

WILL'S CORNER, OKLAHOMA



The Office Of Handicapped Concerns
(Serving the Disability Community of Oklahoma)

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FROM THE DIRECTOR'S DESK

All public entities must designate an employee to coordinate compliance with the Americans with Disabilities Act (ADA). By naming a coordinator that individuals can easily contact, it will help ensure that Title II non discrimination, accessibility, and other requirements are met by each state entity.

This past fall, Governor Frank Keating directed all state agencies to designate an ADA coordinator for each individual agency. Governor Keating's leadership in this issue is extremely valuable in establishing a solid foundation for compliance with the Americans with Disabilities Act. The Office of Handicapped Concerns is currently providing a list of ADA coordinators for each state agency. This list can be accessed on our OHC website at www.state.ok.us/~ohc or by calling 1-800-522-8224 and requesting a copy be sent to your address. I urge you to contact the ADA coordinator if you have concerns or comments. I believe that good communication between Oklahomans with disabilities and their governmental entities can lead to creative problem solving and foster improved communication and mutual understanding.

APRIL 19, 1995

(8:45 a.m. Social Security office, downtown Oklahoma City)

"I need to pick up an application for my husband for social security disability."

"Go out that door and to your left to the elevators. The receptionist on third floor will have the forms for you."

(third floor Alfred P. Murrah Building)

"The lady at the window downstairs told me that you had the application forms for disability?"

"If you'll wait just a minute. . . . I'm sorry they didn't have them downstairs. I think this is what you're looking for."

"Thanks. Will that door take me to the elevators?"

"Sure."

"Oh my God! Help me someone. I can't see. I can't . . . I . . ."

(basement area of Alfred P. Murrah Building, 11 a.m.)

"This one's dead. Hey, I see someone wedged under that pillar over there. I have a live one. I have a live one! Can you hear me? Do you know what happened?"

"My stomach h-u-r-t-s."

"Can you hear me?"

"Uh huh. Why didn't the tornado siren go off?"

"There's been an explosion and . . ."



Lessie and Justin Chacon

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“Get out of here. They say there’s another bomb. Everybody out, n o w!”

“Don’t leave me here... a l o n e.

(basement area amid the rubble of concrete, 1 p.m.)

“She’s unconscious but still alive. Check her vitals. We’re going to have to cut her out.”

“I can hear you. I’m pregnant. I’m three months pregnant.”

“Get a medic over here. She’s saying she’s pregnant.”

“Are you in pain?”

“My head hurts.”

“Can you feel this?”

“I can feel in my right leg, but I can’t feel anything in the left.”

“You’re going to be OK, but first we’re going to have to cut this concrete pillar away from you where we can move you. Is that all right with you?”

(Oklahoma Memorial Hospital)

“Mam, do you know who you are? Do you know where you are? Lessie, we’re taking you into surgery.”

“Is my baby OK? IS MY BABY OK!”

(Hospital ICU, evening April 19)

“Honey, you’re going to be OK. You’ve had surgery. I’m going to give you something to make you easy.”

“Am I still pregnant? I don’t want to take anything. I’m afraid it will make me lose the baby.”

“You’re going to be OK. You have a real fighter in you.”

This afternoon, some seven years after the bombing of the Alfred P. Murrah Building in Oklahoma City, I am sitting in the office of Lessie Chacon. Lessie admits that this is the first time she has told her story in print. At first she says that she did not want to talk about what happened because it was too painful for her. She needed space to process the traumatic events of April 19. Also she says she has learned from the 9-11 New York tragedy to see events from the perspective of rescue workers and the general public. This broader picture has helped her detach from the intense personal tragedy which occurred seven years ago.

But there was more than psychological trauma which happened for this woman. She continues to live with physical disability

as a result of her being in the Alfred P. Murrah Building on that fateful day. Today Lessie still experiences nerve damage in both hands which leaves them partially paralyzed in an unnatural position. Buttoning clothing is no longer a possibility.

I am astounded to hear that Lessie and her family are faced with a huge medical and hospital bill today which they are faithfully paying down a month at a time. Reportedly the Murrah Building had some insurance which was shared by the survivors, but this did not cover all the medical expenses. Even coupled with contributions from private individuals, the Chacon family was left with many unpaid expenses.

