

OFFICE OF HANDICAPPED CONCERNS

WILL'S CORNER, OKLAHOMA



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(Serving the Disability Community of Oklahoma)

INSIDE THE DISABILITY DETERMINATION DIVISION

It is a gray day in central Oklahoma when I pull up into the parking lot of a large building just off the highway. There are no signs indicating what kind of activity goes on inside. There is little public parking in front of the building although I see a long driveway on the south side of the building which leads to extensive employee parking in the rear. I open the front doors and see a security guard sitting behind a glass at reception. He asks me to sign my name, the time I entered the building, and the person with whom I have an appointment. He gives me a badge number and asks me to wait.

I have an appointment with Noel Tyler who is the division administrator of the Disability Determination Division of the Oklahoma Department of Rehabilitation Services. What a mouthful. Let me explain. It is the Disability Determination Division which actually processes your claims for Social Security disability to the tune of 54,000 claims last year in the state of Oklahoma alone. You may not have known that. Here she comes now—Noel Tyler.

Noel Tyler

“Will, the Disability Determination Division is not a big mystery. We want the public to know that Social Security contracts with us to determine the medical eligibility of people who have applied to them for Social Security benefits. We welcome public knowledge of who we are and what we do. We need the assistance of the public in getting all the information on their application for Social Security so we can process that application speedily and accurately to get those who are qualified approved.”

Will

“You know I hear all the horror stories from people who are waiting what seems like forever to get approved. Many people are discouraged.”

(Continued on page 6)

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THE CHALLENGE OF AUTISM

Autism has a human face. She may be the young girl in your neighborhood who always plays alone. He may be a boy who continually repeats “take out trash” disconnectedly with what’s going on around him. You have about a 1 in 166 chance of having a child who has an autism spectrum disorder. Autism presents with varying degrees of severity causing difficulty with social interaction, repetitive behavior, difficulty with communication, and sensory processing difficulties (more sensitive to touch, sound, pain or less sensitive to these stimuli). The child with an autism spectrum disorder seems to live in another world—a world far away from peers, teachers, and parents. But we cannot and must not be content to allow these two worlds to exist unrelated to each other. We must build a bridge for the child with autism to the world we live in so that child can function in our world. To gather information for this article, I have spoken with Kathy Rand who is the president of the Autism Society of Central Oklahoma and holds a Ph.D. in biological sciences. Kathy is also the parent of two children with Asperger’s Syndrome (a milder form of autism).

A child with autism may have difficulty understanding the behavior of his or her teacher. For example, the teacher explains that it is time to stop the reading activity and proceed to another activity in the school day. The child with mild autism who is able to read hears the teacher say that he or she is not able to read, and this frustration provokes an intense reaction of emotion. A problem can arise that easily.

In this case, the parent helped that child calm down

by carefully writing down an explanation with the child of what had happened and helping the child understand on a level other than the literal. The parent tries to find out how the child is thinking. In order to learn a skill, it may be necessary to break it down into smaller steps.

Schools can be a challenge too. According to law some professional on the IEP Team (Individualized Education Plan) must have training on the disability category which the child has. The Oklahoma State Department of Education can provide training on autism, but many times the training an individual educator has may be minimal. You have to ask the Team for what you think your child will need in school. If you do not ask, it may not be offered. We are not where we need to be yet in education for a child with an autism spectrum disorder.

The Oklahoma State Department of Education does some oversight in the schools for children with disabilities. A parent of a child with disabilities could advocate that the Department of Education provide guidelines for an appropriate education for children with autism or any other disability. Schools could provide one-on-one assistants for children with autism to provide the social coaching these children need to learn effectively. We fall short of these goals now, and we let the cost drive our programs more than we let the needs of the children drive our programs.

It is important to learn as much as possible about autism spectrum disorders in order to learn how to approach a child who presents with this way of processing. It appears that a child with autism or one of its many degrees has a difference in the wiring of the brain. Circuits were not there or were there in a weak form to facilitate appropriate interaction with others. There is clinical evidence that intensive, early intervention with a child with autism can make a big difference in this child’s future.

