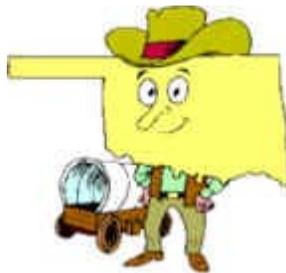


# WILL'S CORNER, OKLAHOMA



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(Serving the Disability Community of Oklahoma)

## The Choices We Make

Nobody would ever choose to have a stroke with the disability which results. Nobody would ever choose a blur of medics, nurses and doctors with furrowed brows looking down on their gurney. Nobody chooses a brain attack. Or do we?

**ODC web site:**  
**[www.odc.ok.gov](http://www.odc.ok.gov)**

We choose what we eat and how much we eat. Yes? We know the importance of getting our blood pressure checked, but sometimes we're in a hurry. We know that smoking raises blood pressure, but it calms our nerves and we can forget about the other. We know we should exercise, but it's so much more conven-

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## Advocacy, Advocacy, Advocacy

By Marilyn Burr of the Office of Disability Concerns

One out of five people (conservative estimate) have a disability. That is 20% of our population. Yet over and over the Office of Disability Concerns gets calls for needs that are not being addressed by social resources. How can this be corrected?

Like everything else, if it doesn't affect your life you may not realize there is a need. People with Disabilities have to make their needs known. The question is, how do they do that?

Joining with other people of like disabilities is one way. Support groups frequently become advocacy groups. Joining with people that represent many or all disabilities is another. This would be a powerful show of power.

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## The Choices We Make (continued)

ient to take the elevator than the stairs.

That's called denial. Stroke is the leading cause of adult disability in Oklahoma. Our state has one of the highest incidences of stroke in the nation. It can and it does happen here. It can happen to you and to me. It's not just a disease of the elderly. It is increasingly common in younger people—much younger.

If it does happen, think FAST. **F** stands for FACE. Ask the person to smile to see if one side of the face drops. **A** stands for ARMS. Ask them to hold their arms out to see if one arm doesn't go up straight. **S** stands for SPEECH. Listen for slurred or garbled speech. If you notice any of these, **T** is for TIME to call 911 immediately. Let the paramedics sort out what is happening because they know what they're looking for.

Time to get emergency help is important where stroke is involved. The hospital you go to is also important. People need to go to the closest local "stroke-ready" hospital where they can be administered the clot-busting medication TPA which can dissolve the clot causing the stroke, and then if needed, they can be transferred to a Joint Commission Certified Primary Stroke Center for more care.

In an ischemic stroke a blood vessel gets clogged with a clot in the brain and cuts off oxygen to cells. It is important to dissolve that clot that is causing the problem because you are losing brain cells. In a hemorrhagic stroke a blood vessel in the brain actually ruptures. The first kind is far more common.

Having a stroke is a life-changing event. But, surprisingly the average stay in a hospital is a little over four days. That's four days of intensive therapies, doctors, nurses, case managers and discharge planners.

Fortunate people with insurance may get two weeks of inpatient or outpatient rehab to adjust to their new lives. People without insurance may have to get creative to find ways to meet their needs.

The Stroke Center at Integris Southwest Medical Center in Oklahoma City has an hour and a half stroke class every first and third Tuesday morning at 10. This class teaches about preventing another stroke as well as tips for living with stroke. The Stroke Center at Integris Baptist Medical Center in Oklahoma City has that same class from 1:30 to 3 the first Tuesday afternoon of the month. The classes are held at Jim Thorpe Rehab in both hospitals, are free and all you need to do is show up. Stroke survivors and family are welcome.

Therapies are important in recovering ability after a stroke. If you can't afford rehab after acute care, call a nearby university which offers masters-level speech therapy. Affordable speech therapy may be available that way.

The Rylyn Meacham Center offers occupational therapy/physical therapy on a donation-only basis and is available to stroke survivors Tuesdays and Thursdays from 4:30-6 p.m. Call 405-603-5974 to schedule an appointment. Call Neuroresources Outreach Services at 405-605-1466 as another affordable resource. Physical therapy and occupational therapy can be very important in recovery.

**OK State web site:**  
**[www.ok.gov](http://www.ok.gov)**

To learn more about strokes, go to [www.integris-strokecenter.com](http://www.integris-strokecenter.com). This will be the first day of the rest of your life.

