

We the People

LEARNING AND EXERCISING OUR HUMAN RIGHTS

JANUARY 2010, PUBLISHED BIMONTHLY BY

TOPEKA INDEPENDENT LIVING RESOURCE CENTER

Budget woes mean tough days ahead for Kansans with disabilities

The current economic recession has led to major cuts in the state's budget. As we enter an unprecedented fourth year of declining state revenues the future is looking bleak! In November, Governor Parkinson announced the latest in five rounds of budget cuts so far this year which total nearly a billion dollars. Even with these painful cuts, Kansas is already facing a 400 million dollar deficit in the 2011 budget, which means that unless the state legislature comes up with additional revenue more cuts are almost inevitable.

The latest round of cuts included a 10% reduction in Medicaid reimbursement rates, which will affect doctors, hospitals, nursing facilities, and sadly the state's Home and Community Based Waiver Services (HCBS) Programs.

The MediKan and General Assistance programs, which provide benefits for people who are waiting to be approved for federal disability benefits, will be reduced from the current 18 months to 12 months. The average waiting period for federal benefits is about two years, leaving these people without any financial assistance for a full year or more.



We the People

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We the People is produced in the offices of Topeka Independent Living Resource Center (TILRC). Articles, letters to the Editor, consumer compositions, displays and classified ads are encouraged. Please contact Kevin Siek for deadlines for submission of materials. The Editor reserves the right to edit or omit any material that is submitted. Opinions expressed in "Letters to the Editor" are not necessarily those of TILRC.

Placing an ad in *We the People* is a good way to target the marketing of a product or service to people in the disability community, especially in the Topeka and Shawnee County area. For more information, contact Jamie.

TILRC receives funding from Kansas Rehabilitation Services, Rehabilitation Services Administration, US Department of Education and from contracts and fees for services. Private donations are welcomed. Topeka Independent Living Resource Center, Inc. is an Equal Opportunity Employer and Service Provider.

Board Meetings: TILRC's Board of Directors meets on the third Thursday of the month, except in December. The meetings are open to the public. If you would like to attend, please contact Jeannine at (785) 233-4572. If you are interested in becoming a TILRC Board member contact Jeannine for an application.

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The additional cuts to grants to community mental health centers will make it even more difficult to serve people who don't have health insurance. This will include many of the people who will be losing or have already lost their MediKan/General Assistance coverage.

With the almost certain need for additional cuts in the near future the Department of Social and Rehabilitation Services (SRS) has reinstated the "hard freeze" on the HCBS waiting lists, which means no new consumers will be able to get on the Physical Disability or Developmental Disability waivers. SRS is further cutting costs with additional limits to or elimination of HCBS services, including limiting plans of care to only 10 hours of attendant care a day, eliminating dental coverage and limiting assisted services requests to "crisis only" situations.

The Department on Aging made further rate reductions to service providers for programs like Meals on Wheels, but any additional cuts could lead to a waiting list on the Frail Elderly HCBS Waiver.

SRS & Aging have tried to minimize the effects of budget cuts on the HCBS programs, but they are forced to operate within the budgets that are set by the state legislature.

Throughout this budget crisis, TILRC has been advocating for adequate funding for programs to help people with disabilities get the long-term services and supports they need in their own homes and for decent wages and benefits for attendant care workers. We believe Kansans with disabilities deserve the right to choose where they live and receive services. In addition, it makes economic sense to have a system that supports more cost-effective HCBS programs instead of forcing people into more costly institutions.

We will continue to advocate for a state budget that provides for the needs of Kansans with disabilities that depend on Medicaid programs. You can join fight to fully fund our HCBS programs and for fair wages and benefits for attendant care worker by becoming part of the Consumer Attendant Action Network (CAAN). People who are interested in getting involved with CAAN can contact Jeannine at 233.4572.

