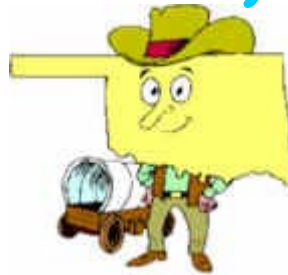


# WILL'S CORNER, OKLAHOMA



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(Serving the Disability Community of Oklahoma)

## SELF-DIRECTED SERVICES

As you are reading this, your reaction may be that it sounds good, but you wonder what it is. Self-directed services is a new way of doing business where an individual with disabilities or the family of that individual is empowered to function in many of the roles which agencies who offer services to people with disabilities currently occupy. So what does this mean?

In the 2005 Oklahoma Legislature, Senate Bill 1015 was passed. This law authorized a pilot project in Oklahoma of families on the In-Home Supports Waiver in the Developmental Disabilities Services Division to self-direct their support services. This may seem like something very insignificant to those of you who have a disability or have a family member who has a disability.

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## THE LITTLE LIGHT HOUSE

To tell the story of The Little Light House not using words like miracle, faith, and God would be like recounting the history of the United States without reference to George Washington or Abraham Lincoln. It would considerably alter the story. Marcia Mitchell is a woman whose faith in her God inspired her to ask for a miracle. That is how she explains the birth of The Little Light House and its continued existence today some 34 years after it began.

The story began in Tulsa, Oklahoma way back in 1972 when Marcia Mitchell and a friend took their young daughters to a local pediatrician and requested services. That pediatrician basically told them that if they wanted a place to serve pre-school children with disabilities that they would have to open it up themselves because there was just nothing in Tulsa at the time to meet the needs of their little girls.

Marcia told her husband Phil that they were going to open up a pre-school to serve children with disabilities much to his dismay. He told her she'd need two to three thousand dollars to start up. She made \$65 at her first garage sale to raise money for the school, but that was not the end of her fundraising efforts.

Marcia was a speech and drama teacher at a Tulsa high school and they had put on a production of *The Wizard of Oz* at school. She asked her students if they would be willing to donate their summer to producing *The Wizard of Oz* to raise money for her school. They raised \$3000, and within five months The Little Light House was born.

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**OHC web site:**  
**[www.ohc.state.ok.us](http://www.ohc.state.ok.us)**

## THE LITTLE LIGHT HOUSE (continued)

Today The Little Light House serves sixty-four children with various disabilities in a 22,000 square foot, state-of-the-art building in east Tulsa. They have 41 full-time employees and 200 volunteers in a program costing \$100,000 **per month** to operate. The Little Light House charges no tuition to the families of the children they serve, and it takes no government money of any kind. They operate on the donations of corporations, churches, civic groups, Sunday Schools, and individuals. Safe to say, this is not the typical social service organization.

On my tour of the building, I watch a small child on a portable respirator frolicking with his nurse in the gym. He has a nurse provided all day through his parents' insurance, but he has available paid pre-school staff who are licensed speech therapists, occupational therapists, and physical therapists. If he had a visual impairment, he would have available a low-vision specialist to assist him during his day at school. These professional staff are in addition to teachers who operate in each classroom.

And then there are the volunteers. There are volunteers who work in each of the classrooms to help feed the children or whatever might be necessary. The Little Light House employs no person to do maintenance in spite of being a 22,000 square foot building. Volunteers fix the equipment, keep the heating and air going, and maintain the grounds.

Back in the 80's Marcia tells of a neo-natal pediatrician who spent hours volunteering at The Little Light House at a time when Tulsa only had two such specialists in the whole metropolitan area. Reportedly this medical doctor was so impressed with what was going on at this pre-school that she felt compelled to donate her time to meet the needs of these children who needed her services so badly.

They told Marcia Mitchell that there was no place for her to take her daughter with disabilities in 1972. Marcia knows what it is like to be a parent of a young child with disabilities. Parents may have difficulty accepting that they have a child with



disabilities, and in today's economic situation often both husband and wife must work to make ends meet. The Little Light House opened a family learning and intervention program to train parents how to care for their children with severe disabilities. When they can hire a licensed counselor, Marcia hopes to establish support groups for parents of children with disabilities to help them adjust to the needs of their children. This beautiful story goes on and on.

