



Educating, Assisting, Supporting, and Informing through this newsletter...
A newsletter for and by parents with sons & daughters with disabilities and education advocates.

Families Together, Inc.

Wichita Administrative Center
3033 W. 2nd Suite 106
Wichita, KS 67203
(316) 945-7747 or 888-815-6364

Kansas City Center 1-877-499-5369
Garden City Center 1-888-820-6364
Topeka Center 1-800-264-6343
Statewide Spanish parent line 1-800-499-9443

(All toll free numbers for Kansas
parents & education advocates)

www.familiestogetherinc.org

Volume 76

March 2008

Inclusion Conference a Success!

Submitted by Kim Murphy, Wichita Center

The Wichita Center of Families Together hosted their third annual statewide inclusion conference on December 8, 2007, at the Hyatt Hotel in Wichita. This is the third year the conference was held at this location and once again, it was a wonderful decision.

On a cold wintry Saturday morning, our keynote speaker, Michael Remus, replayed a theme he has delivered throughout his career to a crowd of over 140. "If I walk into a classroom and the kids are doing fractions," he says, pacing in front of parents, teachers, professionals and administrators, "I want to know what the special education kids are doing to learn fractions. The curriculum needs to be linked to everybody." Remus has been spreading the message of inclusion for special needs children for many years throughout the country.

Mr. Remus wants all children with disabilities to be educated in the same classrooms, with the same curriculum as the other students, whenever possible. He has told the staff that most self-contained classrooms for special education students will become a thing of the past, and so will cross-town busing to special programs. "We can make curriculum accessible to every kid," he says "Place doesn't make the difference."

We were also very excited this year to bring the founders of the reading program "Out of the Box" to share their concept with us. Denise MacDonald is the President and Founder of MacDonald Learning & Resource Center, Peterborough, Ontario. Karen Evershed's first child, Robyn, was born with Down Syndrome. That set her on a course to find avenues that would make her dreams for Robyn as well as Robyn's dreams for herself come true. That determination became the "Out of the Box Reading Program" to assist all children who learn differently.

Another highlight this year was our closing keynote segment of the conference. This year Circle of Friends, an innovative mentoring program that matches special education students with their general education peers, performed a portion of their talent show. It was very moving to see the interaction between the friends and how hard all of the young people worked to make this possible.

Other topics offered this year were: Parent Child Interaction Training- Tools in Treating Challenging Behavior in Autism, Helping Young Children with Challenging Behavior, Behavioral Supports for Students with Dual Diagnoses, Seclusion and Restraint, Brothers and Sisters from a Siblings Point of View, How to Write an I.E.P. and a Transition Panel.

We also hosted exhibitors from across the state who provide services or resources to families and their children with disabilities. As in the past, we held a silent auction, with funds raised going towards future conferences. This year we had several wonderful items ranging from an overnight stay at the Hyatt hotel to a children's bicycle and season passes for WSU Women's Basketball. We also had various gift baskets and gift cards offered as well. The auction was a success and enjoyed by all.

In closing, despite the presence of old man winter and unavoidable cancellations, the 2007 "Together We're Better" statewide conference offered attendees the opportunity to learn new and wonderful ways to include all youth in all facets of life.

