subject go to the Senior Center at www.ouphysicians.com. You may also contact your local American Association of Retired Persons (AARP) or you may go to the American Automobile Association.

Strive for excellence instead of perfection.

CALENDAR OF EVENTS

September 8, 2008 Easter Seals at 701 N.E. 13th Street in Oklahoma City is opening a day care for intensive treatment of young children with autism. For more information contact Wayne Rohde at 405-239-2525.

September 18&19, 2008 The Zarrow Mental Health Symposium is an annual event in Tulsa. For more information on cost and hotel call 918-585-1213 or contact the website for the Mental Health Association of Tulsa, www.mhat.org.

October 1-3, 2008 The Oklahoma Mental Health Consumer Council will sponsor their 17th annual conference at the Bricktown Hotel & Convention Center, 2001 E. Reno in Oklahoma City. For more information call 405-604-6976 or email consumercouncil@okmhcc.org.

October 8, 2008 The METRO disABILITY RESOURCE ALLIANCE is sponsoring their third annual resource fair at the Business conference Center of Metro Technology Centers, 1900 Springlake Drive in Oklahoma City. The event will be from 9 a.m till 3 p.m. For more information and costs contact Peppi Boudreau at 800-522-8224.

If you have an event coming up relating to disability, let us know at 800-522-8224 and we'll help you publicize.

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