People from all over the world have come to The Little Light House to serve as interns free of charge so they can learn how this beacon of light operates and take that expertise back to their own countries. I ate lunch with a young volunteer from the Philippine Islands whose aspiration is to open a similar facility in Manila.

Marcia recounts the story of a Chinese volunteer who opened up a facility for children with disabilities in his hometown in 2000. Staff from The Little Light House were present and watched as Chinese communist government officials contributed their own money to educate children with disabilities at a time when China did not believe in educating such children. And let's look closer at home.

A Little Light House now exists in Jackson, Mississippi with plans for similar organizations in Iowa and Denton, Texas. (I'm thinking to myself that we could use some Little Light House centers in other towns right here in Oklahoma.)

Marcia tells the story that she never had a doubt that she was going to open up The Little Light

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## Assistance at Self-Serve Gas Stations

A caller approached me recently asking about assistance in pumping gas at self-serve gas stations in Oklahoma. I went to my supervisor to ask about this, and he handed me a U.S. Department of Justice printout entitled *Americans with Disabilities Act: Assistance at Self-Serve Gas Stations*. I am including that printout within this article. For the 8000 plus Oklahomans who are mobility impaired, this information may be of special interest to you.

People with disabilities may find it difficult or impossible to use the controls, hose, or nozzle of a self-serve gas pump. As a result, at stations that offer both self and full service, people with disabilities might have no choice but to purchase the more expensive gas from a full-serve pump. At locations with only self-serve pumps, they might be unable to purchase gas at all.

The Americans with Disabilities Act (ADA) requires self-serve gas stations to provide equal access to their customers with disabilities. If necessary to provide access, gas stations must—

- Provide refueling assistance upon the request of an individual with a disability. A service station or convenience store is not required to provide such a service at any time that it is operating on a remote control basis with a single employee, but is encouraged to do so, if feasible.
- Let patrons know (e.g., through appropriate signs) that customers with disabilities can obtain refueling assistance by either honking or otherwise signaling an employee.
- Provide the refueling assistance without any charge beyond the self-serve price.

If you have additional questions concerning the ADA, you may call the Department of Justice's ADA Information Line at 800-514-0301 (voice) or 800-514-0383 (TDD) or access the ADA Home Page at [www.usdoj.gov/crt/ada/adahom1.htm](http://www.usdoj.gov/crt/ada/adahom1.htm).

If you need assistance with pumping gas at self-

service stations in your local area, ask for it. Talk with the manager of the store about your needs. Question the manager about a good time for you to fill up, maybe a time when two employees are on duty and one would be available to assist you.

If you need further assistance, you may want to call Vance McSpadden or Connie Henderson at the Oklahoma Petroleum Marketers and Convenience Store Association in Oklahoma City. (This association is a trade association for gas stations and convenience stores in Oklahoma.) They may be willing to talk with your station manager on your behalf. They may also assist you in getting assistance in pumping gas on your travels outside Oklahoma when you need this service. Call Vance or Connie at 800-256-5013.

### Ways to Maintain A Healthy Level Of Insanity



**Specify that your drive-through order is "to go".**

**When the money comes out of the ATM, scream "I won!, I won!".**



## When My Wheelchair Doesn't Fit

One man shared that he relied on a local wheelchair provider to purchase his new chair, and this provider actually had no working knowledge of the effects of ALS and how the body needs additional support over time because of the disease. All of us have been in this situation where a big federal program such as Medicare or Medicaid is paying for a new chair for us. We presume that other people know better what we need. After all, they are the professionals.

But just maybe we do too much relying on other people to decide what is best for us. Maybe we can be more discerning of our own needs and speak out as appropriate. Let's talk more about getting a new chair and the process we usually go about doing that. Typically our doctor will write a generalized prescription which we will take to a local provider.

