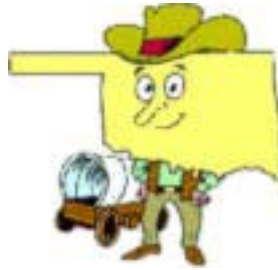


OFFICE OF HANDICAPPED CONCERNS

WILL'S CORNER, OKLAHOMA



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(Serving the Disability Community of Oklahoma)

LOVE CONQUERS ALL

Two women in Agra, Oklahoma have found out first hand that the love of a foster family makes life worth living. Life would have been difficult at best without foster family Nancy and Jerry Durbin. It would have been a life of impersonal institutions with a revolving door of staff working for minimum wage who might themselves have had some kind of physical or mental disability. It would have been the life of a throw-away from society who nobody else wanted and was left to slowly atrophy without the care and concern of a natural family. Both women have severe developmental disabilities. One of the women was abandoned by her mother and father as an infant at the doors of Children's Hospital in Oklahoma City.

Both women who are now young adults were warmly welcomed into the Durbin home many years ago when they were still young children. They were accepted into a home

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MEDICARE PRESCRIPTION DRUG BENEFITS

Health and Human Services Secretary Michael Leavitt visited Oklahoma City August 24 in a whirlwind of media interviews and questions from elderly and disabled Oklahomans. Secretary Leavitt brings good news to Oklahomans and indeed all Americans who are eligible for Medicare benefits. Medicare will be offering prescription drug benefits beginning January 1, 2006. Let's look at what you have to do in order to initiate these benefits.

First you will have to actually sign up for this prescription drug benefit. It will not automatically come to you because you are receiving other Medicare benefits such as hospitalization or medical. Secondly, you will have a specific time to enroll for the program, and that is from November 15, 2005 through May 15, 2006. If you currently are receiving some Medicare benefits, you will be receiving the little booklet *Medicare & You* in the mail sometime during the month of October. This little booklet will list different plans for prescription drug coverage available to you. You will have to choose the plan which is best for you and sign up during the enrollment period to finalize your benefits.

The new prescription drug coverage does not come free of charge to the Medicare recipient. There will be monthly premiums to the organization offering the prescription drug coverage plan which you choose. There will be co-pays on each prescription you fill under the plan, and there will be a deductible. The drug plans should cover about 75% of your first \$2000 cost of prescription drugs during

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OHC web site:

www.ohc.state.ok.us

LOVE CONQUERS ALL (continued)

which looked beyond their disabilities and saw two beautiful little girls who needed the opportunity to be everything they could be.

Lynn was born without disabilities and was progressing through normal developmental milestones until developing autism so severe that she lost some of the skills she had already learned. She could no longer talk. She developed a cognitive disorder. The Child Welfare worker begged Nancy to take Lynn. If she could not find a foster home for Lynn, she would have to look at her going to one of the state schools at Pauls Valley or Enid. Nancy promised to talk to her husband, Jerry, about it and Lynn has been with them ever since. That was nineteen years ago. What would her life have been?

Dawn was the infant abandoned by her parents at the doorsteps of Children's Hospital. What I didn't tell you was that Dawn had been shaken so severely that she suffered a brain injury and subsequent severe mental retardation. She had seven surgeries in six weeks to remove fluid from her brain. They said she wouldn't survive. The doctors didn't know the power of love. They didn't have any idea that there was a family out there who wanted Dawn and who were intent that Dawn was going to have a chance in this life in spite of her disabilities.

I spoke to Nancy Durbin on the telephone to get the story about Lynn and Dawn. I have never met Nancy Durbin in person although I would certainly like to shake her hand. I have met Jerry Durbin at professional conferences and know him as an advocate for children with disabilities. Last quarter we did an article about Nancy Durbin and her efforts to get a golf cart ordinance passed in her city. Her advocacy was successful. Talking to her on the

phone several months ago peaked my interest in her. When I heard that Nancy had two foster children who are now adults and still living with her, I had to inquire further. I quickly saw that the Durbin's were advocates for people with disabilities in much more than getting a golf cart ordinance. They had raised two girls in the local public schools. Both girls had special needs, and there would be many struggles with school administrators on educational priorities.