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Garden City FEW

Submitted by Yolanda Corral, Garden City Center

¡Saludos! Espero que la gripe no haga pegado demasiado duro en su familia. ¡Yo estoy tan contenta que a mi me sacó la vuelta! ¡Yo siempre digo que las mamás realmente no pueden permitirse el lujo de enfermarse! Este fin de semana (Feb.15-16) nosotros tuvimos nuestro FEW (fin de semana familiar) en el hotel Clarion. ¡Nos divertimos mucho aprendiendo y la "Subasta Silencia" fue un gran éxito! ¡Los niños pudieron ir a buscar tesoros, nadar, y muchas otras actividades excitantes! Aunque nosotros tuvimos un grupo más pequeño de padres debido a la gripe hubo varias familias nuevas y siento que nosotros lográramos y contestamos la mayoría de sus preguntas. Los que sienten que les gustaría más información o que fueran a presentarles cualquiera de los talleres, por favor llámenme a la oficina. Uno de los talleres de gran beneficio para todos incluso las personas que están involucrados con la educación de nuestros niños es el "Conocimiento de Discapacidades". No hay ningún costo para cualquiera de estos talleres. Nosotros estamos aquí para ayudar a los padres para que sus hijos tengan éxito en la vida. Padres, no puedo dar bastante énfasis en lo importante que es aprender como ustedes pueden ser los mejores defensores de la educación de sus hijos. Asistiendo a los eventos como este es simplemente una de las muchas cosas que ustedes pueden hacer para lograr esa meta. Yo leí en alguna parte que nosotros vemos los ojos de Dios en los niños que ayudamos. ¡Esto es muy cierto! Otra cosa que las familias pueden hacer es empezar un grupo de apoyo para los padres. ¡Esto es muy beneficioso! Me encantaría ayudarle a empezarlo, solamente lámeme. Yo estoy en mi oficina lunes - jueves, 8:30-4:00 llamen al 620-276-2380.

Recuerden: *¡Amor por el trabajo que usted hace, compasión, averiguando de las muchas discapacidades que enfrenta en su trabajo o la vida es cómo nosotros podemos ayudar a nuestros hijos a tener una educación mejor y éxito en su futuro!* No se olvide de estos sitios Web: www.ksde.org, www.kansped.org

A Note From the Director's Desk...



Dear Families and Education Advocates:
All the staff members are anxious for Spring!!! I hope that your winter has been relatively healthy and productive. Our staff is always here to help you navigate the waters of special education and community services across the state.

This might be a good time to reevaluate your child's IEP and get ready for the next school year. Take a look at the current IEP and think about what classes and/or services need to be changed for next year. You can call and talk to a Parent Information Specialist or make an appointment to come in for a visit. Working with your child's school in the spirit of cooperation will get much accomplished.

The Kansas Legislature is in session and talking about issues that will affect your family. There are several bills which will impact funding for schools and community services to people with disabilities. Your legislators have a very hard job. Your expertise, about how the system works (or doesn't work) for your child, is information that they need to make informed decisions about the many pieces of legislation they have to vote on each year. Call you nearest center to find out how to contact your representative and senator. You can also go to the KU Institute for Policy and Social Research website to get that information: <http://www.ipsr.ku.edu/ksdata/vote/>

Send someone at your child's school a Thank You Note for something they have done recently for your child or your family. They will appreciate a little good news!

Thanks for all you do for your child, their teachers, and schools.

Connie Zienkewicz

99 Drums!! Music & Cultural Camp



Saturday & Sunday
April 26-27, 2008

\$55 by April 15
\$75 after April 15
\$100 after 23rd

Some Scholarships

West African, Native American, Caribbean,
Mexican: Drumming, Dancing, Music for
children ages 9-15 of all abilities

Presented by Accessible Arts.

Call (913) 281-1133

www.accessiblearts.org



Autism Resource Library

Submitted by Connie Zienkewicz, Executive Director

The Women of Wichita Foundation has funded a new and enhanced resource library to meet the needs of families which include a child or youth with autism. If you are a parent of a child or youth with autism, please tell us what would be the most helpful items to have for you and other families. It might be books or CDs about autism, or perhaps a particular book that you found helpful, or DVDs about social skills for your child. If you have specific titles or vendors for those items please include them in your recommendations. Please call the center nearest to you or email wichita@familiesstogetherinc.org.

When the library is complete, the titles will be online for check-out to any family who needs them!

Thank you, Women of Wichita, for this extraordinary gift to the families of Wichita and all of Kansas.



Family Story

By Sheril Bergman

It was the night of the school Christmas program.

The play had just ended, the children were buzzing with excitement backstage and down front, waiting for their turn to talk to Santa. Parents and extended families were visiting, tired babies were crying, cameras were flashing, the holiday spirit was in the air!

