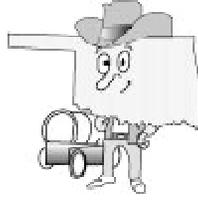


WILL'S CORNER, OKLAHOMA



The Office Of Handicapped Concerns
(The Best Kept Secret In Oklahoma)

Volume 2, Issue 4

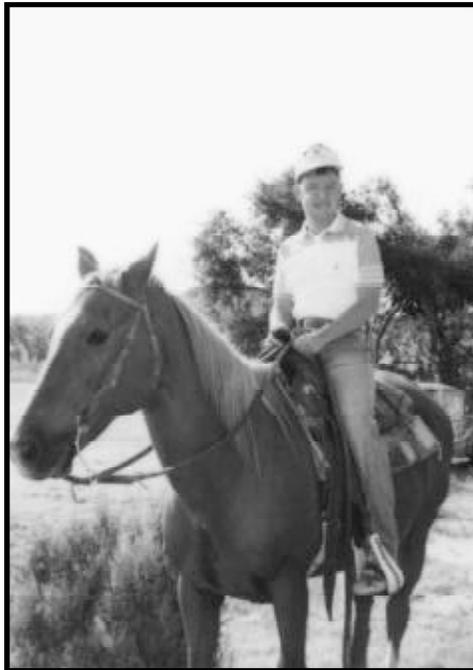
October, 2001

ANOTHER WORLD

There is a place where Kansas and Colorado and New Mexico and Texas all converge in beauty and peace. There is a land of the big sky populated with mule deer, antelope, and even elk. Some say the buttes and mesas hide bear, and the scanty lakes and streams are home to trout. It is a land of independent people who have struggled to live far from the cities and have learned to love this rugged land where the night is broken by the lonesome wail of the coyote. Where is this special place? Where is this other world? Well it's in Oklahoma, of course. You don't believe me? Come on out here and see for yourself. I'm on the Oklahoma Road visiting distant Cimarron County, the farthest western stretch of our own beautiful Panhandle, and I am here to see what services are available to the elderly and disabled in this most untypical Oklahoma land.

When I first arrived at the Hitching Post Bed and Breakfast outside Kenton Oklahoma, Jane Apple gave me a hearty welcome as she showed me around my log cabin near the big ranch house which had been in her family since 1886. Mr. Apple modestly answers my question about the size of this working ranch that it stretches from those buttes

over there on the horizon east half way to Boise City. Out here they talk in sections of land rather than acres. Jane introduces me to her grown son, Lester, who is developmentally disabled. Lester consents to having his picture taken on horseback before he goes to work. Lester is a 21st century cowboy,



LESTER APPLE
ON HIS WAY TO WORK

and he works on the family ranch doing all the things that need to be done on a ranch. He herds cows. He feeds cows. He rescues calves. He participates in branding time which comes

around every year in May. Lester is doing what his father does and what his grandfather did and what his great grandfather Labrier did before them all. It is natural. It fits into the rhythm of life.

Out the other direction in Cimarron County in the flatlands stands Keyes, Oklahoma. Keyes is a sleepy Oklahoma town of 400 souls in the middle of a gardenland of maize, wheat, and irrigated corn. Keyes has a new business in town, the PSA Sporting Good Store in its small business district. That's where I met Eddie Brown—the proud owner who is working hard to get his business started in smalltown Oklahoma. We talk about the Oklahoma Small Business Administration and how Eddie might access funds to expand his business onto the internet. Eddie appears interested and talks about the equipment he would need to receive credit card payments. By the way, Eddie Brown has been in a wheelchair since 1991 when he was in a pickup truck accident which left him paralyzed from the waist down. It was scary to wake up in that ditch with frightened people all around, but there

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is no choice but to accept it. To put it in Eddie's words, "You can whine or you can take your life and make the best you can."

But Eddie was lucky. He had good insurance which paid for a four months' stay at the famous Craig Rehabilitation Hospital in Denver, Colorado. A doctor in Amarillo had bluntly said he would never walk again, but the Craig doctor did not shut the door given the advances of modern medicine and conditions being right. In the meantime, Eddie wheels his chair eight blocks to work everyday, and about the only thing which stops him is snow. But, as Eddie says,

"People know everybody out here. They grew up together. When tragedy strikes, they support each other."

"If it's snowing hard outside, no one's going anywhere in Keyes anyway."