## Homelessness in Oklahoma City

If you want to know just about anything about homelessness in Oklahoma City, talk to Dan Straughan. He is the Executive Director of the Homeless Alliance since 2004.

OKC has about 1500 people on any given night who stay in a homeless shelter, or live in time-limited housing or sleep on the streets. That figure jumps to 10,000 people if you consider the folk who stay with friends sleeping on their couch.

The Homeless Alliance does an annual Point-in-Time survey every January to get a count. Surprisingly they have found a large number of homeless people camping out in the far northwest part of the city.

Many homeless people choose not to stay at the shelters for various reasons. Some have mental health disorders where they find it difficult to be around large numbers of people. Some have substance abuse problems, and shelters turn away people who are intoxicated or under the influence.

Dan cites information from the last Point-in-Time survey that 34% of people self identify with a substance abuse problem. Twenty-eight percent identify with a mental health diagnosis. There is overlap between these two groups.

This is the problem in Oklahoma City. Now let's hear the solution. The Homeless Alliance just broke ground for an 18,000 square foot Resource Center at 1729 N.W. 3<sup>rd</sup> Street. That Resource Center (West Town) should be complete in the late fall of this year. Its purpose will be to provide resources for families and people who are temporarily homeless.

It will include an office for Social Security, a place to apply for OKDHS services and a TEEM office to

educate on employment skills. Staff from local community mental health facilities will be available to treat mental health problems.

A doctor will be on site part time to address medical issues, and a lab will be staffed to process medical testing. West Town will be one-stop shopping.

Coming soon is a Day Treatment Center for the chronically homeless who cannot stay in the shelters during the day. People will have the opportunity to get off the streets.

The Day Treatment Center will be a safe, warm and dry place for people to come when they have nowhere else to go. It will have a laundry and showers. It will be air conditioned in the hot summers. Books and audio/visual materials will be available from the Metropolitan Library system as well as six computer stations with internet and email capabilities.

Maybe we'd all enjoy that kind of treatment with a

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**What U.S. state has the highest percentage of people with disabilities?**

**A. Oklahoma B. Florida C. West Virginia D. Alabama**



**Answer bottom of page 6**

## Advocacy, Advocacy, Advocacy (continued)

Think of it—twenty percent of the population joining in for a common cause, addressing the needs of all people with disabilities. This number swells considerably if family members and friends that are also knowledgeable of the needs of people with disabilities join in advocacy efforts.

The OK Rehabilitation Council has an advocacy tool box on their website [www.okrehabcouncil.org](http://www.okrehabcouncil.org). Click on “Legislative Toolbox” for the ABC’s and the 123’s of advocating with legislators. You may not picture yourself as able to do it but the suggestions you find there will make it become possible.

There are other ways to make needs known to agencies that serve people with disabilities. Many of them hold public hearings at various times of the year and for many purposes.

For instance, The OK Department of Rehabilitation Services holds public forums in Oklahoma City, Tulsa and Lawton every year after they review their policies of services for clients of the Department. Any proposed change must be presented to the public before it is voted into their policy by the Commissioners of the OK Department of Rehabilitation Services and the state legislators.

These changes affect the way services are provided by the department to meet the requirements of the Rehabilitation Act, as amended in 1998. Because the Act leaves many of these services to the interpretation of each state your public comment is of great value to influence how the state will provide services in many areas. The public is invited and yet there is rarely any individual or support group represented there.

There are public forums held in Oklahoma City, Tulsa and Lawton for the recommended annual state plan for the OK Department of Rehabilitation Services. This plan is presented yearly to the Federal Rehabilitation Service Agency to declare how

the state Department will meet their objectives of assisting people with disabilities to become employed.

Again, very few from the disability community come. Public comments for both of these events can be made in writing directly to the agency by postal mail or e-mail. The State Independent Living Centers also have public forums throughout the state for their contribution to this state plan. They invite the public to state what their needs are.

The Client Assistance Program Director from the Office of Disability Concerns and the Program Manager of the OK Rehabilitation Council provide statements of their concerns regarding consumers needs at all of these public forums.

This last year, the OK Department of Rehabilitation Service held meetings for a statewide task force for the Blind to voice their needs. Many of the suggestions have been activated already within the Department and some are being considered in their long range planning. It wouldn’t have happened if people hadn’t come to tell of their concerns and needs.

The OK Department of Rehabilitation Services holds a Disability Awareness Day every year in April at the State Capitol. This year it will be April 7<sup>th</sup> from 9:00 a.m. until 12:30 p.m.