The Durbin's lived in a town so small that it did not have its own special education program. Instead, it bused the children with special needs to a nearby school system to provide their education. The problem was the bus itself. The bus picked up not only Lynn and Dawn but ten other students with disabilities and transported them over rough, rural roads in hot and cold weather without air conditioning. Some of the students were blind, and there was no aid on the bus to assist with entry and exit. The bus driver had no radio to ask for help in an emergency, and more than once the bus broke down with all the difficulties that you can imagine in that circumstance.

Nancy saw that she had a job to do. She wanted a dependable, safe, air conditioned bus not only for her children but all the children with disabilities in her community. Nancy Durbin was going to talk to the school board about the needs of children with disabilities. She had to do what she could do to let the people who had the authority know about the needs of those whom they served.

One school board meeting was not enough. Nancy came prepared to attend each meeting as long as it took. She made it a point to get on the agenda for the meeting and she learned how to say what she had to say within the three minutes allowed her to speak.

Nancy pointed out that the school system had recently bought a \$95,000 activity bus to drive athletes to out-of-town games. \$25,000 would pur-

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State of Oklahoma

www.ok.gov

MEDICAID REFORM

The latest figures show that about 545,000 Oklahomans receive Medicaid benefits. Medicaid is a broad range of benefits to children and adults many of whom may have a disability. Medicaid funds long-term care for eligible Oklahomans as well as Medicaid waived services which directly benefit people with disabilities. There are a wide variety of eligibility requirements in the various Medicaid programs in Oklahoma but most programs insist that the qualified individual have a low income and limited resources to meet their needs.

The Medicaid program began forty years ago under President Lyndon Johnson. It is a federal program but requires state matching funds. The program has continued to grow in scope over the years. In many states Medicaid is now the single largest item in the state budget surpassing education which has traditionally held that place. A number of different groups are looking at Medicaid right now both nationally and within the state to consider changes in the way we currently operate the program.

In August, 2005 the Bush Administration made its proposals. In the same month the federal Commission to study Medicaid also reported their findings and recommendations. The National Governors Association has addressed the subject in its August 29 report. The Legislative Task Force on Medicaid Reform chaired by Representative Kris Steele of Pottawatomie County is meeting twice per month beginning in August, 2005 through December 7, 2005. Thus Medicaid is under scrutiny both on a federal and a state level.

If you or a member of your family is a beneficiary of some type of Medicaid service, it is worth your time to consider how the program is currently operated and some of the ways that various groups are proposing to change it. It appears to me that cost containment is a primary factor in the attention Medicaid is receiving on the federal and state level. Let's look at a few of the proposals to change Medicaid.

Reduce the price that Medicaid pays for medica-

tions. Setting a cap on what Medicaid will pay for a given medication sounds very reasonable but it could have direct fallout on the consumer who is going to fill that Medicaid prescription. Some pharmacies may not agree with the cap and may choose not to serve Medicaid customers on the particular prescription with which they disagree. They may agree to fill prescription X where they feel they are satisfactorily reimbursed through Medicaid and not fill prescription Y where they feel otherwise.

Currently applicants for Medicaid are asked if they have transferred any of their assets in the last three years. If they have transferred an asset, that asset may be added to their total assets in determining their eligibility for Medicaid. Today Medicaid looks back three years on the transfer of assets. The proposal is to increase that look back period to five years. The effect this would have is to make it more difficult to satisfy the resource eligibility requirements of the Medicaid program.

Another proposed change in the Medicaid program would narrow the definition of a particular service which Medicaid reimburses and thus make it more difficult to meet the criteria for that service. The National Governors Association has recommended states should be given the ability to implement common-sense, enforceable cost-sharing throughout the Medicaid program to increase the responsibility of Medicaid beneficiaries for the cost of their health care. Consumer cost sharing is a disincentive to overuse, but it may also be an impediment to getting the real medical services one needs.