Sierra had done a great job on stage, a miracle in itself for a little girl who just three years ago barely uttered a single word. And then the wait in line to see Santa...and the noise...and the kids all talking at once...and it happened. Sierra broke down. The noise surrounding her had become too much. Sister Delores brought her over to us, thinking she was ready to go home, we headed outside to get her out of the noise. But, her desire to speak with Santa was stronger than the pain she was enduring from her sensory overload.

So...we walked up front to get back in line. Immediately, Lisa Stallbaumer offered to have Sierra go in front of Jonathan in line so she wouldn't have to wait. As we were walking over, Kristen, Riley, and Austin came forward and said she could get in line in front of them! This beautiful act of friendship spoke volumes of the spirit of this awesome first grade class! And then the three of them sincerely wanted to know what was making Sierra cry, and I tried to explain it to them as we waited in line.

All week I felt the need to let the kids know how that one act of kindness had made me feel, and to use it as a moment to try to explain why this happens with Sierra. So, with Sierra's permission, I recounted the events of that night to the class, and how very touched I was by their kindness and compassion.

To try to explain Sierra's sensory issues, I asked the kids to listen to all the noise that they could hear (we were in the cafeteria) when we were all very quiet. We heard a cooler motor, kids running up the stairs, feet shuffling under the table, chairs scraping the floor, sniffing, and outside noises.

Then, for just a little while, we all talked at once. When it was quiet again, I asked the children if they had heard the cooler, the shuffling, the chairs, the two kids who had just come down the stairs, etc, amidst all that talking, and most had not.

I then explained that most of us have brains that filter or shut off any noises that we don't want or need to listen to when we are talking to each other. That gives us the capability to listen to others, even when there is a lot of noise in the background.

For someone with autism like Sierra, the brain doesn't shut out all those noises, and even amplifies some of them to the point of being physically painful. The shuffling of bodies in the crowded area, the smells, the camera flashes, and suddenly the brain says "Enough".

We talked about how some brains are better at math, and not so good at spelling. Some brains work well in sports, but not in science. So, we all have to teach our brains by practicing what it is that we are not that good at. And so it is with Sierra. She will have to teach her brain to shut off some of those outside noises so she can better focus on her friends and all the fun.

What Steve and I really want you all to know is how very blessed we feel Sierra is to be in this class of 12 of the kindest, most loving, totally awesome children in the whole world. Even with Sister Delores as their inspiration, we feel that these children must have very wonderful parents at home to have become the great human beings that they are!

So...please give your first grader a great big hug from us...and God bless each of you for "training them up in the way they should go".

RESEARCH AT THE UNIVERSITY OF KANSAS

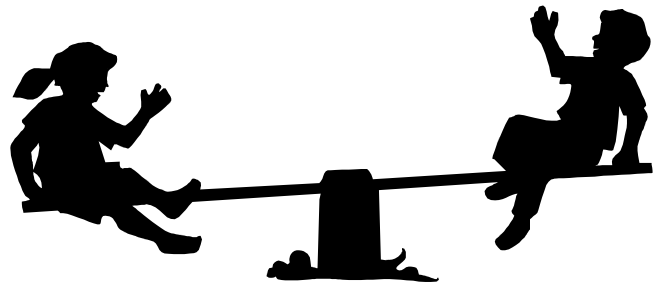
Children with autism, children with Down's syndrome, and typically developing children are needed to participate in an autism research project at the University of Kansas.

Dear Parents:

Autism is a neurological disorder that is marked by impaired development in social interaction and communication and a restricted repertoire of activities and interests. Although we know that autism is a neurological disorder, the root of the neurological dysfunction is unknown. Therefore, research efforts have been focused at trying to identify what brain areas may primarily contribute to the disorder. In addition, because children with Down's syndrome share some of the language delays with children with autism, we are interested in determining whether or not children with this diagnosis share similar neurological dysfunctions with children with autism. Hopefully, through various research efforts, we will obtain a clearer idea about the causes of autism and Down's Syndrome. The research project that we will be conducting will study the function of the two brain regions to determine if either of these areas may be a key to identifying and diagnosing children with autism and /or children with Down's syndrome.