On the night of April 19 Lessie underwent three surgeries to stop internal bleeding and to see how the fetus was doing. In addition, a large piece of concrete was removed from her large intestine which had completely blocked it and was causing swelling. It wasn’t until fully four years later and a total of nine surgeries that the doctor said he was reasonably sure that he got out all of the concrete which had lodged in her body cavity. Initially doctors hesitated to probe for everything in fear they would disturb the growing child.

Justin Chacon was born two months early on July 20, 1995—apparently just in a nick of time as Lessie’s reproductive system began to shut down. Immediately after the baby was born, she had surgery to remove organs which had been damaged in the explosion but which had almost miraculously continued to function through the baby’s development. Numerous ultrasounds had been performed to track the development of the growing child. At one point Lessie received steroids which were to help the unborn baby develop more rapidly and buy time for a successful delivery.

Does Justin know today the circumstances of his birth after the largest incident of internal terrorism in United States history? No, not yet. But, Lessie shares that she and her husband are going to tell him this year. They have tried to hint at some of what happened without giving him the complete story.

Justin talks with his dad this year after seeing a report of the Oklahoma City bombing on television. “Is that explosion like what mom and I were in?”

“Yea, it was a lot like that.”

“Gosh, that would be scary!”

Today Lessie Chacon lives and works in the Oklahoma City area. By the way, she was 45 years old when she gave birth to Justin who has nieces and nephews who are older than he. Lessie becomes almost philosophical as she considers the people who planted the explosives which turned her life around. She shares that she has forgiven those responsible for the disaster in Oklahoma City. She only wants to get on with her life, to help others find fulfillment in life, and to enjoy her young family. In honor of those who lost their lives or who suffered disability in the events of April 19, 1995, may they be remembered always.

INSIDE THE OKLAHOMA

HEALTH CARE AUTHORITY

The Oklahoma Health Care Authority is a state agency which rank and file Oklahomans know very little about but at the same time an agency which affects the disability community profoundly. Maybe we know less about this agency because we do not deal with it directly as say we deal with the Department of Human Services which is highly visible to most Oklahomans. But just because the Health Care Authority affects us behind the scenes does not make it any less important to us.

To give you an idea of the significance of this state agency, let's look at some statistics. Last year the Health Care Authority served 600,000 Oklahomans who fell into the categories of poor, aged, and disabled. Adjusted to the latest 2000 census figures, that is almost one in six citizens of the entire state. How does this almost unknown agency affect so many people in our state? The answer is simple. The OHCA administers the Medicaid program in Oklahoma. Now let's look at another statistic. The annual budget of the Health Care Authority is \$2.4 billion including both state and federal dollars. This is big business in Oklahoma, folks. It is worth our time to become more familiar with this agency which has such an impact on our lives and our state economy.

Let us begin by making a distinction in the role of the Health Care Authority

and its sister agency, the Department of Human Services. The Department of Human Services has offices in the county seat of most of Oklahoma's 77 counties. We go there to sign up for food stamps, the TANF program, DDS services, or medical services. And it is the DHS worker who determines our eligibility for Medicaid which is the umbrella payment mechanism embracing most of these individual programs. The Health Care Authority operates behind DHS and serves as its bursar processing and paying claims. Through its three boards and 285 employees in Oklahoma City the Health Care Authority decides how Medicaid will be administered in Oklahoma. Which medications will we cover in our prescription drug coverage? At what rate will we pay providers of Medicaid services? Which medical procedures will be covered? What models of durable medical equipment will be paid for? Does this begin to touch your life if you are a beneficiary of Medicaid services in Oklahoma? You bet your life it does.

As we said before, Medicaid in Oklahoma is big business. It embraces three Medicaid waivers which drive services for Oklahomans with cognitive impairment and one waiver which serves elderly and disabled Oklahomans who are not cognitively impaired. These waived services are bundles of services administered to eligible in-

dividuals according to their needs. Some other services which Medicaid pays for are dental, inpatient hospital, prescription drugs, physician services, therapy services, transportation to doctor's offices, behavioral health, long term care, vision services, and durable medical equipment. Medicaid serves as the primary health insurance for Oklahomans who are poor and disabled.