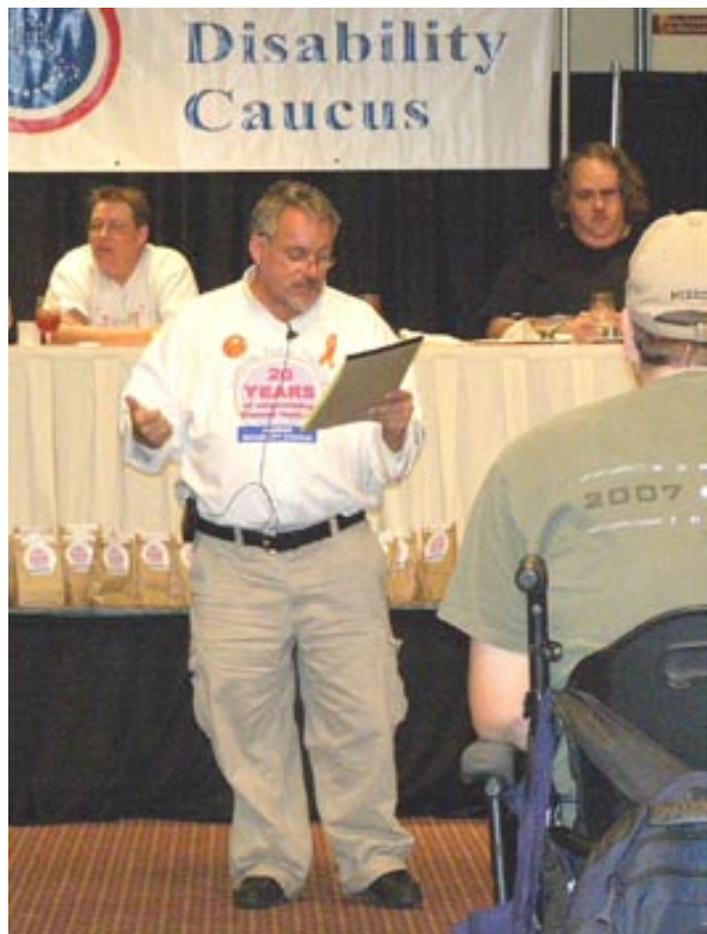


11TH KANSAS DISABILITY CAUCUS CELEBRATES 20 YEARS OF EMPOWERING KANSAS WITH DISABILITIES

The 2009 Kansas Disability Caucus was held August 12th through 14th at the Capitol Plaza Hotel and Convention Center in Topeka, Kansas. In 1988, Michael Lechner, who at the time was Executive Director of the Kansas Advisory Committee on Employment of the Handicapped (now the Kansas Commission on Disability Concerns), conceived the idea of a state-wide forum where Kansans with disabilities could come together to discuss issues of importance to the disability community and formulate an agenda to address them. Working with the Kansas Association of Center for Independent Living (KACIL) and other advocates, this idea blossomed into the first Kansas Disability Caucus.

The first Caucus was held in Salina and was attended by less than 100 people from across the state. This relatively small group planted the seed that led to passage of House Bill 2012, which created the first self-directed attendant care program in Kansas. That began a tradition of the Kansas Disability Caucus, which meets every two years to coincide with the two year cycle of the Kansas Legislature. Over the years, as the Caucus grew sponsorship for the event was passed on to the Statewide Independent Living Council of Kansas (SILCK). The Caucus helps focus the advocacy efforts of Kansans with disabilities on numerous issues of importance. In the past the Caucus' has taken on rallying support for passage of the Americans with Disabilities Act and working to create the "Working Healthy" Program, a Medicaid buy-in program that lets people with disabilities work while retaining their medical coverage and attendant services through Medicaid. This year's Caucus was the biggest ever with over 600 people attending.

The theme of this year's Caucus was "Yes We Can ... Work!" In keeping with that theme many of the breakout sessions centered on work related topics, like the value of peer support for people with disabilities seeking to enter the workforce, and an informational session on the Working Healthy/WORK Program. Andy Imparato, President of the



Bruce Darling talks about CCA.