People with disabilities are assisted in finding their legislator’s office in order to express their needs directly to the state representatives and senators or their staff. Many vendors of disability products and service agencies have booths in the rotunda to let people with disabilities know about what they can offer.

*(Continued on page 7)*

## Adaptive Equipment to Fit

People with disabilities purchase a lot of adaptive equipment to improve their function in everyday life. For a person with a hearing impairment, that equipment might be a hearing aid. For a person with a mobility impairment, that equipment might be a wheelchair.

That hearing aid permits its wearer to be more aware of the sounds in their environment. That wheelchair permits the person with impairment to their legs to ambulate through their environment in a chair. Adaptive equipment can make a tremendous difference in the quality of life a person enjoys.

Sometimes people with disabilities purchase the equipment they need out of their own pocket. The majority of hearing aids are purchased this way. Sometimes people with disabilities are eligible for programs which can pay the cost of the adaptive equipment.

Many wheelchairs are purchased through either the Medicaid or Medicare insurance programs. Medicaid is an insurance program for people with low incomes and low resources. Medicare is an insurance program for people who are elderly or disabled and have paid into the Social Security program for a number of years in order to qualify.

Some people have private insurance which pays for their adaptive equipment needs. Of course, sometimes people use more than one source to meet their needs. They may have private insurance but also have a co-pay which comes out of their own pocket.

Whatever method used to purchase equipment, people may not be aware of their rights and responsibilities to make sure they get the piece of equipment which meets their needs. This is not as simple as it sounds. It is possible to bring that wheel-

chair home and find out it will not go through the doorway.

Some people take that hearing aid home and find it magnifies the sound at too high a volume. They feel they have been victimized by a provider, and they are very unhappy with the expensive equipment they have purchased. (There is a law in Oklahoma that says anyone can return a hearing aid for any reason within 30 days of the date of purchase.)

Buyer beware. Even if someone else is paying for the equipment, that does not mean you do not have a responsibility to make sure your individual needs are met. If you purchase the equipment out of your own pocket, that does not guarantee that your money by itself will get you the equipment you need.

So does the individual have to become an expert on the equipment they need? No, it does not mean that although it is wise to learn what you can about various kinds of equipment.

It is mistaken to assume that the equipment vendor is going to measure you for the perfect fit. Except when Medicaid purchases a wheelchair for an individual, Oklahoma law does not require licensing of vendors. Vendors are businesses, and they have their own needs to meet in selling equipment.

Some people feel that because Medicaid or Medicare has purchased the equipment that those programs will insure the needs of the individual with disabilities are met. This is not the case. These programs may actually pay for the equipment, but they have little further involvement.

The individual should ask questions of the vendor. They may have a very general prescription from a

*(Continued on page 6)*

## Adaptive Equipment to Fit (continued)

doctor. Are there other models which would satisfy the prescription which fit the consumer better? What are the exact dimensions of that wheelchair, and will it fit through the front door?

Does that hearing aid feel all right in the ear? Can you hear well with it? It is not so much being an expert on various kinds of adaptive equipment as it is being an expert on your needs. Nobody knows you better than you do, and that includes your medical equipment vendor. If it doesn't feel right, it may not be right.

It's OK to say, "This fit is too tight." "This wheelchair feels too heavy." "When I have this hearing aid on, it sounds like everyone is shouting at me." The professional working with you will not be offended. They have no way to know that you are unsatisfied and why unless you tell them.

If someone brings your equipment into the showroom and gives you a paper to sign that you are satisfied, it's OK to say I'd like to try out the equipment a few days to make sure it is a good fit. Negotiate with the provider before you pay for the equipment.

Trying to get a provider to make changes to the equipment to meet your needs after you have already paid that provider is like trying to make the snow fall back up into the sky. It probably isn't going to happen. Ask the provider to satisfy your concerns before you sign anything or authorize any payment.

This is not a foreign idea to consumers. How do we shop for a car? Do we expect the car salesman to sell us exactly the model we need. We may sit down even before we go out shopping to write down what we expect from this car. We take a lot of family vacations and want a car with good gas mileage.

We drive a lot of local miles and want a small car that negotiates well in tight spaces. If we pay such good attention in buying a car, why can't we use that same diligence when we buy adaptive equipment? Do we think the car salesman knows more about our needs than we do? Of course we don't.