The simple connection with a cushion on a divan

(Continued on page 5)

State of Oklahoma

www.ok.gov

RX FOR OKLAHOMA

Way back in October, 2004 we talked to you about the Prescription Assistance Program through the retired senior volunteers in Norman. In that issue of *Will's Corner* we told you about this new program in Norman which worked with the drug manufacturing companies to get free or discounted medications for Oklahomans who could not afford to pay for their prescriptions. Julie Lovegrove and the volunteers who worked in her office received the simple two-page application of consumer demographic information which they merged onto the application of the various drug manufacturers. Your doctor verified which medications you were on and sometimes your medication was sent to your doctor for you to pick up and sometimes the medication was sent directly to your home.

The Prescription Assistance Program in Norman asks that consumers have an income of less than 200% of poverty for the county in which they reside. Prescription Assistance particularly helped the working poor who did not have coverage through any other state or federal program such as Medicaid or Medicare. People who were working but did not qualify for Medicaid and had no health insurance with their employer typically fall into the group which would be helped significantly through Julie Lovegrove's program.

Considering that Oklahoma has the third highest percentage of citizens with no health insurance in the country, Prescription Assistance is a wonderful program to come to our state. It is legal. It operates with the full cooperation of the drug manufacturing companies, and it is filling a very real need of Oklahomans. The Oklahoma Legislature was so impressed with these facts that in May of 2005 they passed House Bill 1853 which expanded the Prescription Assistance Program statewide. I decided to go back to Julie Lovegrove in her Norman offices to see what the Prescription Assistance Program looks like now—a year and a half later. Boy was I in in for a surprise!

In October of 2004 we told you that the Prescription Assistance Program had helped five hundred

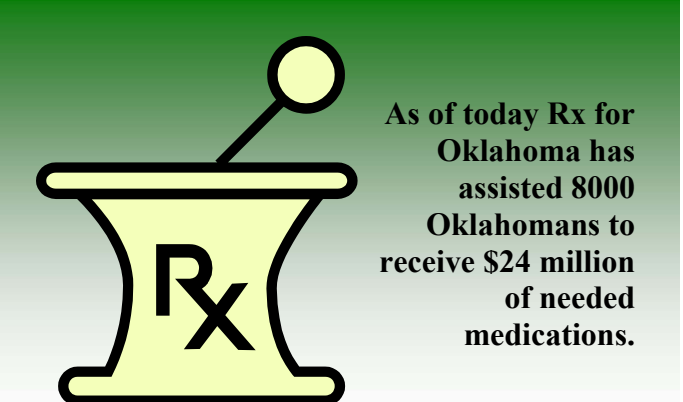
plus Oklahomans receive over \$3 million worth of medications. As of today those five hundred Oklahomans assisted through the program has exploded into eight thousand people statewide getting over \$24 million worth of needed medications. It seems like the program has been quite successful.

Way back in 2004 the program operated only in Norman and served mostly people who lived in Cleveland and McLain Counties. Julie Lovegrove hands me the current list of 31 partnering agencies who operate from Tahlequah to Altus and from Beaver to Durant and all points in between. Prescription Assistance has obviously taken off in the Sooner state.

In December of 2005 Rx for Oklahoma (the new name for the Prescription Assistance Program) received a contract with the Oklahoma Department of Commerce to assist Oklahomans who did not qualify for other prescription assistance programs like Medicaid and Medicare to receive free or discounted medications.

Julie Lovegrove who is the Director of Rx for Oklahoma tells me about the man who had a daughter with an abnormal growth problem. Reportedly this man did have health insurance on his daughter, but just the co-pay for this particular new medication was \$1100 per month. His daughter now receives this needed medication free from the manufacturer through Rx for Oklahoma. That is one story of thousands in our state who had de-

(Continued on page 5)



As of today Rx for Oklahoma has assisted 8000 Oklahomans to receive \$24 million of needed medications.