American Association of People with Disabilities, was the keynote speaker. Imparato referred to Kansas as the “Mecca” for disability rights advocacy, but reminded those in attendance that we still have far to travel on the road to equality and justice for people with disabilities. Another nationally recognized disability rights leader, Bruce Darling, Director of the Center for Disability Rights in Rochester, New York and a national organizer for ADAPT, fired up the crowd when he spoke about the need to end the institutional bias in our nation’s system of long-term services and support and encourage everyone to redouble their efforts to get the Community Choice Act passed during the current administration. The Community Choice Act is national legislation that would require state to give people on Medicaid the choice to get their long-term services and supports in their own homes instead of being forced into institutions.

The core of the Caucus is always the Caucus Sessions where people are divided into three separate geographic regions of the state to discuss and prioritize issues of concern. The priorities identified during the Caucus Session are used by SILCK and other organizations to help set their legislative advocacy agendas for the next session of the Kansas Legislature. Issues of concern that were identified by the groups were:

- ❑ a lack of affordable accessible transportation across the state,
- ❑ high unemployment and limited training opportunities for disabled job seekers,
- ❑ a lack of accessibility in healthcare facilities and a lack sensitivity to the needs of people with chronic health conditions by healthcare professionals and,
- ❑ the need to end the institutional bias in long-term care, in particular the need to eliminate waiting lists for home and community based services waiver programs.

The Caucus ended with a spirited presentation by motivational speaker Christine Pechstein who exhorted the crowd to carry on their grassroots advocacy efforts as they returned to their home communities.



The Kansas Low Income Energy Assistance Program (LIEAP)

LIEAP provides an annual benefit to help qualifying households pay winter heating bills. To qualify, applicants must be responsible for direct payment of their heating bills. Income eligibility

guidelines are set at 130 percent of the federal poverty level. The application period is January 19, 2010 to March 31, 2010.

For more information call 1-800-432-0043 or go to: <http://www.usa800.net/LIEAPortal/Home.aspx>.

YOUTH BECOME ADVOCATES, GAIN WORK EXPERIENCE THROUGH THE GEORGE WOLF YOUTH INTERNSHIP PROGRAM

Every summer, TILRC offers local middle and high school student the opportunity to participate in the George Wolf Youth Internship Program. The program honors the memory of deceased TILRC board member George Wolf who was a tireless advocate for equal justice and full inclusion for people with disabilities.

Students learn about Independent Living philosophy, the history of the disability rights movement and legislation to protect the rights of people with disabilities. One of the main goals of the program is to give students with disabilities work experience, so the interns are assigned a group project to be completed as part of their internship.

They receive hands-on experience working on an advocacy or public education project. Past projects have included conducting accessibility surveys of local parks and presenting recommendations for improved access to city and county staff, design and construction of an accessible flower garden and last year's interns developed a public service announcement on the transition from high school to adult life.

The program is a six week program that begins in late June and is open to all students, with or without disabilities, who are between the ages of 14 to 19 years old. The internships are paid positions and interns work 4 hours a day every Monday, Wednesday and Friday. The application period is generally during the months of April and May. If you or someone you know is interested in obtaining more information about the George Wolf Youth Internship Program they can contact Paul O'Dell at 233.4572.



TILRC CELEBRATES THE 19TH ANNIVERSARY OF THE AMERICANS WITH DISABILITIES ACT

On July 25, 2009 TILRC held the Annual Americans with Disabilities Act (ADA) Celebration. The event took place in the new Oxford Conference Center Building* at 408 S.W. Jackson Street. TILRC Executive Director Mike Oxford kick-off the event at 10 am. He welcomed the crowd of about 100 people and reminded them of how far we have come since the “bad old days” prior to ADA and the work still ahead of us to achieve full equality for people with disabilities.