To find out the purpose of this research project, who may participate in this project, What type of activities the children will participate in and how long these activities will take and how to sign up for participation, please contact us directly at our **Lawrence office at (785) 312-5345** (please ask to speak with **Christa Anderson**, or leave a message if no one is available) or e-mail Christa at **cjanders@ku.edu**. We hope that you will consider participation.

Christa J. Anderson, M.A. and John Colombo Ph.D.
Doctoral Student
University of Kansas
Schieffelbusch Life Span Institute
KU Infant Cognition Lab



Thank you for your generous donations!

Crazy House
Temple Inland Container
Scheopner's Water Conditioning
West Lake Hardware
Kansas Department of Transportation
Garden City Visitors & Tourism Bureau
Garden True Value Hardware Store
Steven Briggs Trucking
Sonic East
D.J.'s Lock & Key
Center for Independent Living of
Southwest Kansas
Finney County Extension Office
Tumble Weed Girl Scout Council
Mexican-American Ministries - Early
Detection
Swede Creek United Methodist Church
Independent Living center of
Northeast Kansas Inc.
Capital Federal Foundation
Hinkle Elkouri Law Firm LLC
Kansas Council on Developmental
Disabilities

Kansas Department of Health &
Environment Special Health Services
Kansas State Department of Education
Student Support Services
Quik Trip Corporation
Greater Kansas City Community
Foundation
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SRS - Working Healthy
YMCA
Youth Vision

Steve & Laurie Gerber
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Sue Harris
C. Mortensen
Yolanda Corral
Joann McConnell
Deanna & Jeremy Wisdom
Ashley & David Enns

Deborah & Bryan Bedigrew
Wes & Linda Kress
Terry & Judy Weddle
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Sarah Woodward
Dana Young
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Rash & Thomas Allen
Mary & Joe Graves
Diane Wilkes
Larry & Cheryl Prothro
Lauren Chapman
Larry Jost
Wilma Andrews
Max Wilson
Michael & Sarah Szymanowski
Zo Ann Torrey
The Holley family
The Girard family
Michael Webb
Rocky Nichols the Lalumondier family
The Wheat family
The Zienkewick family

Independent Living Resource Center Seeks Children & Youth with Disabilities to Participate in Bike Camp



Independent Living Resource Center (ILRC) is seeking children and youth with disabilities ages eight and older to participate in the "Lose the Training Wheels" bicycle camp in Wichita from May 27 – 31, 2008. The program teaches individuals with disabilities to ride a conventional bicycle without training wheels.

The program is an indoor day camp format utilizing adapted bikes and techniques developed through over 20 years of university level research.

Participants that have benefited most from this program are typically those able to ride a tricycle or bicycle with training wheels and have a desire to learn to ride independently. Medical studies have proven that children with disabilities who learn to ride a bike experience improved mental and physical health as well as the freedom and independence that comes from being able to ride a bike like their non-disabled peers.

Participants will be instructed for 75 minutes each day at Immanuel Baptist Church, 1415 S. Topeka in Wichita. The cost to participate is \$100 for the week. Scholarships are available based on need.

The program, limited to only 40 participants, is expected to fill up quickly. ILRC is accepting applications for qualified applicants on a first-come, first-served basis and are due no later than May 1.

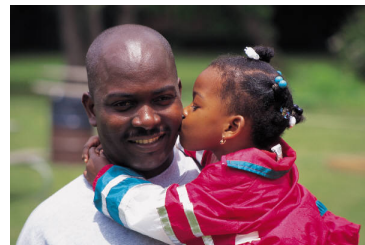
For participant applications or for more information, contact Cindi Unruh at ILRC at (316) 942-6300 or by email at cunruh@ilrcks.org.

Independent Living Resource Center, located at 3033 W. 2nd Street in Wichita, is a non-profit agency that provides resources and services to people of all ages with disabilities in south-central Kansas. Services and resources include information and referrals, independent living skills training, advocacy, medical equipment loans, computer training, social and recreation activities, peer support and speaker bureau presentations. For more information, call (316) 942-6300.

