



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](http://www.familiestogetherinc.org)

Volume 70

Sept. 2006

## New School Year, New Opportunities

*Submitted by Darla Nelson-Metzger, Topeka Center*

The end of summer marks the beginning of school supplies, enrollment, open houses, and the first day of school for our kids. Because our business is assisting families with sons and daughters with disabilities, fall starts a new year for our staff as well. Summer is a time when we plan, schedule, and create new and exciting ways to continue our service to Kansas families. A significant part of what Families Together does is offer workshops to parents, foster and adoptive parents, educators, and other interested persons. We offer a variety of topics and are pleased to announce and excited to bring you the addition of three new workshops.

With the 2004 Reauthorization of the Individuals with Disabilities Education Act (IDEA), Congress placed high emphasis on students with disabilities accessing and participating in the general education curriculum. Families Together supports the premise that all students are general education students first, yet some students require special education services to assist them in the general education curriculum. The Kansas State Board of Education has developed standards in language arts, mathematics, social studies and science for ALL Kansas students. This includes students with disabilities. Teams must write Individualized Education Programs (IEPs) to reflect the state standards as well as address how every student will participate in state and district wide assessments.

Families Together has developed a workshop entitled, "Linking IEPs to State Standards". In this workshop, participants will receive tools to help them get to know one another as well as the student and develop strong present levels of academic achievement and functional performance. Also, we will discuss how to develop measurable goals based on the present levels and the state standards. Lastly, participants will understand what supports and services may be given to or on behalf of a student.

A second training which emphasizes all students as general education students first is the "Building Partnerships: Family, School, and Community." This workshop has two formats: one for school personnel and the other for families. It focuses on activities in which schools and parents can engage to build partnerships with one another to benefit all students. Current research is discussed as well as the six core principles of parent participation. This is a fun and interactive workshop for all.

"Planning for the Transition from School to Adult Life" is newly updated workshop available for families and the professionals with whom they work. The reauthorization emphasizes a results-oriented approach and a focuses on improved results for young adults after high school. Measurable postsecondary goals are now to be part of the IEPs of students 14 years of age and older. The postsecondary goal becomes the vision driving the transition IEP. Several other exciting changes will be discussed in this workshop. If you are the parent of a 12 year old or older student, this workshop is a definite must!

Families Together continues to offer many other workshops as well. "Special Education Law and You" and "Five-Oh What?" focus on the educational and civil rights laws which protect your son or daughter with a disability. Team building and IEP development is the focus of "IEP Development: A Team Effort" and "Effective Advocacy". The workshops "Discipline" and "Strategies to Help Uncover the Causes of Challenging Behaviors" highlight suspension and

### Inside this Issue...

- [Siblings in the Spotlight..... p. 2](#)
- [IDEA Regulations..... p. 2](#)
- [Education Advocate Update..... p. 2](#)
- [Kansas Youth Leadership Forum ..... p. 3](#)
- [From the Director's Desk ..... p. 3](#)
- [Family Story ..... p. 4](#)
- [Hispanic Family Enrichment Weekend ..... p. 5](#)
- [Family Voices..... p. 5](#)
- [Draft Regulations on Seclusion & Restraint ..... p. 5](#)
- [Resources..... p. 6](#)
- [Calendar of Events.....p. 7](#)
- [Chiefs Ability Camp..... p. 7](#)
- FEW & PNC Registration .....insert
- Statewide Conference Registration..... insert

[Continued on page 3...](#)



# YOU CAN CHANGE A CHILD'S LIFE FOREVER



Join our team of exceptional parents and share your parenting skills by taking a child with developmental disabilities into your home.

Intensive support, training, and excellent compensation provided.

Contact : Allison Foss  
at Lakemary Center  
(913) 671-1800  
afoss@lakemaryctr.org

## Siblings in the Spotlight

10 am to 4 pm Saturday, September 30, 2006  
Rolling Hills Wildlife Adventure  
Six miles west of Salina on Interstate 70

"Siblings in the Spotlight" is a one day event for siblings who have a brother or sister with a disability. Siblings will discuss concerns they often experience such as: peer issues, resentment, loss, and concerns about the future. They will learn how to increase the unique opportunities often experienced by siblings including advocacy, insight, compassion, and tolerance. Siblings between the ages of 8 and 18 are encouraged to attend. [To sign up, please contact Families Together at 620-276-6364 or toll free at 1-888-820-6364.](#)

Deadline is September 21, 2006.



## IDEA Regulations

The final IDEA 2004 regulations were published in the Federal Register. Please use the links below to access the full text of the regulations.