Attendees enjoyed the Resource Fair where information was available on resources in our community for people with disabilities. There were games for the kids, including Face Painting, Ring Toss and a Cakewalk, and fun activities for adults like ADA Bingo.



People got useful information at the Resource Fair.

For lunch the crowd enjoyed some hot dogs, chips, potato salad, pop & ice.

The 2010 ADA Celebration will be a real milestone for the agency combining both the 30th anniversary of TILRC and the 20th anniversary of the Americans with Disabilities Act (ADA). More detailed information on the event will become available as the Summer of 2010 approaches.

*The Oxford Building is available to individuals and community groups at very reasonable rates. The fully accessible, 75 person capacity facility includes a large, open meeting space with a full kitchen, convenient parking and is located within walking distance of the state capitol. for more information contact Jeannine at 233.4572.

BACKLOG OF CLAIMS AND LABYRINTHINE PROCESS LEADS TO LONG WAITS FOR SOCIAL SECURITY BENEFITS: CAROL DOSS OFFERS TIPS TO HELP YOU THROUGH THE PROCESS

The current economic recession had led to record unemployment, but while the unemployment rate for workers without disabilities hovers above 9%; the rate for workers with disabilities has skyrocketed to over 16%! Many workers with disabilities who lost jobs earlier during the recession have searched for months to find another job. Now they find their condition has worsened to the point that they cannot return to the workforce. Others who depended on an informal support network of family or friends now find themselves without that support as their caregivers are forced to find work or work longer hours to make ends meet. They've put off applying for benefits, but are now left with Social Security Disability Insurance (SSDI) as their only alternative.

Unfortunately, they'll be waiting a long time before they will receive any benefits.

First you have to file a claim to determine if you are eligible to receive Social Security benefits. The backlog of pending SSDI claims is expected to grow to nearly 1 million people in 2010. The average time to process a claim is over five months.

Once a person's claim has been processed they must go through a lengthy process to determine eligibility, which usually involves a court hearing. The average wait for a determination is nearly 500 days and only about 1/3 of those claims are approved on the first try!

Carol Doss, TILRC's Benefits Advocate, knows how frustrating the process can be. According to Carol, the time it takes to complete the benefits process in our area is even longer than the national average. She has been helping people negotiate the complex Social Security benefits process for 20 years. As TILRC's Benefits Advocate, Carol assists consumers with the initial filing for benefits, with appeals when an initial application is denied and with post entitlement issues, like how returning to work can affect benefits or dealing with overpayment of benefits.

Carol offers the following advice for people preparing to apply for SSDI: It is critical to have thorough medical records that explain your condition because that is what Social Security is going to look at to determine eligibility. Carol has forms that she asks consumer's doctors to fill out on both mental and physical conditions that can really be helpful when documenting your condition. School records, like a vocational evaluation, and statements from people who know you well that document how your disability affects your daily life are also helpful.

For people who are appealing a claim she offers the following advice: Often a lot of time will have passed since the original application. As a result, a person's disability may have gotten worse. It is important to stress those facts on the appeal by documenting the change through medical records and any other information on how it has affected your daily life. Sometimes

people may even develop a new disabling condition. If that is the case, you will want to be sure to provide documentation on the new disability and how it affects you. Carol uses the Social Security disability report form to clearly document changes in a person's condition for your appeal.

Carol also assists people applying for Supplemental Security Income (SSI) benefits. SSI is different from SSDI. Carol explains, "SSI is a needs-based benefit. When you apply for SSI they aren't looking at whether you have worked enough. With SSDI

you have to have worked and paid into the system to be eligible, but SSI instead is looking at your income and resources. So initially when you apply your resources are limited to \$2000.00 and if you're currently working you can't be earning more than \$980.00 per month gross."