I am using the term Medicaid and the Oklahoma Health Care Authority synonymously because the agency administers this program in Oklahoma. Yes, there are federal regulations of the program, but the state does have some control of how the program will play out here. We have some state control because we supply some state tax dollars to match Uncle Sam's contribution. In Oklahoma the Legislature kicks in 30 cents to every 70 cents coming out of Washington, and it is precisely at this point where tension can occur in the program.

The Health Care Authority presents a budget to the Oklahoma Legislature every year. They say this is what we will need in state match to run Medicaid in Oklahoma. Medicaid accounts for 12% of the entire budget of the state each year. With other items competing for Oklahoma tax dollars, the Legisla-

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ture feels the pressure in deciding how funds are to be distributed. Now let's complicate the matter a little further. Let's factor in skyrocketing costs of prescription drugs. Let's look at the alarming rate of increases in health care costs in general. Let's consider an aging population with greater disabilities applying for services in greater numbers, and we can glimpse a little into how our Health Care Authority must work together with our Legislature for the benefit of Oklahoma citizens in need.

...both seek to provide quality services to Oklahoma citizens in the most cost-effective way...

OHCA has a mission statement and it is very similar to the goal of the Legislature. They both seek to provide quality services to Oklahoma citizens in the most cost-effective way. But let's be realistic for a moment. Sometimes there are trade offs. Sometimes the balance swings towards one or the other in the natural tension between quality and cost. Hard decisions have to be made which affect people's lives.

What can we do as citizens of this great state? We are doing it right now in learning more about federal/state programs which affect us and the governmental process which affects the program. The Health Care Authority Board meets every second Thursday of the month at 1 p.m. in the boardroom of the Health Care Authority, 4545 N. Lincoln Blvd. Suite 124 in Oklahoma City. The Medical Advisory Committee meets every other month at the Health Care Authority on the third Thursday of the month. This committee advises the agency on policies and procedures. The Drug Utilization Review Board meets every second Tuesday of the month and they

discuss pharmacy practices and coverages. All of these committee meetings are open to the public, and the MAC and the DUR have automatic opportunities for public comment on the agenda. If a private citizen wanted to get onto the agenda of the OHCA Board meeting, they would need to contact the

Director of the agency in advance with a request.

Citizens may request a copy of the Oklahoma Health Care Authority annual report by calling the main number 405-

522-7300. OHCA runs a toll-free number statewide where citizens may express their concerns such as billing or services covered. This customer assistance number is 800-522-0310. Another toll-free number is available specifically for providers who have concerns about claims. If you do not feel your concerns are being heard through these channels, contact your Legislator. If you do not know your Legislators, call your local County Election Board and request their names and telephone numbers. Most Legislators have local numbers in their district as well as offices in Oklahoma City.

The Oklahoma Health Care Authority and its federal/state program, Medicaid, affect all of us in one way or another. We are recipients of services or we have family who receive services or we have a friend in services. Sixty-five percent of eligible Oklahomans are children and twelve percent of consumers are over the age of sixty-five. People receiving Medicaid benefits are some of the most vulnerable citizens in our population. Providing them with quality services at affordable costs is a great responsibility.

OLD WORDS IN NEW LIGHTS

Flabbergasted—appalled over how much weight you have gained

Intoxication—euphoria at getting a refund from the IRS which lasts until you realize it was your money to start with!

Giraffiti—vandalism spray-painted very high

UPDATE FOR JOB SEEKERS

Last issue we told you about the brand new job bank furnished by the Department of Rehabilitation Services. Over **300** applicants have entered their employment information since then. Even though the Department of Rehabilitation Services has barely begun calling on employers to obtain their job information, **FOUR** people with various disabilities have been hired.

Is your job information entered yet? If not, **WHY NOT?**

If you do not have access in your home to the Internet, you can go to the public library or contact your vocational rehabilitation counselor to use theirs. The website is very user friendly, but if you have any problem, call **Marilyn Burr at 1-800-522-8224 or 405-521-3756 for assistance.**

If you are seeking a job, **LOG IN TODAY!** Make sure your information is there as DRS calls on employers to demonstrate the job bank. Your perfect job may be with the next employer they contact.