Family Voices

Submitted by Susan Arnold, Topeka Center

So often we hear that in order to be effective with advocacy efforts, there needs to be data, documentation, or proof to substantiate the cause.



A resource tool for Kansas Data for Child and Adolescent Health is the Data Resource Center, a project of the [Child and Adolescent Health Measurement Initiative \(CAHMI\)](#), housed at Oregon Health & Science University. It is supported through a cooperative agreement with the [Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Dept of Health & Human Services](#).

The most recent account included in the Data Resource Center is from the National Survey of Children/Youth with Special Health Care Needs, 2005-2006. Children with special health care needs are defined as having or being at risk for "chronic physical, developmental, behavioral, or emotional conditions that have lasted or are expected to last at least 12 months."

Some families may have been participants in the named surveys. You can see how input into these avenues for data collection can be used for future policymaking efforts. Check out the state's data on the DRC website at www.childhealthdata.org

Education Advocate Update

Submitted by Kari Herr, Topeka Center



As the warmer March winds begin to blow it's time for the 2008 Education Advocate Survey. This survey enables the program to keep in touch with all education advocates who serve such an important role in the life of children in the state.

When advocates return their survey, we are able to update your contact information and continued willingness to serve as an advocate. We are also able to verify that you are still serving as an education advocate. If there has been a move, your survey allows us to follow-up with the workers and request current information for the child.

Remember to spread the word about the Education Advocate program. We are always in need of people who care about kids and are willing to make educational decisions for children. Thank you for your continued support.

RESOURCES



FAMILIES TOGETHER TOLL FREE NUMBERS:

Wichita	1-888-815-6364
Topeka	1-800-264-6343
Kansas City	1-877-499-5369
Garden City	1-888-820-6364
Spanish line	1-800-499-9443

www.familiestogetherinc.org

MAKE A DIFFERENCE INFORMATION NETWORK

1-800-332-6262

An information service for children and adults with disabilities, their families, and their service providers.

www.makeadifferenceks.org

KPIRC

Kansas Parent Information Resource Center
(A resource for parents of any child)

3500 SW 10th Room 011E • Topeka, Kansas 66604
785-783-2975 • e-mail: jgroff@kpirc.org
website: www.kpirc.org

NICHCY

*National Information Center for
Children and Youth with Disabilities*

NICHCY Website

www.nichcy.org

- ★ All text-only publications have been reformatted to a new easy-to-read layout
- ★ A side-bar menu makes navigation easy
- ★ The ALL-NEW resource library featuring the Technical Assistance & Dissemination (TA&D) Network makes finding information a breeze

Call us or visit
our website!

1-800-695-0285
www.nichcy.org

Check out these Internet Resources!



www.familyfriendlyschools.com

Family Friendly Schools is dedicated to helping schools and districts around the country to increase student achievement by developing networks of integrated relationships between leadership, staff, and families that creates a culture of high performance and learning outcomes.

www.goodsearch.com/default.aspx

Please start using this search engine and pass it along to others. Every time someone searches we get a penny. Now there are some of you who search alot! So we can really make a difference with a simple click. No catch - just make sure you choose Families Together, Inc. (Wichita) as the non-profit. The donation will support our statewide efforts. Thanks for all you do for Kansas families!

www.readingrockets.org

Reading Rockets offers a wealth of reading strategies, lessons, and activities designed to help young children learn how to read and read better. Our reading resources assist parents, teachers, and other educators in working with struggling readers who require additional help in reading fundamentals and comprehension skills development.

Support Group

Grandparents Raising Grandchildren & Relatives Raising Children

Come join us for support, information and more.
Starting January 29, 2008

When - The last Tuesday of each month

Where - The Topeka & Shawnee County
Public Library

1515 SW 10th Avenue
Topeka, KS 66604-1374

Time - 10:00 am to noon

For more information, please contact:

Marva Williams, Relatives As Parents Program
Administrator, Kansas Department on Aging
785-291-3357

Here are tips to encourage your child's self esteem in ways that may influence healthy lifestyles

Reprinted with permission from PACER Center



Spend quality and quantity of time with each child.