"The process can be very slow, and if there is any way we can expedite it we will certainly try to do that," Carol explains. For example, Social Security has a Compassionate Allowance Program that allows them to provide benefits quickly to people with medical conditions that are so serious it is obvious they meet disability standards. Carol says, "I always look at that and if a person has a condition that falls under the Compassionate Allowance Program we certainly want to follow through with Social Security and let them know ... to see if we can't get that case expedited."

Carol says, "When it gets to the hearing stage and you're looking at a possible two year wait until you have a hearing it gets a little trickier as far as expediting the process." In critical cases, where someone has a terminal illness, can't get access to the medications they need or is homeless, sometimes Carol can help speed up the process. In such cases she will often write a letter to the judge that spells out the situation asking that they expedite getting a hearing scheduled.

For people who don't have an advocate to help them Carol says the system can some times be "overwhelming." She says, "An advocate can help line everything up in a way that might make your decision come in a little faster." Sometimes it is easier for an advocate to request and compile the documentation you need. Unlike an attorney, TILRC doesn't require a "retainer" fee or any up front payment for her services. TILRC doesn't charge for expenses like copying records or travel either. TILRC's fee is paid out of any back benefits that consumer may be owed. Back benefits are the benefits you would have been eligible for while you are waiting for



Carol Doss assists a consumer over the phone.

a determination. TILRC's fee is 25% of any back benefits the consumer receives. Regardless of whom you may hire as an advocate the maximum amount they can charge is \$5,300.00.

If you want to know more about applying for Social Security benefits or need an advocate to assist you, give Carol a call at 233.4572 or if you are outside the Topeka area you can call her toll-free at 1.800.443.2207.

WELCOME, RICHARD HEUER



Richard Heuer

Welcome, Richard Heuer, TILRC's newest Independent Living Advocate. Richard is originally from Omaha, Nebraska, but has lived in Tonganoxie, Kansas since 1985 where he was a special education teacher for the Leavenworth Special Education Cooperative, working primarily with high school and junior high school age students. Because of his experience working with students with disabilities, Richard looks forward to working with the George Wolfe Youth Interns this Summer. He says, "It's new to me, but I'll help in whatever way I can."

Recently, Richard decided he was ready for a change when he heard about the Independent Living Advocate opening at TILRC. Richard says, "I've always been interested in this type of work, but I never knew how to get into it." He says that the money is "not what this is all about." He looks forward to the opportunity to help more people with disabilities be as independent as they want to be.

Richard finds that overcoming "the pre-conceived notions that people have of a person with a disability" can be a "stumbling block." Often times all a person needs to be independent are some simple changes, like access modification to their home. His message to folks that pre-judge is to give people with disabilities a chance to be independent. Richard says, "You haven't walked in my shoes. Don't have a pre-conceived notion of what I can or can't do. Help me make these few changes and let me show you what I *can* do."

Richard is an avid reader and likes to keep abreast of current events, but he likes "getting out and about," too. "I love being outside and going for walks and things. I like to travel some ... I'm just interested in people," he says.



SUPPORT ADAPT!

Grab your wheels, your bike, your dog, your kid or your skates. But most important sign up your sponsors, to support Disability Rights while you run with ADAPT. This is not a race. You will run, walk or roll around a 1/4 mile track for an hour and count your laps. We do the rest. We provide T-shirts, food, drinks and lots of music for sponsored participants! All proceeds go to support disability rights.

Date: Sunday, April 25, 2010

Time: 1:00–4:00 p.m.

**Location: Upper Senate Park
Constitution and 1st Street
Washington, D.C.**

For more information or to register:

512-442-0252

bob.adapt@sbcglobal.net

www.adaptfunrun.org

The ADA: Rights Worth Fighting For!

SLOUGH CREEK POINT OFFERS A VARIETY OF ACCESSIBLE OUTDOOR RECREATIONAL ACTIVITIES



The accessible restroom on the trail. One of several ponds on the site is visible in the background to the right of the restroom.