In the process of wheeling around Keyes, Eddie has visited the mayor. Eddie points out that sidewalks in Keyes are buckled and curb cuts are non-existent. Eddie shares with business owners that he cannot get into their place of business to buy the things he wants. One business in town (besides his own) has a bathroom he can get into. One of these days, we're all going to suffer a disability, and then we'll understand what Eddie Brown has been trying to tell us.

Let's look at nearby Boise City, Oklahoma—the county seat of Cimarron County. Boise City has spent some money on new sidewalks and has built a ramp into the county courthouse. In the basement of the courthouse, I visit with Linda Burns, one of the 2.5 workers in the Cimarron County Department of Human Services. Linda Burns has helped me a great deal to get a better picture of social services for the elderly and disabled in this county.

Boise City has a rural hospital with a nursing home actually attached to the hospital. Unfortunately, the only doctor who serves Soonercare Medicaid recipients is 45 miles away. People who have a real need and are unable to travel the long distance will be seen in the emergency room at the Boise City Hospital. Linda outlines for me the same problem we face all over Oklahoma. It is what I call the Social

Security bottleneck. People who have desperate medical needs and do not have private insurance have a long wait before becoming eligible for Medicaid because Medicaid is waiting for Social Security to determine disability. In the meantime the individual may be tied up in lengthy appeals to receive Social Security. This bottleneck can cause real hardship for the medically needy individual who is disabled and uninsured.

Linda explains to me that the churches in Cimarron County have been wonderful to chip in and help the elderly and disabled—even when the individual does not belong to that church. "People know everybody out here. They grew up together. When tragedy strikes, they support each other." I hear this over and over. Families close ranks around their member in need. Friends and community volunteer their help. Do you need a pair of glasses? Linda Burns will find a resource for you somewhere. Some doctor will see you and treat you for the \$50 which the local community action agency can contribute to meet your emergency need. And don't forget the local Salvation Army for emergency assistance.

Sometimes Oklahomans in the larger cities are tempted to feel pride at the facilities and programs at our disposal. Sometimes we look with pity on our rural cousins who have to travel so far to that rehab. hospital or do not have that emergency shelter or have not developed that expensive treatment program. But before you pity the folks in this far western Oklahoma county, you might consider one thing. Tonight I am staying in a small house in Kenton. The owner who lives at another location tells me to go on in whenever I arrive because the doors are always open. When's the last time you left your door unlocked? It's been a long time for me.

Thanks Linda Burns from the Cimarron County DHS who so graciously arranged for me to visit Lester Apple and Eddie Brown. Your concern for individuals with disabilities is apparent. Your hospitality to me was warm and kind.

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

THANKS,

WILL

A TRIBUTE TO A DISABILITY ADVOCATE

THELMA REX

Thelma Rex is a Disability Program Specialist at the Office of Handicapped Concerns where she has worked for twelve years. By the time you read this article, Thelma will have graduated into the wonderful world of retirement where she is looking forward to spending more time with her family. Thelma has worked in the area of disability for over twenty-eight years with special emphasis on deaf education. Because of her long experience in working with disability issues, I began by asking Thelma, "What has changed for the good in the disability arena and where do we still have room for improvement?"

Thelma Rex "The passage of the Americans with Disabilities Act (ADA) July 26, 1990 has made a major change in making services more accessible, making education more accessible, and providing reasonable accommodations for individuals with disabilities who are joining the workforce. People with disabilities have raised their expectations as a result of the law. More of us are advocating for our needs because the force of the law is behind us. On the downside, laws affecting persons with disability are not always being enforced, and things are changing slowly."

"Can you give me an example?"

"When I began working at the Office of Handicapped Concerns fully 65-70% of persons with disabilities were unemployed. This included only those persons who are in the normal employable years from age 16 to 64. Unfortunately, this high percentage of the disabled who are unemployed continues at roughly the same rate today. We still have a long ways to go."

"Do you see other areas that need improvement?"

"Yes, I do. There are still barriers for persons with disabilities getting jobs or getting a good education. In spite of the passage of the IDEA, there is a big gap between what the law says and the real experiences that people have. Physical barriers continue to be everywhere. Interpreters are not always available for persons who are deaf. Public places are not always accessible for persons with mobility impairment. The list goes on and on for each disability. But, in some ways, the attitudinal barriers are even worse. We still see the disability before we see the person. We automatically

think of all the things the person with a disability cannot do rather than focusing on the positive. Yes, there are still areas that need improvement."