This local provider then sells us a wheelchair and bills Medicaid or Medicare. The deal is done. But is the deal really done? Are you satisfied with that chair? The man mentioned at the beginning of this article had ALS, and his disease was progressive leading to his retaining a lot of fluid to the tune of increasing two shoe sizes and four inches in the waist. The wheelchair he went home with no longer fit.

A chair which does not fit is a real problem to the consumer because the big federal programs typically will purchase only one in five years. You come home with a chair which will not fit through your doors. Perhaps you develop pressure sores because you are in a wheelchair which is rubbing unnecessarily. Poor seating can lead to many problems down the road. You need to ask some questions, and you need to do some thinking about your needs.

In addition to a consideration of your needs, you can do more. Rather than asking your doctor for a prescription for a wheelchair, you may ask the doctor for a prescription for a seating evaluation with an occupational or physical therapist. These professionals are going to know something about your

**We could certainly slow the aging process down if it had to work its way through Congress.**

**Will Rogers**

disability and how this disability factors into your needs for a wheelchair. They are in the position to provide you some professional recommendations.

There are also some national accrediting licenses such as Assistive Technology Practitioner (APT) and Certified Rehabilitation Technology Supplier which can verify a person has had training on seating and equipment which can meet your needs. Generally your therapist may or may not have had the APT certification. Your medical supplier may or may not have the CRTS license. Presently there are only three people in Oklahoma who have the Certified Rehabilitation Technology Supplier license. These three people work in Lawton, Oklahoma City and Tulsa.

Obviously people who have a license such as the Assistive Technology Practitioner and the Certified Rehabilitation Technology Supplier can be held responsible for a recommendation for a wheelchair. As we said, these licenses are not presently common in Oklahoma, especially if you live in more rural areas of the state. But there are still things you can do.

Ask your doctor and/or physical or occupational therapist about any special needs you have due to your disability. Of course, you too are an expert on what feels good to you. Is the wheelchair you are trying out too heavy to push if it is a manual chair? What kind of warranty goes with the chair you are considering? Who will repair your chair should something go wrong with it? Is your vendor willing to adjust your chair to meet your individual needs?

You may ask to look at several models of wheel-

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## When My Wheelchair Doesn't Fit (continued)

chairs. You may ask your vendor for a catalog from a manufacturer to get a better idea of what is on the market. We make a lot of different cars all over the world which are available to you to purchase, and I would almost guarantee you that you are discerning about which car best fits the needs of you and your family. Is a wheelchair any different? Of course not.

Asking questions before purchasing a wheelchair is a lot better than trying to get somebody to do something after the chair has already been ordered and Medicare or Medicaid has already paid the vendor. That final responsibility falls on you. Your doctor certainly knows about you and your disability, but they may not be fully aware of all the types of

equipment which are being manufactured. The vendor has some knowledge of what kinds of equipment are being manufactured, but they may not be really aware of what your needs are because of your disability.

This leaves you. You can compare information from your vendor, your doctor, and your therapist, but before you sign off on an order for a new wheelchair you must consider your own needs very carefully. Basically, you get one shot at it in five years. When you take aim, make sure you hit within the bull's eye. You'll be a lot happier in the long run.

## SELF-DIRECTED SERVICES (continued)

ity, but believe me when I say that it may be the beginning of a big change in how social services to people with disabilities are offered.

Empowerment of individuals with disabilities and their families may offer new opportunities to these people as they are trying to get the services they need. Let's look at Doris Erhart and her eight-year old son, Aaron, who are a part of this pilot project which affects Aaron's services.

Aaron is a young man with Down syndrome. His mother, Doris, applied for waived services for her son when he was only three years old. In July, 2005 Aaron was approved for the In-Home Supports Waiver of the Developmental Disabilities Services Division (DDSD). Doris was looking for some rather simple supports. She wanted someone to work directly with Aaron after school and occasionally on weekends. She also needed assistance in purchasing some simple medical supplies that her son used on a regular basis.