Even on a grey winter day like the one when most of the photos for this article were shot, Slough Creek Point Environment Education Area is worth the trip for anyone seeking an enjoyable, accessible outdoor experience. Slough Creek Point is located on the east side of Lake Perry (see directions at the end of this article) which is located north of Highway 24 between Topeka and Lawrence. Although it is not very well known, Slough Creek Point is one of the most accessible areas at Lake Perry.

Some the outdoor activities that can be enjoyed at Slough Creek Point are hiking, picnicking, camping, birding and observing wildlife. The area has

a 2 mile asphalt trail that is wheelchair accessible to anyone using a power chair or scooter. With the exception of the first stretch down the hill from the parking lot, most of the trail can be managed independently by folks who use a manual chair, but the entire trail can be easily managed with assistance. There is also a side trail, about a quarter of a mile long, which diverges from the main loop that ended at an accessible shelter house near the primitive camping area. The camping area has an accessible bathroom, but the campground itself is accessible only to power wheelchairs designed for outdoor use.

The trail meanders through a variety of habitats, including native grasslands, woods, marsh and lake shore. This makes is an excellent site for birding and wildlife observation. I have personally encountered deer, beaver, Canada geese, wild turkeys and bald eagles at the site.



A beaver lodge is located near this rest area.



One of the accessible picnic shelters. The ends of the tables are extended to accommodate a person in a wheelchair.

There is an accessible restroom and water source at the foot of the hill near the trailhead and accessible rest stops every few hundred feet on the main trail. There is an accessible picnic shelter on both the main and side trails. They both have wheelchair accessible picnic tables, but no grills.

The main trail has interpretive and educational signs along the course of the trail that provide information on the habitats in the area and the animals and plants that inhabit them. The lettering on the signs is large enough for folks who need large print, but sadly not in raised letters or Braille.

For information on reserving the campground, shelter house or other facilities at Slough Creek Point contact the Jefferson County Conservation District at (785) 863- 2201.

To get to Slough Creek Point Environmental Education Area from Topeka take Highway 24 east to Ferguson Road in Perry. Go north on Ferguson Rd about 2.5 miles to Marion Road where you turn right. Drive another 5.5 miles to the 70th Street where you turn left. Take 70th Street to Lincoln Road and turn left again. Slough creek Point is about another half mile up the road at the intersection of 64th Street and Kiowa Road. If you're coming from Lawrence take Highway 24 to Highway 59 and go north to 70th Street where you turn right and follow the same directions for folks coming from the west.

People interested in a day trip outing to Slough Creek Point may contact the TILRC Recreation Club at 233-4572.



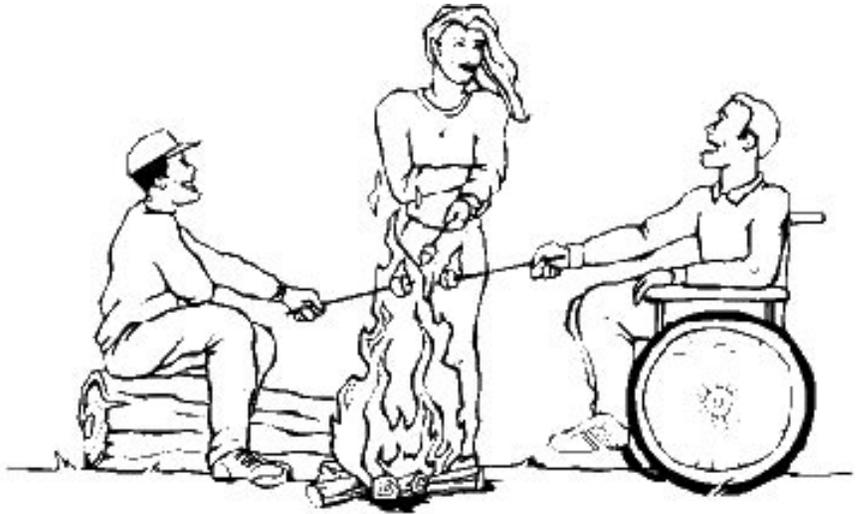
The author disturbed a bald eagle from its perch near the shelter house on the day these pictures were taken.