"Thelma, I know one good thing that has happened is the passage of House Bill 1340 here in Oklahoma. Would you comment on that?"

"House Bill 1340 passed the Oklahoma legislature in 1987 and became effective in 1988. It provides that individuals with severe disabilities applying for jobs in state government do not have to take the various written tests in order to be eligible for employment in their areas of expertise. In the twelve years I have been with the Office of Handicapped Concerns, between 500 and 600 individuals with severe disabilities have been hired in state government as a result of this bill. This is a definite plus for individuals with disabilities in the employment arena."

"Thelma, I know you have been specializing more in the area of employment for individuals with disabilities since you have worked in this office. I believe you are also the staff liason for the **Governor's Committee on the Employment of People with Disabilities**. Can you tell us a little about that committee?"

The Governor's Committee is a group of people appointed by the Governor of Oklahoma who are concerned with promoting employment for persons with disabilities in our state. It is the state counterpart of what used to be the President's Committee on the Employment of People with Disabilities on the national level. The President's Committee has recently changed its name to the Office of Disability Employment Policy of the U.S. Department of Labor. On the state level, we are still called the Governor's Committee."

"What are some of the things the committee does to promote employment?"

"In the beginning the President's Committee and State Governor's Committee did a lot of disability awareness and sponsored awards ceremonies and journalism contests. In re-



THELMA REX
A DISABILITY ADVOCATE

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HELP IN THE HINTERLANDS

“What kind of self abuse are we talking about here? Yes, and are there no seizure medications prescribed? The family will not allow medical treatment? I have a suggestion for you.” Cindy Eagon was on the phone to a teacher in the public schools when I arrived at the Regional Education Service Center (RESC) in Burns Flat, Oklahoma. So what’s in Burns Flat? Actually, I found out there’s a lot in Burns Flat. Oklahoma has quite a gem in the Regional Education Service Centers located across our state.

Cindy Eagon is a psychometrist/supervisor at the RESC VI in Washita County. She supervises four other employees in a school on the north edge of town and her catchment area includes the counties of Washita, Custer, Roger Mills and Beckham. Cindy shows me around a room filled with assistive technology and

videos dealing with various aspects of disability.

“I like the Alpha Smart Communicator over here. Say for some reason I was a student who could not write. The Alpha Smart has a keyboard like a typewriter, and I can use it to write down class assignments, take notes, or do homework. If a student needed it, we have a way to fasten an appendage to their head or shoulder to permit them to use the keyboard if they do not have use of their arms. It is really quite amazing, and this is a piece of equipment available for loan to either a school or a student who has a need.”

“So, Cindy, you are saying that the adaptive equipment you have on hand can be loaned to individuals for school use as well as school personnel?”

“Yes, we are a resource for families as well if the equipment is to be used in a public education setting.”

“I’m thinking that a lot of people do not know about you or the resources you have.”

“Let me show you a couple other things we have. Here we have a Touch Window which fits over a computer screen like this. It allows the student to touch the screen and pull up the information they want rather than type the information if that student does not know the keyboard. Oh, and over here is our most popular item, the Blackhawk Communicator. This can be used with a child who is non verbal. It’s just a simple laptop board with 16 windows where we can program in certain pictures. If a student

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cent years the President’s Committee has evolved into more active promotion of employment issues. The President’s Committee sponsors the Employment Assistance Referral Network where employers can go to locate applicants with disabilities who are qualified for the job openings they have. There is also the Workforce Recruitment Program where employers recruit college students with disabilities for jobs. Some states have the Business Leadership Network where business leaders network to promote hiring of individuals with disabilities. Some states have the Youth Leadership Forum which sponsors youth with disabilities to attend a career leadership program when they are either high school juniors or seniors. The Oklahoma Governor’s Committee will possibly become more involved in these programs in the future.”

“Thelma, what have you most enjoyed about your job at the Office of Handicapped Concerns?”

“I have enjoyed being in a position to inform people about employment programs and services and see them actu-

ally obtain their vocational goals. That has been a tremendous reward to me.”

“What has most frustrated you about this job?”

“I can see that many people still don’t know about the employment programs that can help them.”

“How can we change that?”

“We need to do more publicity. Lawyers today advertise their services to the general public. Government programs, schools, and employers need to advertise who they are and what they do and actively recruit the people they seek to serve. We cannot just depend on word of mouth to get the message out. This is not enough.”

“What can the person with a disability do to promote their own employability?”