HTML: <http://a257.g.akamaitech.net/7/257/2422/01jan20061800/edocket.access.gpo.gov/2006/06-6656.htm>

PDF: <http://a257.g.akamaitech.net/7/257/2422/01jan20061800/edocket.access.gpo.gov/2006/pdf/06-6656.pdf>

DEPARTMENT OF EDUCATION

34 CFR Parts 300 and 301

RIN 1820-AB57

Assistance to States for the Education of Children With Disabilities and Preschool Grants for Children With Disabilities

AGENCY: Office of Special Education and Rehabilitative Services, Department of Education.

ACTION: Final regulations.

SUMMARY: The Secretary issues final regulations governing the Assistance to States for Education of Children with Disabilities Program and the Preschool Grants for Children with Disabilities Program. These regulations are needed to implement changes made to the Individuals with Disabilities Education Act, as amended by the Individuals with Disabilities Education Improvement Act of 2004 (Act or IDEA).

DATES: These regulations take effect on October 13, 2006.

## Education Advocate Update

Submitted by [Karen Snell](#), Topeka Center

### Q & A

What are the qualifications to serve as an education advocate?

Education advocates must be 18 years of age or older; attend a training on special education law, discipline, and the rights and responsibilities of education advocates; have knowledge and skills to ensure adequate representation of the child; complete an application form with three references; and, have no interest that conflicts with the interests of the student. Private contract workers, foster/adoptive parents, group home workers, educators, administrators and community volunteers may serve as education advocates.



# Kansas Youth Leadership Forum

The Kansas Youth Leadership Forum (KSYLF) is an innovative, intensive, four day career, leadership training program for high school juniors and seniors with disabilities. Students will be selected to gather at Washburn University in Topeka for activities which cultivate leadership, citizenship and social skills. This past June, 16 delegates attended this forum and learned first hand the impact of YLF and the impact they have on their community as a young leader with a disability.

Starting in August, we will begin our recruitment for the June 2007 Kansas Youth Leadership Forum. We will be scheduling presentations through November so that the application deadline of December 15 is met.

Presentations in the past have been given to schools, special education classes, community organizations, Centers for Independent Living and parent organizations. If you know of a student with a disability who has demonstrated leadership qualities or know of someone who does, schedule your presentations today! Presentations are at no cost to you.

Applications will be available August 15th. You may request a presentation or application by contacting me: Julia Fonseca at 785-215-6655 ext. 3 or [juliaf@kyea.org](mailto:juliaf@kyea.org)

Please do not hesitate to pass this information on to everyone! KSYLF DOES make a difference!

Julia Fonseca  
Kansas Youth Empowerment Academy  
Director of Programs  
517 SW 37th St. Suite B  
Topeka, KS 66611

[...continued from page 1](#)

expulsion laws, functional behavior assessments, and positive behavior supports and interventions. Three of our workshops focus on transition, whether it be at age three or planning for adulthood. They are: "Step Ahead at Age Three: Transition to Preschool", Planning for the Transition from School to Adult Life", and "Grade to Grade... School to School". "The Yellow Pages on Inclusion" workshop provides participants with an understanding of the legal basis for inclusion, and "Stress Management" and "Siblings" focus on meeting the needs of family members.

All of our workshops are free to participants and most are ninety minutes in length. To request a workshop, contact the center nearest you. Our staff and trainers will be happy to speak to support groups, school groups, or any other group who is interested in the lives of young people with disabilities.

## A Note From the Director's Desk...



Dear Families and Education Advocates:

Welcome to the beginning of a year long celebration of the 25<sup>th</sup> Anniversary of Families Together, Inc.

In the summer of 1982, the first Family Enrichment Weekend was held in Lawrence, Kansas. That inspiring weekend motivated several families to collaborate to begin what we now know as Families Together. We hope to bring stories to you over the next year of those founding families. If you know a founding family or if you were at that first weekend, call and tell us about your experience. We would love to know what has happened since then with each of your children who may have attended. We will be trying to contact as many families as we can find, but feel free to call or visit the website to give us your story.

During the year, each Center will plan an Open House. Come see our offices, bring your child's teacher, invite your political representatives, and come **celebrate what families do for each other**. At each event this year, we will invite families to celebrate this birthday. In the summer of 2007, a large statewide party is being planned – watch for details.

We are glad that you are part of our statewide family. Spread the word "We are 25 years old".

See you at an event this year!!