In order to get this rather streamlined package, she had to say yes to some regular intrusions into her home from a DDSD case manager and an agency program coordinator. She had to select a Medicaid

provider to order medical supplies and let her son's budget be billed a higher rate than she could purchase the same supplies at the local Wal-Mart. This was frustrating with the limited budget permitted by the In-Home Supports Waiver. Sometimes the money was just not there to purchase the medical supplies at the higher rate and pay an agency to provide staff for her son.

Then in September, 2006 Aaron was selected as one of fifteen DDSD clients in Oklahoma and Tulsa Counties to be on the pilot project to self-direct their services. Doris smiles broadly as she shares how this new way of doing business has affected her son's services. "I just have to say that self-directed services have permitted Aaron to get more and better services at a lower cost than when we went through an agency to provide his services."

Doris went on to discuss how she hires Aaron's direct-care worker directly now and negotiates a salary for that worker which will insure she gets quality care for her son. She purchases the medical supplies she needs at the local Wal-Mart at a cost considerably less than when she was forced to go

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## SELF-DIRECTED SERVICES (continued)

through a regular Medicaid contracted provider. This has translated into money left over in Aaron's budget for special things that come up.

Acumen, a national company headquartered in Mesa, Arizona, functions as the fiscal intermediary in Aaron's case. Acumen actually cuts the checks to Aaron's direct-care worker every two weeks based on the time sheet which Doris sends in, and they take out the proper money for Social Security and other things just like an agency which provided services to Aaron would do if he was going through an agency. Doris can also get a voided receipt from where she goes to get Aaron's medical supplies, and Acumen will cut a check to that vendor which she uses as cash to purchase the supplies.

Doris Erhart actually becomes the employer of record for her son. No one knows her son better than she does, and she interviews, hires, and trains that worker to meet the specific needs of Aaron. By becoming the employer of record, the family exercises a great deal more control of the case, and this leads to a greater customer satisfaction with the Medicaid services Aaron is receiving.

My question to Doris was about the paperwork which I feared she would be responsible for now that she was directing Aaron's case. Doris proudly produced a simple, one-page monthly report which she turns into Aaron's case manager. The report has four questions where all she has to do is circle yes or no and one question where she simply describes the progress/results Aaron has achieved through the services he has received. There is minor paperwork to do when hiring staff. That's it.

Doris also has a form entitled *Request for Vendor Payment*. She can pretty much purchase anything Aaron needs in the way of services and/or supplies through this easy purchase order. Acumen provides Doris a monthly statement of account showing exactly what has been paid through Aaron's case for that particular month together with year-to-date information to let her know what has been spent out of Aaron's DDS budget and what

money is left in his account.

As we said earlier, Doris hires Aaron's direct-care worker and negotiates with that person what she will pay per hour for working with Aaron. Because an agency is not involved, administrative costs are considerably less, and more money is available to pay the worker directly. Doris shares that she pays more for Aaron's direct-care worker than most agencies pay their workers. Higher pay can translate into better-quality services.

This whole thing of self-directed services sounds like a win/win situation. Doris Erhart certainly appears to think it is a good way of providing DDS services for her son. However, she qualifies that self-directed services may not be for everyone. She specifically cites families who are very busy who may not have the time or expertise to direct the services for their child. For those families, going through an agency may still be the better way to go. She explains that this is just another option which is being offered in an effort to meet the needs of people with disabilities. She hopes that when Aaron becomes an adult that he may be able to self-direct his own services, and she is building on his skills now to enable him to do just this.

**Beginning in July of 2007 as the annual date for the Individual Plan comes due for people who are on the In-Home Supports Waiver, they will have the option to choose self-directed services. People coming off the waiting list after this date will also be offered this same option.**



**I signed up for an exercise class and was told to wear loose-fitting clothing.**

**If I had any loose-fitting clothing, I wouldn't have signed up in the first place!**

## THE LITTLE LIGHT HOUSE (continued)

House way back in 1972. Even though everything seemed stacked against her, she somehow just knew that this was going to happen. Her first fears showed up with a big article in the *Tulsa World* showering praises because of her success and generating some serious public interest in what she was doing.