“First, I believe we have to grieve our loss. We have to grieve the loss of physical or mental function. We cannot just deny what has happened. We must accept the reality of what is, and this can

be very hard. When we accept the reality, we are free to go inside ourselves and find the essence that motivated us before our disability. That same power is there now that was there then, only it must take a different course as a result of our disability. Some of the people I talk with share that their disability actually led them in a new direction that is better for them than before. This is amazing.”

“Thelma, as you take a new direction in your life, what final word would you leave for those of us who have come to know you in this capacity?”

“It has been very rewarding to see government and how it works in people’s lives. It has been wonderful to see laws passed and implemented and see the world change for the better because of these laws. To all my friends who I have talked to these many years in my professional capacity, I can only say I’ll miss you all.”

Thelma Rex’s last official day at the Office of Handicapped Concerns was on Friday, September 28 of this year. I think I can speak for us all that we’ll miss you also.

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wanted to communicate their need to use the bathroom, they might point and touch the window which displayed a picture of a commode. These pictures are interchangeable depending on what the student is needing to communicate.”

While Cindy answers the phone, I glance over some of the other equipment in the room. There is a Big Mac Communication Aid, a Big Red Switch toy, Jelly Bean switches, and a Talking Spell Checker. I glance over at some book titles, The Teacher’s Encyclopedia of Behavior Management, A Parent’s Guide to Attention Deficit Disorder, Helping Children at Home and at School. And here are some video titles, The New What To Do When You See a Blind Person, ADA and Public Schools: Access For All, Behavior Management for ADD in the Classroom.

“Cindy, these titles are great. How else can you help me if I am a parent or teacher of a child with disabilities who is attending the public school?”

“We provide one service about which I am very excited. This service is called Project Peak which stands for programing and evaluation for autistic kids. We receive referrals regarding children who are in need of an evaluation for autism. We have teams of persons who respond to these referrals in either the home or school setting. We can test the child for autism and suggest ways for dealing with the autism. We can also be a support to the parent and teachers involved.”

“In what way?”

“I know a case in which a child with autism was repeatedly asking the teacher where her mommy was. It was a very real concern for the child, but it was very disruptive to the class. The teacher was advised to create a figure to represent the mother and some visual symbol of the child’s home and the place where her mother worked. Early each day the teacher learned to move the figure of the mother over to the mother’s workplace image. At first when the child asked about her mommy, the teacher only had to point to the figure of mommy in the workplace. As time went on, the child did not have to ask. In this small way a big problem was solved.”

“Cindy, if parents and teachers just want to learn more about their local RESC, what would you suggest they do?”

“There are twenty-one RESC’s located across Oklahoma and two satellite offices. Ask your principal where the nearest RESC in your area is. Then make an appointment and visit those folks. See what’s available. If you know of a specific piece of equipment or material that you need, I’ll be happy to help you locate it. I can do research in local school districts or I may call the O.U. Health Sciences Center in Oklahoma City to locate equipment for loan. We’re here to serve schools and families with school children.”

“Cindy, I know a lot of parents and teachers have concerns about the IEP (individualized education plan) of students who are in special education of the public schools. Do you have any tips for helping the IEP process?”

“I attend about four IEP’s per week in our four-county area. The IEP is the driving document for services for the child with special needs over a given one-year period. There is a box at the bottom of the first page in our 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. Discuss this in your family. Do you have a concern about your child’s behavior? Do you have a concern about your child’s grades? Do you have a concern about your child’s homework completion? If so, provide this input to the IEP team. Since your concern is actually documented in the form, the Team will

address your concern and attempt to resolve it. Your child may need a behavior management plan. He or she may need some form of adaptive equipment to make them successful. It is important that the Team find out how to deliver a ‘free and appropriate education’ to

your child.”

“You’re touching on one of my favorite issues here, self-advocacy.”

“Come to the IEP meeting with your ideas. Share your concerns in a non-threatening way. If you agree to get assessments on your child’s disability from a doctor or other source, follow through with what you have agreed to do. Written reports from professionals will help the IEP team to devise a plan which will meet your child’s needs.”

“Do you ever provide evaluation for children with disabilities from this office?”

“Of course. We provide evaluations in cognitive/intellectual, academic/achievement, sensorimotor/perceptual as well as developmental which includes gross and fine motor, communication/language as well as social/adaptive behaviors. Our tests do not replace the need for doctors’ reports, nor do we do testing to verify emotional disorders. (The Oklahoma Department of Health does that.) The purpose of our evaluations is for education placement and program development.”