FOLLOW YOUR DREAMS

It is easy for people to conceive their dreams and live forever in the fantasyland of their own making. At one time or another we have all won the lottery, proudly collected our million dollar check at a big photo op event, and spent the grand prize on the projects of our choice. What is not nearly so common is to do the hard work necessary to realize those same dreams. This work may last over a period of years and may involve lots of other people buying into that dream. Yes, the real dream is the one which makes it out of the womb of our endless imaginations and actually comes to birth in this terra firma earth of ours. The real dream becomes bigger than we ever hoped for and touches the lives of other people we never knew. Come with me into the passageways of my mind and look through the windows into my soul.

I see a woman with a dream that all children should have the opportunity to play together in unity and harmony—regardless of ability. I see a woman with a vision of what the future could be if we were only willing to share our time, talent, and treasure in a single-minded focus of human efforts. She leads us gently into that which could be if only we worked together for that dream which she had conceived and nurtured so lovingly.

Barbara Schaefer is a pre-school teacher for children with developmental delays. She had seen the children of her classroom wheeled up to the playground and sit forlornly as their able-bodied peers frolicked in the sheer ecstasy of being a child in the just-forming springtime of life. These were children who were so young and yet had experienced the disappointment that only those of us who have lived much longer would typically know. These were children who never really had a chance in this cruel world where fate wills some to struggle torturously without reward while others prepare in childhood for the glorious future they will know.

Barbara wanted to even the playing field if you do not mind that too often-used metaphor which we hear so frequently in the disability community. And—even the playing field is what she did liter-

ally as the county hauled in dump truck load after load of dirt to prepare the site for what would one day be referred to as *the dreamcatcher playground*.

The headlines read *State-of-the-art playground to be EastOC attraction*. A county commissioner inspired the Oklahoma Legislature to push through a bill allowing county employees and equipment to be used to prepare the site on school property. And then there were the endless fund raisers—four annual spring carnivals with more to follow, the silent auctions where the little old grandmother donated the hand-made afghan and enthusiastically promises to make another for next year. One dollar at a time this half million dollar project is coming to life with community buy in over the long haul.

Phase one was welcomed into our world a year and a half ago with a play pod fully accessible from level ramp extending over the fun zone. Phase two will begin next fall completing a play pod for younger children ages two to five, a swing area with full-body swings allowing children to play who do not have upper trunk control, and an outdoor basketball court. Children with disabilities will be able to participate with their peers in structured play activities. They will no longer have to play vicariously through others but will instead be able to join in the fun. They will be included. Through this specially-designed play equipment, they claim their rightful place under the sun and prepare for their own glorious future just like all of us have done before.

The Dreamcatcher Playground has galvanized the support of a community which stands in solidarity with all its citizens regardless of ability. Many local politicians have written their special letters of support for the project, but perhaps the most inspiring comes from the young mother of a child with disabilities who applauds this equipment “designed to make childhood dreams come true for every child.” All children being able to play together on the same equipment is a gift for the entire family.

(Continued on page 7)

RX FOR OKLAHOMA (continued)

spaired of being able to afford the medications they and their families needed.

A woman with cancer and a poor prognosis was not able to afford her pain medication nor the medication used in her chemo treatments. Through Rx for Oklahoma this woman now receives this much-needed medication and is at least freed from the impossible financial burden while she deals with the reality of living with a terminal disease. The stories like this are repeated over and over again across Oklahoma. People have been forced in many instances to choose between paying for their prescription drugs or eating. Julie tells me about the other people who are cutting their pills in half because they cannot afford to pay for a new prescription every month.

Hope is here. Oklahomans are getting the medications they need and beating the high costs involved. I don't want to tell you that everything is perfect. It is possible that even with liberal qualifying requirements you might not be eligible for this program. It is true that a new application will need to be completed every year for those eligible. It is even possible that the program's funding could be cancelled because the money to operate it must be re-allocated every year by the Oklahoma Legislature. Even realizing all this, check into the benefits for you.

Rx for Oklahoma operates in 31 offices across the state—mostly in local community action agencies or the area agencies on aging. Call toll-free 877-794-6552 for contact information on the office nearest you. Ask for an application and how you may access the help you need in affording your medications. I think you'll find people working in this program who sincerely want to help their fellow citizens. It may be a very detailed and time-consuming job, but it offers deep satisfaction in assisting people who have real needs to afford the medications they so desperately need.