Remember the website address is www.okdrs.jobfit.com.

Another tip I have if you are interested in getting a job is to let you know about the Job and Technology Fair for People with Disabilities to be held at the Omniplex (2100 N.E. 52nd in Oklahoma City) on April 17 from 10 a.m. until 4 p.m. Employers will be there as well as VR counselors who can approve applicants for HB1340 on the spot. Assistance with job applications and resumes will be available. Come on out and see what's available.

WILL YOU BE THE NEXT HIRE?

HOLD THAT THOUGHT

When a young girl was in elementary school, her teacher pinned a note to her shirt for her parents to read. It said, "Charlene is not coloring inside the lines." Charlene's parents contacted the teacher and asked what the purpose of coloring inside the lines was. The teacher didn't quite know what to say, except that the direction she had given was to color inside the lines. Charlene's father told her to color any way she wanted and when she was done coloring, to draw a black line around her picture.

Conversations with Representative Al Lindley

Representative Al Lindley represents a district in South Oklahoma City in the Oklahoma Legislature. He was nice enough to come to the Office of Handicapped Concerns and chat with me a little about Special Education in Oklahoma and his own daughter, Wendy, who received special education services through the public schools.

“Representative Lindley, what was your experience as a parent of a child with disabilities when Wendy received special education services?”

“I’m glad you asked that. Wendy was diagnosed with neurofibromatosis as a young child, and this genetic disorder runs in our family. In the process of getting surgery to remove a fibrous tumor which resulted from the disability, her sympathetic nerve was severed. This nerve controls the heart rate and regulates body temperature. She had a temperature spike which registered 109.6 degrees. All these problems surfaced in the fall of 1978 when she was in the first grade.”

“So what were services like in the public schools back in 1978?”

“We were lucky in that Public Law 94-142 (federal legislation) had passed in 1975. I remember clearly back in those early days. I was ashamed my daughter had a disability, and I thought it was my fault. I called my big sister in Illinois to ask her advice on what we should do for Wendy’s education. My sister told us about Public Law 94-142, and we went into school meetings asking about this. To answer your question, schools were beginning to serve students with disabilities.”

“Did Wendy receive services?”

“Yes she did. In fact, the Oklahoma City Public Schools conducted an actual classroom in Children’s Hospital during Wendy’s extended stay in the hospital. This was a wonderful service which I understand continues at that hospital.”

“What is the IDEA?”

“IDEA stands for Individuals With Disabilities Education Act. It was passed by Congress in 1997 and is a successor

to Public Law 94-142 which I mentioned earlier. IDEA states that all children with disabilities are to get a free and appropriate education which occurs in the least restrictive environment.”

“What does least restrictive mean?”

“Least restrictive means that whenever appropriate, children with disabilities will be mainstreamed into regular classrooms. An important issue in IDEA is the level of services the child is to receive. Will we get the Lexus, the Ford, or the Yugo model?”

“So what’s preventing us from getting a better model?”

“Attitude, attitude, attitude. What is our attitude toward serving children with disabilities? Are we willing to invest in our children with disabilities? The Federal Government says YES, but sometimes we don’t see the value in providing an education for a child with disabilities. We see the child, or for that matter, any person with a disability, as not having value. As we change our attitude, services will improve.”

“How can we improve educational services for children with disabilities in Oklahoma?”

“We must work at many levels in our state. We in the Legislature can authorize more money for public education, and we actually have the authority to earmark that money to be used for Special Education. Local school systems can make sure they fill their vacancies in their special education department so there is an occupational therapist to give the services prescribed on the Individual Education Plan. State advocacy groups like the Parent Center and the Disability Law Center can work to get information out there to families which will help them to advocate for the needs of children with disabilities. And families can become informed and use their knowledge to advocate for the very best education of their children.”

“How can we empower our families?”