Connie







# Family Story

## Our Family Story

*Written by Kathy Johnson*

**A**lmost twenty-five years ago to date our family was blessed with another beautiful baby girl. Megan made her appearance a month early which immediately presented a number of challenges. Although Megan was a nice healthy size, 7lbs. and 21 inches long, her lungs were not mature and she quickly developed problems that required her to be put on a ventilator and whisked off to the Neonatal Intensive Care Unit at KU Medical Center in Kansas City. Megan's spent 81 days in intensive care and finally came home to us in Topeka. She was eventually diagnosed with cerebral palsy and seizures.

Megan was welcomed home by her 20 month old sister, and of course, a rather anxious, but very happy Mom and Dad. It was during those subsequent months of many doctors' visits, and early intervention appointments that I tried to envision my rather fragile baby's future. Our families had all been blessed with healthy babies, how do you cope with a baby whose future seemed to be filled with so many questions? I often felt, in those days, like no one really understood how I felt, or why I had so many questions.

One of the things that Megan helped me learn about myself was that I seek to understand everything as a way to cope. If I can envision the worse, and put that into perspective then I can cope with and rejoice if the reality is better. I also learned that my husband copes in a much different way. He envisions the best possible scenario and operates on information only on a need to know basis.

It was during this time that I learned about Families Together, Inc. I jumped at the chance to participate in a Family Enrichment Weekend. Great, a chance to talk to other parents and understand what a child with special needs in a family looked like. Maybe this would help me understand how to put this in perspective.

We attended our first enrichment weekend at the Lawrence Holidome and I felt like the weight of the world had been lifted from my shoulders. Meeting other families with children with special needs helped me feel normal again. I met Chris Curry, who seemed so sensitive and listened so intently to what all the parents said, and she loved our children with special needs – truly enjoyed them for who they were! Chris's goal for the Enrichment Weekends was simple; she wanted parents to enjoy themselves first and foremost, as well as bring them helpful information. I was hooked, I wanted to help.

I volunteered to help with Family Enrichment Weekends. It became a family event for the whole family. My hubby, Keith, helped trouble shoot with the hotel facilities. I helped organize speakers, volunteers and eventually fund raise. Amy, our oldest daughter was always shy, and liked it best when she could just hang out with Chris. I certainly have no idea how many weekends we attended over the ten years, or more. I volunteered and then worked for Families Together. My volunteer job turned into a full time job when Families Together became the Parent Training and Information Center for Kansas. I learned to do the Parents Rights and Responsibilities workshop, and took parent assistance calls at the center.

I can't begin to share how much I learned and benefited from my experiences with Families Together. Life long friendships, so many people that I admire became friends, and many memorable experiences. Megan turns 25 this year too, and just started a new job. She is doing what she is passionate about - working with infants as a teacher's aid at a child care center for teen mothers. I have worked at TARC, INC. as the Shawnee County Infant Toddler Coordinator for almost fourteen years and three years ago began working as a consultant for Community Action Head Start as well. Our shy little Amy finished the first two years of medical school and just passed her medical exam boards and will begin doing her clinical rotations. Amy describes one of her first memories as seeing her sister in the neonatal intensive care unit. Her goal is to become a neonatologist, but first, will bring her own little one into the world in September. Keith and I are so looking forward to being grandparents!

So, Happy 25<sup>th</sup> Birthday Families Together, Inc. and to borrow a well known phrase. . . thanks for the memories.





# Hispanic Family Enrichment Weekend (25 Years!)

*Submitted by Yolanda Corral, Garden City Center*

Come join us at our birthday party! Families Together is having a weekend of fun, games and learning. Since 1982, Families Together has been helping families who have a child with a disability and this year we will be celebrating our 25th birthday at our 2nd Hispanic Family Enrichment weekend. Last year the first Hispanic Family Enrichment weekend went really well. I understand everyone had a great time. This year I'm looking forward to meeting everyone and celebrating Families Together's birthday with you. We hope to have at least 15 families join us in celebrating our 25th birthday. Our mission is to motivate and educate our families so that they can be the best advocates for their families. All information, orientation, and workshops will be presented in Spanish. Come learn about special education law and other services available in Kansas. Our birthday celebration will be held on October 20 and 21 at the Garden City Plaza Hotel. You must register to attend this Hispanic Family Enrichment birthday celebration. Deadline is October 9, 2006. Please get your application in ASAP. For any questions please call Yolanda Corral at 620-276-2380 or 800-499-9443.