TILRC RECREATION CLUB BEGINS PLANNING ACTIVITIES FOR 2010

The TILRC Recreation Club (formerly the Fishing and Camping Club) has begun planning events for 2010. We want your input on fun activities to organize for the coming year. We also want to hear from you if you have encountered accessibility problems when you have tried to participate in local recreational activities. Below is a list of ideas for some potential recreational activities. If you are interested in having some fun with the Recreation Club, please check the top five activities you're interested in and mail this page to:

TILRC Recreation Club
 Attention: Cori Dryer
 501 SW Jackson St.
 Topeka KS 66603

If you prefer you can call Cori with your choices at 233.4572, Fax them at 233.5072 or email them at cdryer@tilrc.org. If you are interested in helping organize recreational activities for the club or have encountered access problems in the community please contact Cori.



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|---|--|---|
| <input type="checkbox"/> Nature trails | <input type="checkbox"/> Collecting | <input type="checkbox"/> Reading |
| <input type="checkbox"/> Exercise | <input type="checkbox"/> Music | <input type="checkbox"/> Writing |
| <input type="checkbox"/> Drawing | <input type="checkbox"/> Politics | <input type="checkbox"/> Volunteering |
| <input type="checkbox"/> Current Events | <input type="checkbox"/> Camping | <input type="checkbox"/> Cooking/Baking |
| <input type="checkbox"/> Fishing | <input type="checkbox"/> Cards/Cards | <input type="checkbox"/> Scrapbooking |
| <input type="checkbox"/> Sports | <input type="checkbox"/> Photography | <input type="checkbox"/> Movies |
| <input type="checkbox"/> Crafts | <input type="checkbox"/> Bird watching | <input type="checkbox"/> Live theater |
| <input type="checkbox"/> Swimming | <input type="checkbox"/> Museums/Art | |
| <input type="checkbox"/> Zoo | Galleries | |

Other suggestions:

Name _____
 Phone _____
 Email _____

Do you have something to sell or would you like to submit a letter or an editorial?

Do you have some disability-related items or equipment that you don't need anymore, but is still in good condition? We can advertise it for you in We The People. Just call, write or e-mail Kevin with a description and a person to contact. There is no charge for people with disabilities.

Placing a letter or an editorial in We The People is a good way to express your feelings and ideas on issues to people in the community especially in the Topeka and Shawnee County area.

Kevin Siek
785-233-4572
ksiek@tilrc.org

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Are you interested in reading about specific issues, but it hasn't been in the newsletter? If so, please contact Kevin Siek at the above contact information.

Classifieds

Invacare Storm TDX5 - has all the options, gearless motor, head rest, tilts, reclines, raises, multiple speeds, suspension and new batteries on it. It's barely been used. \$5,000, Contact Shelley Long at 785-256-6799

1996 Dodge Caravan - basic model, 4 cyl automatic, new transmission, 115,000 miles, lowered floor with fold-out ramp both front seats are removable, \$8,000, Contact Doug Gerdel at 785.221.0277

2009 Mazda 5, pwr strg, windows, A/C, CD, sliding doors, 10,700 miles, factory wrnty, hand controls, "Speedy Lift" for manual chair, \$24,500, Contact Tom at 785-221-8906.

For sale by Owner: 8 month old new construction house in Potwin area. 2 BR, 1 1/2 baths, sgl garage + parking, custom built for paraplegic, wide drs, roll-in shwr, lower counters, storm shelter, A+++ finishes, full appliance package, low main. exterior, super energy pkg for cheap utilities, \$135,000. Contact Tom at 785-221-8906.

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