2005 is not the first time that Medicaid has been seriously considered for changes. Neither will it be the last time which policymakers scrutinize the program. Certainly skyrocketing costs of medical services and prescription drugs is a factor in current consideration. You may feel helpless wondering what you can do as an individual in such a thing that has Congressional and Oklahoma Legislative interest.

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MEDICARE PRESCRIPTION DRUG BENEFITS (continued)

a one-year period. If your annual drug bill is more than \$2250, Medicare will pay nothing from \$2250 until your annual bill reaches what is considered "catastrophic" levels at \$5100. At the catastrophic level and above, Medicare will pay about 95% of prescription drug costs.

In his visit to Oklahoma City, Secretary Leavitt said, "In the past we (Medicare) may pay \$100,000 for a heart operation but nothing for the drugs to manage the heart problem. Medicare must concentrate more on prevention." This makes sense both for the citizen and the government. Secretary Leavitt continues, "Ninety-five percent of the \$300 billion spent by Medicare in a given year is spent after a person has had a bad medical problem. We need to get ahead of the problem instead of reacting to a problem already manifest."

According to Secretary Leavitt, costs of Medicare continue to rise. He told the group in Oklahoma City that in the presidency of President Truman in the late 1940's that the United States spent 5.1% of the gross national product on health care. Today we spend 15.5% of our entire economy on health care alone. Making people healthier is a goal of expanding Medicare to include coverage of prescription drugs.

Secretary Leavitt also underscores that he feels the various drug plans offered will create competition in providing prescription medications which will have the long term effect of driving the cost of medications down. Some people criticize the government for not allowing Medicare to negotiate directly with drug companies to lower the cost of medications. The Congressional legislation authorizing the expansion of Medicare to include prescription drugs specifically denies Medicare this power of negotiating directly with the drug manufacturers. Secretary Leavitt reminds us, however, that prescription drug coverage is the biggest expansion of Medicare since the program was born forty years ago. "This drug coverage doesn't cover everything for everybody, but it's a start."

Even if you do not take a lot of prescription drugs now, it's still good to consider joining. As we age, most people need prescription drugs to stay healthy. Enrolling during the enrollment period of November 15, 2005 through May 15, 2006 means you pay a lower monthly premium than if you join after the open enrollment period ends on May 15.

Medicare prescription drug coverage is insurance. Private companies provide the coverage. You choose the drug plan which meets your needs and pay the monthly premium. When you join a plan, Medicare helps pay the bill. As with any insurance program, you have options. In October you will receive information on what your drug plan options are. Although each of these plans will meet Medicare's stringent requirements, they may differ in terms of costs and coverage.

Study each plan offered to see which is best for you. If you need more information about the new Medicare prescription drug benefit, call 800-633-4227 twenty-four hours per day seven days per week. If you have capacity to go online, visit www.medicare.gov. Information is available to answer all your questions. Some people will find the costs of premiums, co-pays, and deductibles in the new prescription drug coverage prohibitive because of low incomes. If you fall among these people, ask how Medicare may assist you in overcoming these barriers.

Secretary Leavitt says there are three good reasons to sign up with a prescription drug benefit plan. "Affording your prescription drugs will allow you to keep your health. It will also save you money, and finally it will give you some peace of mind that you will not have to choose between affording your prescription medications and providing for other necessities."

We can't change the fact that things happen, but we can change how we let them affect us.

ADAPTIVE EQUIPMENT, UNITED CEREBRAL PALSY

Do you need a shower seat at your home while you recover from a hospital stay? What about a manual wheelchair for your family member who was just released from rehab. Do you have insurance to cover the cost of that special piece of adaptive equipment that has been recommended? The latest statistics say that Oklahoma has the third highest rate of uninsured people in the nation. That fact with the high cost of adaptive equipment presents families with some real challenges during an already stressful circumstance.