## Fin de Semana de Enriquecimiento Familiar Hispano (25 Años!)

¡Venga a reunirse a nuestra fiesta de cumpleaños! Familias Unidas, Inc. estaremos teniendo un fin de semana de diversión, juegos y aprendizaje. Des de 1982 Familias Unidas, Inc. ha estdi ayudando a familias que tienen un niño con una incapacidad y este ano nosotros estaremos celebrando nuestro cumpleaños de los 25 años en nuestro segundo año de "Fin de Semana de Enriquecimiento Familiar Hispano". El año pasado en el primer "Fin de Semana de Enriquecimiento Familiar Hispano" salio todo muy bie. Tengo entiendo que todos tuvieron un buen tiempo. Este año yo estoy ansiosa de conocerlos y reunirnos a celebrar el cumpleaños de Familia Unidas, Inc. Nosotros esperamos tener por lo minos 15 familias para celebrar nuestro cumpleaños. Nuestra Misión es motivar y educar a nuestras familias para que ellos puedan ser los abogados mas eficaces para sus familias. Toda la información, orientación y talleres se darán en español. Venga para aprender sobre la Ley de la Educación Especial y otros servicios disponibles en Kansas. Nuestra celebración del cumpleaños se llevara acabo el 20 y 21 de octubre en el hotel Garden City Plaza. Usted tien que registrarse para asistir a esta celebración de cumpleaños de "Enriquecimiento Familiar Hispano". Usted tendrá que registrarse no mas tardar del 9 de octubre do 2006. Por favor llene su aplicación lo más proto posible Para cualquier pregunta por favor llame a Yolanda Corral al numero 620-276-2380 o 800-499-9443.



*Submitted by Susan Arnold, Topeka Center*

**The Maternal and Child Health Library at Georgetown University** is part of the National Center for Education in Maternal and Child Health (NCEMCH), funded under a cooperative agreement with the Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services. It provides the MCH community including families accurate and timely information on a broad range of topics. The home page includes '[Resources for Families](#)' and consumers via searches on topics, links, knowledge paths, the Bright Futures website, and more. Materials include the weekly newsletter MCH Alert, resource guides, full text publications, databases, and links to quality MCH sites. Visit this resource at: [www.mchlibrary.info/](http://www.mchlibrary.info/)

## Draft Regulations

**on Seclusion and Restraint in Schools Prepared**

*Submitted By Connie Zienkewicz, Wichita Center*

At the direction of the legislature, the Kansas State Department of Education, in collaboration with stakeholders (including schools and family organizations), has presented draft regulations for the Seclusion and Restraint of Special Education Students to the State Board of Education.

Like all good compromises, not everyone is happy. Parents want more stringent rules and schools obtained many concessions. The KSDE staff took these different concerns and crafted a fair compromise that addresses the problem based on the growing national consensus on this issue.

If the State Board of Education releases the regulations for public comment, Families Together, Inc., the Attorney General's office, The Disability Rights Center, and Keys for Networking will provide training about the regulations for parents. Watch our website for further developments in this important issue. [www.familiestogetherinc.org](http://www.familiestogetherinc.org)



# 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](http://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](http://www.makeadifferenceks.org)

## KPIRC

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

PO Box 320 • Lecompton, Kansas 66050

785-887-6711 • 866-711-6711 • fax: 785-887-6711

e-mail: [nkraft@nekesc.org](mailto:nkraft@nekesc.org) • website: [www.kpirc.org](http://www.kpirc.org)

## NICHY

*National Information Center for  
Children and Youth with Disabilities*

**NICHY Website**

[www.nichy.org](http://www.nichy.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.nichy.org](http://www.nichy.org)

## Check Out these Internet Resources!



[atmatch.com](http://atmatch.com) is a new website which is an electronic marketplace where anyone can list a piece of assistive technology equipment or durable medical equipment for sale and anyone can bid on it. On February 20, the auctions begin and listing fees will be in place after that.

### RAPP (Relatives as Parents Program)

Several agencies concerned with the welfare of older adults, children and youth are coming together to begin the Relatives As Parents Program. Referred to as "RAPP", this program will work to help relatives who are raising children; especially as it relates to grandparents raising grandchildren. RAPP offers grandparents and other relatives raising children the opportunity to share their experiences, to understand the children's special needs, and to learn how and where to seek community resources.

Go to [www.agingkansas.org/](http://www.agingkansas.org/)

Click on KDOA Programs.

Then go to Relatives as Parents Program.

Anyone who is interested in sharing a website with other parents, by placing it in this column, is welcome to send their suggestions to the Families Together Topeka Center. Please send it "Attention newsletter".

## SUPPORT GROUPS

### Sensory Processing Disorder Support Group

2nd Thursday of the month

7:00 pm

First Presbyterian Church  
Derby, Kansas

**SPD Parent Connections** is a grassroots organization of the **KID Foundation**, created for parents to provide information, resources and understanding to parents, friends, relatives, teachers, community members, professionals and anyone touched by the impact of Sensory Processing Disorder.