“Thank you, Cindy Eagon, for the information. I appreciate your time.”

The local Regional Education Service Centers provide a resource for parents and teachers of children with disabilities in the public schools. They provide adaptive equipment and other materials for loan. They research ways to meet the needs of children with disabilities. They test children, and they disseminate information to families, schools, and civic organizations. Contact the principal at your local school to find out the address and phone number of the nearest center to you.

THE DOROTHY HAMILTON STORY

Last summer we went on a wonderful journey across the Atlantic to the Emerald Isle and on into Great Britain. We visited the ancient city of Edinburgh, Scotland where the man who was to become King James I of England was born almost 500 years ago. It was in Edinburgh that we met Mrs. Dorothy Hamilton and got an invitation to visit her in her home in the Portobello section on the east side of the city. The double-decker bus pulled over to the curb. We entered a stairway rising some 50 feet between two stone buildings in a commercial district. The stairway led to a residential street paralleling the main road. Mrs. Hamilton lives in a row house sandwiched between similar stone houses about ten feet back from the road with a postage stamp front yard. She wants to talk with you about her disability and how it plays out in a different setting from our own.

(Mrs. Hamilton)

Will told me that he writes for a newsletter on disability in the United States and that he comes from a place called Oklahoma. I do not know about Oklahoma, but I do know that I have relatives living on your side of the Atlantic Ocean. Hello to all of you people in the United States. Thank you for the chance to share my story with you.

I have been in a wheelchair since 1982 when I was injured in a fall at an airport. I was able to walk after the fall, but my pain became worse and worse, and I developed double vision. Eventually I became unconscious, and my son took me to the hospital where I went into intensive care. They did a scan of my brain, but nothing showed up. They decided to take me down to London where a cat scan showed that my brainstem had been pushed down into the spinal column. The surgeon in London said they could do an operation with a 50/50 chance of survival. I decided to have the operation.

We have socialized medicine here, and I was lucky to be able to get the operation fairly quickly. During the operation, they shaved away part of the bone in the spinal column. Afterwards I had three months of rehabilitation in a London hospital. When they got ready to transport me back to Edinburgh, I could not get into a carriage car on the train.

They actually had to put me into a boxcar which was unheated for the eight-hour trip back north. I went back into a hospital up here because hospital stays were free. (We do not do rehabilitation stays in nursing homes here because nursing homes cost). There were a few people in every hospital ward who had permanent injuries.

When I was in the hospital I had nothing to do. I remember counting the panes in the window and trying to remember all the people in my graduating class of 1949. When I finally got to come home some nine months later, I was in a wheelchair permanently. I needed 24-hour assistance, and this was difficult to find. Dr. Childs, who was my wonderful doctor here, knew of a family in Sweden who had seven boys. One of the boys who was 17 at the time came to live with me for three months. I had to pay this young man privately. Later he went to medical school to become a doctor and counted his experience working with me towards his school practical. After he left, I was able to get two people to work with me. One stayed here during part of the week and the other completed the week.



In the early 80's I received Social Security as a disabled woman. Today (2001) this amounts to \$100 per week of your money with a mobility allowance of \$40 per week and a personal care allowance of \$55. When I first came home I could not dress myself nor wash myself. It took me nearly five years to work up to where I could dress myself. Today I buy every-

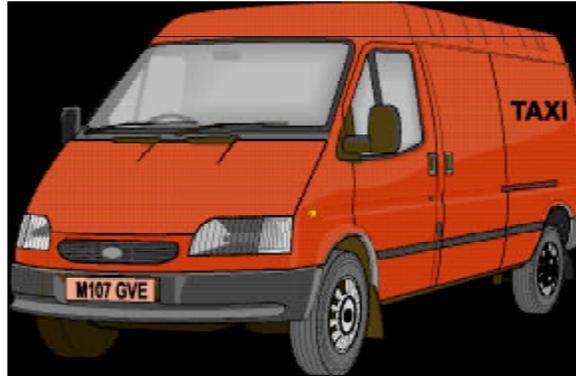
thing one size too big and without buttons so that I can be more independent. I actually dress/undress myself in bed.