Adaptive equipment is a wide variety of equipment that helps people with disabilities function more easily. We are all familiar with the wheelchair which allows people with mobility challenges to get from point A to point B. We may have had an older family member who used a walker to allow them to walk more steadily and safely. But what about a prone stander for a child who is not able to support their body weight and needs to be upright part of the day? What about a communication device which allows a person with little or no speech to communicate their basic needs? We may be less familiar with these things although they do the same thing as a wheelchair for a person with a different kind of disability.

Adaptive equipment is a wonderful thing. It restores function to a person who has temporarily or permanently lost it. I continue to be amazed at the equipment which has been manufactured to help people with disabilities. There are devices which flash at the front door when the doorbell is rung for a person who is hearing impaired. Books on tape are an adaptation of printed material which makes the printed word available to people with visual impairments. United Cerebral Palsy maintains a loan closet of adaptive equipment in the Norman office to help people just like you.

Michelle Jackson is in the Norman office of UCP at 1167 E. Main, suite #2 in the Community Building. She tells me that they maintain a loan closet of adaptive equipment to meet the needs of Oklahomans with disabilities. United Cerebral Palsy is a

private, non-profit social service agency which serves people across the state. They have an office in Oklahoma City and Tulsa, but the bulk of their adaptive equipment is in the Norman office.

Of course my first question to Michelle regarding their loaning adaptive equipment is if a person has to have cerebral palsy to check out equipment. The answer to that question is a resounding "no". Then I begin thinking about eligibility requirements the agency has to loan equipment. What do you have to do to check out a piece of equipment. To my surprise, I find out that you just have to identify yourself as a person with a disability. You do not have to have some kind of a doctor's prescription although many people bring their physical therapist or other therapist with them to select the piece of equipment which more nearly meets their needs.

This is not to say that you are going to find exactly what you need in the UCP loan closet. They have about 500 plus items available now not including the many switch toys for children with developmental disabilities, but the number and variety of items varies depending on donations and loans. Equipment can be loaned out across Oklahoma but UCP does not make deliveries except in very unusual circumstances. There is a one-page intake sheet which Michelle says is mostly contact information. There are no hoops to go through establishing some kind of financial eligibility. UCP believes in keeping it simple.

Many people need adaptive equipment only temporarily, but United Cerebral Palsy also loans equipment on the long term. UCP does not recommend equipment to people and does not take responsibility if a person selects something which does not really benefit them. If you are in doubt if a piece of adaptive equipment could benefit you, ask a professional. Occasionally on very popular items such as shower benches, there may be a waiting list.

The agency does not maintain a listing of their equipment which a person can browse through like

(Continued on page 6)

ADAPTIVE EQUIPMENT, UNITED CEREBRALPALSRY (continued)

a shopping list. People need to specifically identify their disability and the particular item which would help them. It is suggested that those interested call United Cerebral Palsy and make an appointment to visit the loan closet. In central Oklahoma they can call 405-701-2095 or 800-827-2289 toll free state-wide.

UCP also gives away some written information which may be of interest. They have a listing of parent and caregiver support groups across Oklahoma. They have information about joining the Oklahoma Parent Network for families of children and adults with disabilities. Ask about written information they may have of interest to you when you visit.

Michelle tells me that they accept donations of useable equipment as well. For donations they provide a non-cash receipt of donation. They do not provide a specific cash value for the donation. Ask your tax preparer how to claim the donation on your tax forms. If you wish to donate a piece of adaptive equipment but do not have a way to get the equipment to Norman, call the office at the number listed above. They may be aware of an individual or agency in your part of the state which could use the equipment. Donated equipment should be in a reasonable state of repair. UCP does

have access to a provider of minor repairs for wheelchairs in Oklahoma City.

Occasionally United Cerebral Palsy will loan equipment to an organization other than an individual. They may loan a wheelchair to a particular nursing home. They may loan a switch toy to a local school. There is no charge to either individuals or organizations. The emphasis is on meeting the adaptive equipment needs of people with disabilities in Oklahoma.