Contact:

Heather Fuller, SPD-PC Host  
316-519-6859

[HtFull@aol.com](mailto:HtFull@aol.com)

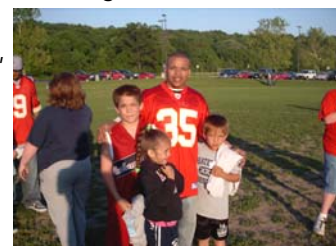


# Fall 2006 Calendar of Events

Date	Event	Contact
Sept. 9, 2006	<i>Families Together, Inc. Board Meeting, Topeka</i>	<a href="tel:888-815-6364">888-815-6364</a>
Sept. 29-30, 2006	NAMI Kansas State Conference, Topeka	800-539-2660
Oct. 4-6, 2006	First International Symposium on Usher Syndrome and Related Disorders, Omaha, Nebraska	402-498-6729
Oct. 20-21, 2006	<i>Families Together Spanish Family Enrichment Weekend, Garden City</i>	<a href="tel:888-820-6364">888-820-6364</a>
Nov. 10-11, 2006	<i>Families Together Parent Network Conference, Kansas City</i>	<a href="tel:877-499-5369">877-499-5369</a>
Nov. 17-18, 2006	<i>Families Together Parent Networking Conference, Salina</i>	<a href="tel:800-264-6343">800-264-6343</a>
Dec. 9, 2006	<i>Our Combined Voices Inclusion Conference, Wichita</i>	<a href="tel:888-815-6364">888-815-6364</a>
Dec. 9, 2006	<i>Families Together, Inc. Board Meeting, Wichita</i>	<a href="tel:888-815-6364">888-815-6364</a>
Feb. 16-17, 2007	<i>Families Together Family Enrichment Weekend, Garden City</i>	<a href="tel:888-820-6364">888-820-6364</a>
Feb. 17, 2007	<i>Families Together, Inc. Board Meeting, Kansas City</i>	<a href="tel:888-815-6364">888-815-6364</a>
Feb. 17, 2007	<i>Together We Can Learn Inclusion Conference, Kansas City</i>	<a href="tel:877-499-5369">877-499-5369</a>

## Chiefs Ability Camp

In May of 2006, my son and the rest of his family were fortunate enough to attend one of the Chiefs Ability Camps in Kansas City Mo. This camp was sponsored by Families Together for children with disabilities, but I can't call it anything other than an ability camp. This was an enlightening experience, not only for my son, but the entire family. My son, Caysean, is diagnosed with epilepsy. We have dealt with this since he was two years old. We have two other children, an older son and a younger daughter. Our family has been involved in sports for a long time. There is a three year difference between Cayleb (my oldest) and Caysean. By the time Caysean was old enough to compete, his older brother was a state qualifier in wrestling. My family has wrestled competitively for the last nine years with all three of the kids competing very well. Unfortunately Caysean has had stumbles and downfalls that have affected him throughout his wrestling career. I coach a youth wrestling program in western Kansas and have had the enjoyment of watching my children prosper in a very competitive environment. As a father I have also watched my son struggle in his greatest moments because of his disability. When we received the information for the camp we were unsure whether it would be worth the expense and trouble to make the trip to K. C. for the camp. After discussing the situation with Caysean, we made arrangements for the trip. We do a tremendous amount of traveling for the wrestling season, and this expense was definitely not in the budget. We made the arrangements for the trip, and I can thankfully say this was one trip that was worth the trouble. My son has made comments about his medication, and medical condition. This obviously makes my wife and myself realize how uncomfortable it makes him feel. This camp gave Caysean a time to feel good about himself. It gave him a chance to realize he wasn't so different. It was a wonderful experience to watch all of the children playing and competing together. No special rules, no special teams. Everyone was out there to help and cheer each other. My older son and younger daughter also participated as "Helpers." They weren't old enough to volunteer, but couldn't help but get caught up in the enthusiasm. I couldn't call this experience as anything less than fantastic. If I could attend all of the camps, I would. Not only for Caysean, but for the positive effect it had on the rest of my family. The volunteers, Chiefs players, and other campers were exceptional. My family may not be able to make all of the camps, but I know we look forward to the Kansas City Chiefs next year.



Thank You,  
Robert Campbell and the Campbell Family





If you wish to receive the Families Together newsletter by e-mail rather than mail, please contact the Families Together Kansas City Center at:

**877-499-5369** or

**[kansascity@famiestogetherinc.org](mailto:kansascity@famiestogetherinc.org)**.

Families Together, Inc.  
501 Jackson, Suite 400  
Topeka, KS 66603