Sometimes a child needs just a quick hug. At other times, he or she may need your continuing presence. Individual attention to your child says that he or she is important to you. Celebrate his or her successes - big and small. It fosters self-esteem.

Build trusting relationships. As relationships build over time, a child has first-hand experience in what trust can feel like. Building trusting relationships in the community, with extended family friends, neighbors, teachers, and others can foster a trusting community for your child.

Teach your child how to be a good friend. Talk about your good friends and qualities you find in each. Discuss with your child what he or she may want in a friend. It may be necessary to talk about honesty, and being helpful and dependable. Patience and repetition are key, say parents and professionals.

Keep family life consistent. Developing routine in bedtime, meals, bath time, and quiet time, as well as establishing other family rituals and traditions, are examples of how to provide consistency in family life. Predictable consequences for both good and bad behavior help children learn boundaries. Consistency leads to feeling stable and safe, which fosters self-esteem.

Be involved in your child's education. Knowledge gives your child a sense of control and builds self-esteem. Something as simple as routinely checking the papers your child brings from school or chatting about the school day can show that your child's education is important to you. If your child has an Individualized Education Program (IEP), share the goals with him or her. If appropriate, involve your child in the IEP meeting. Acknowledge your child's efforts if she or he is working hard, and celebrate successes.

Have fun. Enjoyable activities can relax your child and promote a feeling of well-being. Play a board game, walk the family pet, or ask your child to tell you about something that made him or her smile today. Have at least one "smiling moment" with your child each day.

Communicate respectfully. Encourage your child to share thoughts and feelings with you. Take time to listen, because it teaches a child that his or her ideas are important. If your child has difficulty speaking, use

patience in hearing him or her out. If needed, help your child find assistive technology or other ways to express needs or ideas.

Respectful communication also means listening to all sides of a story and using respectful language at home and in the community.

Help your child solve problems and resolve conflict. Problems and conflict are inevitable and complex. As they arise, talk with your child about the circumstances and his or her feelings. Explain how others may have a different view of the situation. Praise your child when he or she makes a thoughtful decision, or explore what she or he might do differently in a similar situation.

Discipline positively. Everyone makes mistakes. Make sure you have stated the expectations clearly and the child knows the consequences. Identify the issue or behavior as the problem - not the person. Be sure you reward the behavior you want. The ultimate goal of discipline is to teach a child self-discipline and independence, as well as safety. Keep in mind that a child with some disabilities may need more repetition and different learning strategies than a typically developing child.

Teach responsibility. Give your child opportunities to feel pride in doing things for others. Feeling pride in making a contribution to the family or community is important. Some children can set a table or care for a pet. Others may help by mowing a neighbor's grass or carrying an elderly person's groceries from car to house.

Address life situations honestly. Teach your child that life does not always happen as planned. Ask each family member to share a positive event as well as one that went wrong. Share with your child unexpected happenings in your life, both positive and negative, and how you handled the situations. Such open discussions encourage your children - and you - to consider strengths and coping tools, as well as what brings pride and pleasure to each person in your family.

Spring Calendar of Events

Date	Event	Contact
March 12, 2008	DRC Kansas 30th Anniversary Celebration Event, Topeka	877-776-1541
March 15, 2008	<i>Families Together Mini-Conference, Hays</i>	888-820-6364
March 29, 2008	<i>Families Together Transition Mini-Conference, Topeka</i>	800-264-6343
April 2-3, 2008	6th Annual Statewide Kansas Fatherhood Summit, Kansas City	816-537-7801
April 5, 2008	<i>Families Together Mini-Conference for Military /Civilian Families, Leavenworth</i>	877-499-5369
April 11-12, 2008	<i>Families Together Family Enrichment Weekend, Topeka</i>	800-264-6343
April 11-12, 2008	<i>Families Together Parent Networking Conference, Pratt</i>	888-815-6364
April 26, 2008	<i>Behavior Mini-conference (in Spanish), Garden City</i>	800-499-9443

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