THE CHALLENGE OF AUTISM (continued)

with the green color of that cushion may be very difficult in the brain of a child with autism. It takes effort to connect these things together which other people take for granted. The person with autism may have an intensive focus on what he or she finds interesting and any interruption or change in that focus from outside is looked upon with fear.

Family, friend, and professionals have tried to get an understanding of what causes autism. They have studied about 30 genes relating to autism, but so far they have found no single gene to be the cause. Real numbers of kids with autism seem to be growing, but this may be only because we are doing a better job of diagnosing now than in the past. Autism has probably been around a long time.

Some people are saying that autism may be triggered by things in our environment. For years thimerosal was used in children's vaccinations as a preservative. One of the ingredients in thimerosal was mercury which has been suggested as a cause of autism. However, most children have received the typical childhood vaccinations, but only a small percentage develops some form of autism.

Children with autism can overcome its debilitating effects. Temple Grandin is a good example of this. She was the keynote speaker for the recent Governor's Conference on Developmental Disabilities. Temple Grandin had severe autism as a child and has become an associate professor at Colorado

(Continued on page 7)

The man who rows the boat seldom has time to rock it.

Bill Copeland



INSIDE THE DISABILITY DETERMINATION DIVISION (continued)

Noel Tyler

“Actually, we are doing some things right now to speed up the process of disability determination. Do you have a minute to let me explain it to you?”

Will

“Of course.”

Noel Tyler

We have recently begun to shift our processing of information from paper cases to electronic cases on the computer. Oklahoma is the second state in the nation to enter into this non-paper process, and this will speed up disability determination of your case. We have as our goal to process any case within ninety days after it comes into this office from the Social Security Administration. Remember that your application is turned into the local Social Security office and only then sent to the Disability Determination Division.

You can actually apply for Social Security online and submit your application by hitting the send button. Go to www.socialsecurity.gov. If you prefer to complete your application in paper, we have the capacity to scan your application into our computers. The electronic application is easier because if you do not provide the information that a particular box requires, the computer program will not let you go further signaling that you need to get that information. If all the information is on the application in the form we need, it naturally speeds up the process. We don't have to go back to you over and over again for more information.

It is important that in your application and in the information that your doctor attaches that you let the disability examiner who processes your information know your level of functioning and how that functioning may be impaired by your disability. Let me give you an example. One woman wrote that she had poor bladder control without further explanation. On further questioning, she shared that she had to use the bathroom every fifteen minutes. If I say I have poor bladder control, that could mean anything, but if I say I have to use

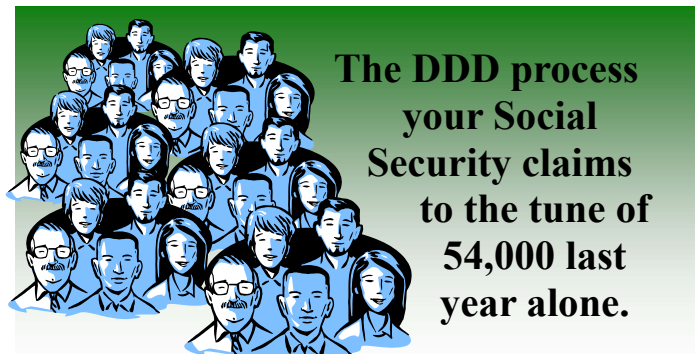
the bathroom every fifteen minutes we all get a very objective understanding of my level of functioning. How does my impairment affect my level of functioning? The disability examiner has no knowledge of you other than what you and your doctor supply.

When the disability examiner receives your information and your level of functioning, they'll make a decision about if you are able to work or not. If the examiner determines that you are not able to work in any capacity, you may be approved for Social Security benefits. The Disability Determination Division of the Oklahoma Department of Rehabilitation Services approves Social Security payments which bring \$1 billion worth of benefits to Oklahomans with disabilities.

Nationally about 37% of applications for Social Security disability benefits are approved after the first application. In Oklahoma, 36.1% of applications are approved on first application. If you receive a denial letter, be sure to read the whole letter to determine what your next step will be. You may choose to appeal your denial of Social Security disability benefits, and your denial letter will tell you how to do this. This office only determines medical eligibility in the application process.