She thought, "What if I can not maintain this momentum? What if I were to disappoint all of these people who were investing in my dream?" The *Tulsa World* article was appropriately entitled "Somewhere Over the Rainbow Dreams Really Do Come True!" in memory of that famous theme song from *The Wizard of Oz*.

Thirty-four years later, Marcia Mitchell is just as enthused about her dream as the day she first opened up her little school for children with disabilities. Her daughter, Missy, is a Christian recording artist and is working on her master's degree in Christian Counseling. Husband, Phil, has recently retired from his career job and now has joined the ranks of the 200 plus people who volunteer their services at The Little Light House. Phil has long since converted to the reality of Marcia's dream. He has served on the Board of Directors since its inception.

Marcia Mitchell has written a book about her experience with The Little Light House entitled *Milestones & Miracles* where she focuses on the children with disabilities rather than on herself. Children who might not get their needs met otherwise are finding a warm, therapeutic atmosphere in which to develop to the maximum of their ability. This is the real miracle. They are the heroes of this story.

**If you would like to know more about The Little Light House, contact their website at [www.littlelighthouse.org](http://www.littlelighthouse.org). You may also contact Linda Steed at 918-664-6746. Among other things, Linda is Director of Children's Services Administration. In these cold days of winter in Oklahoma, I think you will find here a love to truly warm your heart.**

## Earned Income Tax Credit

**The Earned Income Tax Credit is a refundable federal tax credit for working families and individuals who earn low to moderate incomes. Many people do not know about it, and even more, many people do not realize that they can actually receive a refund through filing this. This tax credit is not specifically for people with disabilities although many people with disabilities do qualify because of low incomes.**

Many people do not claim this tax credit because their incomes may be so low that they do not need to file an income tax return at all. They are not aware that they may get money back from the government if they would only file and claim this tax credit.

To claim this tax credit, you need to have worked and earned an income less than \$11,750 if single or \$13,750 if married filing jointly with no qualifying child. You must make less than \$31,030 if there is one qualifying child. You must have a valid Social Security number, and you must be a U.S. citizen or resident alien all year.

The Earned Income Tax Credit provides a refund based on a bell curve from \$1 income to \$11,750 income for a single person. The tax credit refund is a maximum at the income of \$5200. For this income, your refund would be \$399. The State of Oklahoma also provides a tax refund if you qualify for the federal Earned Income Tax Credit, and that figure is 5% of your federal refund. If you qualify for this tax credit, you can actually get back more money than you paid in.

The Earned Income Tax Credit does not generally affect the eligibility for Medicaid, SSI, food stamps, or low-income housing. To find out more information on this tax credit, call the IRS at 800-829-3676 to order free forms and publications. You may order publication #596 entitled *Earned Income Credit*. IRS forms with instructions, tax publications, and other tax materials may be downloaded at the IRS website [www.irs.gov](http://www.irs.gov). See if you qualify. You may receive money back from Uncle Sam.

**CALENDAR OF EVENTS**

- January 24-26, 2007**      19th Annual Substance Abuse Conference at Southern Hills Marriott Tulsa. Contact 405-522-8300 for more information.
- January 26-27, 2007**      2nd Annual Couple's Conference free for families of children with disabilities at Embassy Suites Hotel in Oklahoma City. Call Lauren at 1-877-435-8033 or register online [www.registernow123.com](http://www.registernow123.com).
- February 6-7, 2007**      Oklahoma Federation of the Council for Exceptional Children Conference at Marriott Conference Center Norman. Free to public. Call Staci Vollmer 405-535-2993 for more information.
- March 27-28, 2007**      Oklahoma Association for Persons in Supported Employment Conference at OKC Clarion Conference Center. Free registration before March 15. Contact Judi Golston at 405-325-0448 for more information.
- April 9-10, 2007**      Governor's Conference on Developmental Disabilities at Tulsa Renaissance Hotel. For more information, contact Sheree Powell at 405-521-4972.

**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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