There is no substitute for good self advocacy. Ask questions. If you buy this piece of adaptive equipment, does it have a warranty? Where can you get repairs for the equipment if something broke? If the vendor has to send the equipment back to the manufacturer, how long can you expect to be out of that equipment and will the vendor provide you with a loaner during that period? (There is a law in Oklahoma called the Assistive Technology Lemon Law. It is a one-year limited warranty on any type of adaptive equipment that malfunctions.)

Oklahoma ABLE-Tech in Stillwater is a good authority on adaptive equipment for people with disabilities. They are a reliable resource for information. Oklahoma ABLE-Tech is a public agency connected to the Seratean Wellness Center at Oklahoma State University. Call 800-257-1705 about your concerns for adaptive equipment.

**“Stewardesses” is the longest word in the English language typed exclusively with the left hand.**

### Homelessness in Oklahoma City (continued)

hot breakfast and lunch included. However, on second thought it might not be worth it to be homeless.

Some people say if you treat people well who are homeless you only enable poor choices and bad behavior. Others point out that people who are homeless have undergone a great deal of social stigma already and will only begin to take care of themselves and provide for their own needs when they decide that their life is really worth living.

Dan Straughan would probably fit into the latter category. He is an unusual man. He actually managed the Federal Reserve Bank in Oklahoma City for ten years between 1987 and 1997.

This was followed by seven years working for United Way before joining the Homeless Alliance. A background in banking will help Dan manage two HUD grants for \$4.5 million plus a half million from a private foundation. Even though it sounds like a lot of money, this will only get the buildings completed.

Operating expenses will be \$150,000 per year, and that will take donations and lots of community fund raising. Political and economic support has enabled the Homeless Alliance to achieve what they have. It is not in the best interest of Oklahoma City nor in the best interest of individuals to wander the streets aimlessly. We cannot afford the human cost.

If you would like to donate to support the work at the Resource Center or at the future Day Treatment Center, contact Dan Straughan at [dan-straughan@homelessalliance.org](mailto:dan-straughan@homelessalliance.org). The Homeless Alliance has private, non-profit status.

### Advocacy, Advocacy, Advocacy (continued)

The OK Rehabilitation Council holds candidate forums before elections to give people with disabilities opportunity to hear candidates and to tell those candidates what is important for people with disabilities. The OK Rehabilitation Council will be hosting a free of charge all day conference entitled Building Foundations for Advocacy on September 10<sup>th</sup> of 2010 at the Reed Conference Center in Midwest City.

Nationally known expert, Stephanie Vance will provide information on how to advocate. This will be an excellent opportunity to build your skills in advocacy. For further details of these events, check [www.okrehabcouncil.org](http://www.okrehabcouncil.org).

Public forums are announced on the OK Department of Rehabilitation Service website, [www.okrehab.org](http://www.okrehab.org) and flyers are sent out by the Oklahoma Rehabilitation Council to support groups for various disabilities. The Office of Disability Concerns also posts them and many other items of interest at [www.odc.ok.gov](http://www.odc.ok.gov). Also check the OK Rehabilitation Council website [www.okrehabcouncil.org](http://www.okrehabcouncil.org) for notices.

Stay aware of these opportunities and others. Attend, write, make your voice heard!

All of these occasions are an opportunity for needs of people with disabilities to be presented where their voices will be heard. Without expressing their needs what progress has been made would never have happened. There is much more to be done and it is the people with disabilities that will make it happen with their direct input and it will not happen if they leave it up to others.

**What do you get from a pampered cow?  
Answer—spoiled milk**

## CALENDAR OF EVENTS

- May 4, 2010** Oklahoma Parents Center State Conference at the Embassy Suites Hotel in Norman, Oklahoma. For more information contact the Oklahoma Parents Center at 1-877-553-4332.
- May 18-20, 2010** "The Art of Aging" 35th Annual State Conference on Aging, Tulsa Marriot Southern Hills Hotel in Tulsa, Oklahoma. Contact Paula Cockrell at 800-211-2116 or 405-522-6916 for more information.
- June 7-11, 2010** Make Promises Happen camp for individuals with Prader Willi Syndrome. For more information about this camp and other camps, contact James Wheeler at 800-299-2811.
- June 10-13, 2010** UCO Endeavor Games, nationally-recognized athletic competition for athletes with physical disabilities. Contact Leigha Joiner at ljoiner@uco.edu for more information. The games are held on the campus of the University of Central Oklahoma in Edmond.

**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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