Michelle actually took me back into their loan closet to view the equipment available now. I was surprised to see one power wheelchair available. I was also surprised to see several boxes of adult and children's disposable briefs. There were lots of manual wheelchairs and walkers, but the most unusual item I saw was something called a Roll Aid which Michelle tells me can convert a manual wheelchair to a power wheelchair. There was a pair of lady's diabetic shoes as well as several canisters to hold oxygen. Come by the office to see for yourself or call to ask for the specific item you need. Remember, you may contact the UCP loan closet office in Norman at 405-701-2095 or 800-827-2289 state-wide. What a wonderful resource we have which many people do not know about.



LOVE CONQUERS ALL (continued)

chase the new bus they needed for the children with disabilities. The standard response was that we don't have the money. Nancy then asked the board how they could afford the new ball field lights. They weren't used to dealing with a person who would not accept "no" for an answer. One school board meeting Nancy brought home made cookies and candy to the meeting. It became harder and harder to resist her compelling arguments. The school superintendent said it was time to do something. In the fall of 2001, the school district had a new, air-conditioned bus to transport children with disabilities to the adjoining district.

How was she successful in her advocacy for children with disabilities? Nancy Durbin says, "Once

you start something, you gotta see it through." Nancy kept going to those school board meetings for two and a half years. Sometimes she spoke to the board and sometimes not. Her presence alone spoke a lot. Board members knew who Nancy was and what she wanted. Nancy came home from that last board meeting ecstatic. "We're getting a new bus. We're getting a new bus." Lynn and Dawn didn't fully understand what their foster mother was saying at the time, but later when they began riding in that air conditioned new bus, they knew all over again. Mom loves us, and this is just another way she has of showing it. Love really does conquer all.

MEDICAID REFORM (continued)

First I would suggest that you become aware what services you are currently receiving which are reimbursed through Medicaid. Many people are unaware that the prescriptions which they receive are ultimately paid for by Medicaid. Many people are not aware that the case management services they receive for their child with disabilities are also paid for through Medicaid. Know how the program impacts you personally. This is the first step.

Many of the services funded through the Department of Human Services in Oklahoma are Medicaid services. Talk with your DHS case worker or case worker supervisor about what changes may be coming down the pike. The Oklahoma Health Care Authority is the federally-authorized Medicaid authority in Oklahoma. You may call their customer relations number at 800-522-0310 asking about potential policy changes which may affect you directly in the services you receive. If you are involved with an organization which serves people with disabilities like one of the independent living centers in Oklahoma or perhaps an organization tailored to your specific disability, quiz the director about potential changes to Medicaid. Disability organizations are often more aware of this kind of information than the average consumer of services.

Ultimately the decisions on Medicaid will be political decisions. The U.S. Congress has authority to change the program on a federal level. The Oklahoma Legislature has the authority to change the program on the state level. If you are not yet familiar with your federal and state representatives, you may want to find out who your representatives are from your local County Election Board. Call, email, or set up a face-to-face appointment with your legislator. Always identify yourself as a constituent who lives within their district before you share your concerns.

Medicaid is a big program which impacts hundreds of thousands of Oklahomans. Even small policy changes have the potential to affect your life, especially if you depend totally on those services to meet your needs. Changes in Medicaid are being considered both on the national and the state level now. No one knows how these various proposals from different groups will finally come together in real policies which affect the day-to-day lives of beneficiaries. Now is the best time to find out about the proposals and to tell people in authority how you feel about the issues.

CALENDAR OF EVENTS

- October, 2005** All Medicare recipients will be receiving the pamphlet Medicare & You listing different plans for prescription drug benefits available to you.
- October 24, 2005** There will be a demonstration of new voting equipment for people with disabilities from 1-4:30 pm. at the Oklahoma County Election Board, 4201 N. Lincoln Blvd. in Oklahoma City. (The south entrance is accessible.)
- November 10, 2005** Emergency Summit on Mental Illness, Substance Abuse, and Criminal Justice sponsored by NAMI-Oklahoma. St. Luke's Methodist Church in Oklahoma City. For more information call 405-230-1900.
- December 8, 2005** Oklahoma Turning Point state conference at Metro-Tech Springlake Campus in Oklahoma City. Call Karen at Oklahoma State Department of Health for more information 405-271-6127.

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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