If you have a question about your case which is in process of determination in our office, you may call [405-419-2200](tel:405-419-2200) in central Oklahoma or [800-877-9977](tel:800-877-9977) statewide. Identify yourself, and you will be forwarded to the disability examiner who is processing your case. If your case has already been de-

(Continued on page 7)



FOLLOW YOUR DREAMS (continued)

Certainly inclusion is the catchword for this special place. It is a place for all children—not just those who attend school here. It is a place for those young men to come after work for a quick game of basketball before supper. It is a place for families to have a picnic as the shadows grow longer on a warm summer evening. It is magic—this thing they call The Dreamcatcher Playground. “But Mommy I’ll never be able to slide down the slide like all the other kids.” “Oh yes you can. Because of one woman’s dream you most certainly can.”

Barbara Schaefer is a teacher for children with developmental delays at Choctaw Elementary School in eastern Oklahoma County. I can only imagine how thrilled she would be if you contacted her about how to build a similar accessible project in your community. During school hours Barbara can be reached at 405-390-2225. You too can *follow your dreams*.

INSIDE THE DISABILITY DETERMINATION DIVISION (continued)

nied, it is not productive to call the Disability Determination Division. Follow the appeals process outlined on your denial letter.”

Remember that you apply for Social Security disability benefits either online at www.socialsecurity.gov, by calling the national toll-free number for Social Security (800-772-1213), or by calling or visiting your local Social Security office. Oklahoma has twenty-two Social Security offices in Ada, Ardmore, Bartlesville, Chickasha, Clinton, Duncan, Durant, Enid, Hugo, Lawton, McAlester, Miami, Moore, Muskogee, Oklahoma City, Okmulgee, Ponca City, Poteau, Shawnee, Stillwater, Tulsa and Woodward. When Social Security collects your information, they then send that information to the Disability Determination Division to determine medical eligibility. You may ask questions about your active Social Security case in process of determination by calling the numbers in the preceding paragraph. If a determination has already been made, follow the appeals process.

One dollar at a time this half million dollar project is coming to life.



THE CHALLENGE OF AUTISM (continued)

State University with several books to her credit as an author. She tells the story of how she learns as a person with autism and how that differs from how someone learns who does not experience this condition.

Intense and early intervention is the best tool in addressing the effects of autism. When very young children are evaluated with autistic symptoms and receive intense, one-on-one work for a period of years, these same children become indistinguishable from others. Yes, this costs human effort and resources, but think of the loss to society of a child with autism left untreated or poorly treated. Think of the lost productivity. Think of the social cost to this child who becomes an adult and lives a lifetime without being able to really communicate his or her needs.

Kathy Rand may be contacted at Kathy-Rand@swbell.net. The Autism Society of Central Oklahoma may be contacted at 405-370-3220. April has been declared Autism Awareness Month.

CALENDAR OF EVENTS

April 28, 2006

Your Medicare Part D prescription drug benefit questions will be answered at the Norman Public Library, 225 North Webster from 10 a.m.-2 p.m. A similar event will be held at the Tulsa Technology Center, 3638 S. Memorial Drive in Tulsa from 1-5 p.m.

May 2-4, 2006

Oklahoma Disability Caucus at the Embassy Suites, Oklahoma City Airport. For more information call 888-325-2409 or 405-325-4913.

May 6, 2006

The National Association for the Mentally Ill of Oklahoma is sponsoring a Walk for the Mind of America at Lake Hefner in Oklahoma City. For more information contact Andrea Volk at 800-583-1264 or 405-230-1900 locally.

June 22-23, 2006

The National Association for the Mentally Ill of Oklahoma is sponsoring the NAMI Oklahoma annual conference at the Southern Hills Marriot Hotel in Tulsa. For more information contact Teresa Peden at 800-583-1264.

Summer Camps: See 2006 calendar for Make Promises Happen Camps for people with disabilities at www.centralchristiancamp.org. Get national information on camps for kids with special needs at <http://camping.about.com/library/weekly/aa00204d.htm>

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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