“Even before Wendy began school, we read to her and introduced her to simple arithmetic. We spent time with her to prepare her for a successful education. There are things all families can do. If your child receives physical therapy in the school setting, perhaps the therapist is willing to write up a home program of things that can be done. In Wendy’s case, we incorporated range of motion exercises in her dressing and bathing that did not require a lot of extra time but helped supplement what the school was doing. There are things we can do at home.”

“If I have a complaint about the way services are delivered for my child, what can I do?”

“Mediation is available with mediators trained in education issues. If mediation does not resolve an issue, families may seek due process hearings as one avenue of resolution. In extreme cases, a civil suit through the court system has been filed.”

“Are there other things I can do as a concerned parent to better the special education for my child?”

“Network with other parents who have children with disabilities in the public schools. Learn how to articulate educational goals for your child and consider what supports the child will need to achieve those goals. You’d be surprised

how many families have not taken the time to really do this. Seek out advocacy organizations like the Parent Center which will help you learn more about public education and how to get your child’s needs met. Remember, knowledge is power. Some day we’ll get to the point where we see children first and their disability second. We’ll see that these children really have worth.”

I was ashamed my daughter had a disability, and I thought it was my fault.

The Parent Center mentioned earlier is located in the Oklahoma City area and serves statewide. Their telephone number is 1-877-553-4332. In the metro area dial 619-0500. The

Disability Law Center has offices in Oklahoma City and Tulsa. The Oklahoma City office may be reached at 1-800-888-7755, and the Tulsa office may be reached 1-800-226-5883. The Disability Law Center is sponsoring a day conference on Tuesday, May 7 entitled “Promoting Positive Parent Involvement in 2002”. For more information, call the law center. I received a tip recently about the Individual Education Plan which we published in the October 2001 issue of *Will’s Corner, Oklahoma*. There is a box at the bottom of the first page of the new IEP document which asks for the parents’ concerns for enhancing the child’s education. Think about this before you go into the actual meeting. If you have a written concern, the IEP Team will address your concern and attempt to resolve it.



MARK YOUR CALENDAR

- April 17, 2002** – Job and technology fair for people with disabilities, Omniplex 2100 N.E. 52nd Oklahoma City, 10 a.m. to 4 p.m., employers recruiting employees, assistance with applications and resumes, and much more. Check this out.
- April 19, 2002** – Caregiving from the Individual and Family Perspective, second brown bag lunch sponsored by the Office of Handicapped Concerns, Community Room of Shepherd Mall in Oklahoma City noon to 1 p.m., you bring your brown bag lunch and we supply coffee or tea, for more information contact William Ginn 405-522-6698.
- April 23, 2002** – Job fair 2002, 9 A.M. to 4 P.M. Shephard Mall OKC, contact 405-521-2171 for more information.
- May 7, 2002** – “Promoting Positive Parent Involvement in 2002” from 8:45 a.m. to 4:30 p.m., conference in Oklahoma City location to be announced, free to parents with a child with a disability registering before April 15 (cost for other registrants) call 800-880-7755 or 405-525-7755 in OKC metro 918-743-6220 in Tulsa.
- May 15-17, 2002** – Special Olympics State Games, Stillwater Oklahoma, contact Cathi Morris 800-722-9004 or 918-481-1234 in Tulsa area for more information.
- May 25, 2002** – The Oklahoma Association of the Deaf is hosting a Mr. OAD contest on alumni weekend at the Oklahoma School for the Deaf in Sulphur, Oklahoma. The contest will be at 8 p.m. in the auditorium. Contact Lynn Null 918-832-8742 TTY for more information.
- June 7-8, 2002** – Healthsouth Endeavor Games for athletes with physical disabilities in Edmond, Oklahoma. This is a multi-sport event open to all athletes of any age or ability. For more information contact Katrina Shaklee of the Sports Group 405-722-8744 or <http://sportsgroupinc.com/>.

If you have an event coming up relating to disability, let us know at 1-800-522-8224 and we'll help you publicize.

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*IF YOUR ADDRESS OR OTHER INFORMATION HAS CHANGED, LET US
KNOW SO WE MAY BE ABLE TO SERVE YOU BETTER.*

THANKS,

WILL

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