I have arranged my house so I can function in it. I had a bathroom put into a utility room downstairs. I converted the parlor downstairs into my bedroom, and I rent out my upstairs to students. My kitchen/dining room is accessible to me as well. I have something I wear around my neck which I can press if I get into trouble. Someone will come immediately. The government provides a service on my telephone where I can speak to someone over the phone without picking up the receiver.

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Transportation is another matter. We have what we call handi-cabs which can accommodate my wheelchair. I go to the supermarket and to two shopping malls. The supermarket does have shopping carts which fasten to my wheelchair. The grocery store packs my groceries, and the driver actually comes into the store and carries the groceries out to the handi-cab. He also takes the groceries into my house at the end of the trip. It takes about 15 minutes to get to the store, and the roundtrip costs a little less than \$6.00 in your money. I have to book my trip in the handi-cab a week in advance because there are only five vans in all of Edinburgh which is a city of about 500,000 people.

Getting in and out of my home can be difficult. I have a portable ramp which is stored in the back which has to be taken to the front door for me to exit. We have curb cuts in newer areas of Edinburgh, but accessibility is a major problem in older areas. Big hotels and new hotels now are required to have a certain number of rooms for people with disabilities. Today I have home health workers who do everything for me that I cannot do for myself. They come every weekday for two hours plus one hour on Saturday and the same on Sunday. My doctor writes a prescription for this home health. My direct care workers are paid about \$7.50 per hour American money.



I can go to the cinema where they have special places for persons in wheelchairs and their attendants to sit. The elderly and disabled pay a special rate at the cinema. I get a meal delivered to my home mid-day. My attendant makes breakfast and makes a sandwich for me for my evening meal. My property tax for this 1000 square foot flat amounts to about \$1900 per year in your money, but the government pays part of this tax for me for disability relief. That's about it for my life. I have one son who lives in England with his wife and son. I do not get to see him real often, but we phone a lot. I have a young woman living with me now from Canada who is working here in Edinburgh. She helps a lot too. I am hoping to visit Canada again next year. I like to visit there because it is so much easier to get around.

It is late in the evening, and the streetlights are all shining as I descend the steep stairs to street level to catch the bus back to the city center. Dorothy Hamilton waves good-bye into the darkness as I depart with a wave of sadness thinking how she has shared so freely of her life and that I may not see her again. Dorothy, a warm hello from Oklahoma and your children who live on this side of the great ocean of life.

THE OFFICE OF HANDICAPPED CONCERNS IS CONDUCTING A STATEWIDE DISABILITY NEEDS ASSESSMENT STUDY TO HELP STATE AND LOCAL AGENCIES DESIGN POLICIES AND PROGRAMS WHICH WILL EFFECTIVELY MEET THE NEEDS OF INDIVIDUALS WITH DISABILITIES IN THIS NEW MILLENNIUM. THE STUDY IS THREE PRONGED SOLICITING INFORMATION FROM INDIVIDUALS WITH DISABILITIES, FAMILIES OF INDIVIDUALS WITH DISABILITIES, AND ORGANIZATIONS SERVING INDIVIDUALS WITH DISABILITIES. IF YOU FALL INTO ONE OF THESE CATEGORIES AND WOULD LIKE TO PARTICIPATE, CONTACT EITHER THE OFFICE OF HANDICAPPED CONCERNS AT 1-800-522-8224 OR DR. ESTHER WILDER AT 405-325-2820 AT THE UNIVERSITY OF OKLAHOMA SCHOOL OF SOCIAL WORK AND WE WILL MAIL YOU THE APPROPRIATE SURVEY.

MARK YOUR CALENDAR

- October 19&20, 2001** Family Perspective Conference, for families of people with special needs, individuals, and professionals, Clarion Convention Center Oklahoma City, Registration \$35, call 1-800-426-2747 for more information.
- October 23, 2001** Mayor's Conference on Disability Concerns sixth annual statewide conference "Banning Barriers", Myriad Convention Center Oklahoma City, for more information call (405) 550-5464.
- November 27&28** 16th Annual Autism Symposium, Ramada Inn 4345 N. Lincoln Oklahoma City, For more information call 405-348-1360.
- December 1, 2001** World AIDS Day, candlelight memorial service, call 405-947-3434 for more information.
- December 4, 2001** Assistive Technology Equipment Exposition at Fulton Teaching and Learning Academy in Tulsa, \$10 registration, call 1-800-700-6282 for information.
- December 5, 2001** Assistive Technology Equipment Exposition at Canadian Valley Technology Center, El Reno. \$10 registration, call 1-800-700-6282.

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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