



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  
313 N. Seneca Suite 114  
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 85

June 2010

## Access to the General Education Curriculum and Students Receiving Special Education Services

*Michael L. Wehmeyer, Ph.D., FAAIDD, Beach Center on Disability, University of Kansas*



Ensuring that students with disabilities have access to the general education curriculum was a key feature of the 1997 amendments to the Individuals with Disabilities Education Act, a feature that was strengthened in the 2004 reauthorization. The 1997 amendments required that the IEP of all students receiving special education services include:

A statement of the special education and related services and supplementary aids and services to be provided to the child, or on behalf of the child, and a statement of the program

modifications or supports for school personnel that will be provided for the child

- i. to advance appropriately toward attaining the annual goals;
- ii. to be involved and progress in the general curriculum;
- iii. to be educated and participate with disabled and non-disabled children [Section 300.347(a)(3)]

The 2004 amendments to IDEA contained all of the original IDEA 1997 mandates and added several new requirements, including that schools ensure that the IEP team includes someone knowledgeable about the general education curriculum (and, one should note, the term was changed from general curriculum in the 1997 amendments to "general education curriculum" in the 2004 amendments), and that the team meet at least annually to address any lack of expected progress in the general education curriculum. Finally, the regulations to IDEA 2004 prohibited a student with a disability from being removed from the general education setting based solely upon needed modifications to the general education curriculum.

These "access to the general education curriculum" requirements were implemented to ensure that students with disabilities were not excluded from the accountability systems linked with standards-based reform inherent in the No Child Left Behind Act. According to Richard Riley, who was the Secretary of Education at the time of the 1997 reauthorization, the mandates were intended to ensure that students with disabilities were included in emerging standards-based reform and accountability systems as a

*[Continued on page 2...](#)*

## Inside this Issue...



- [Wonderful Opportunity ..... p. 3](#)
- [Actualización do Seguros del Autismo ..... p. 4](#)
- [Congratulations Connie ..... p. 5](#)
- [Autism Insurance Update ..... p.6](#)
- [Bilingual opening in KC Center ..... p. 7](#)
- [Education Advocate Update ..... p. 7](#)
- [Health Care Reform ..... p. 7](#)
- [AMBUCS ..... p. 8](#)
- [Camp Confidence ..... p. 8](#)
- [From the Director's Desk ..... p. 8](#)
- [Family Story ..... p. 9](#)
- [Resources..... p. 10](#)
- [Kansas Emergency Services for Children .....p. 11](#)
- [Calendar of Events.....p. 12](#)
- [2010 Kaw Valley Special Rodeo ..... p. 12](#)

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

means to raise expectations and ensure access to a challenging curriculum.

Several points should be made in reference to these requirements. The regulations to the 1997 (and 2004) amendments to IDEA defined the general education curriculum as, simply, the same curriculum offered to nondisabled students and stipulated that the educational programs of students with disabilities should include a focus on the general education curriculum to the maximum degree appropriate. The intent was never to create an either/or circumstance, in which students with disabilities received either an academic-content focused curriculum or a functional or life-skills focused curriculum. Indeed, IDEA still requires that the IEPs of students with disabilities include a focus on other educational needs; that is, those educational needs that are not addressed in the general education curriculum. The balance between a focus on content in the general education curriculum and a functional or life skills focus is an individual IEP team decision, and must take into account factors such as a student's age, the demands of the general education curriculum, and the need for community-based or life skills instruction. That said, it is generally understood that no student's educational program should be without some focus on the general education curriculum.

Second, IDEA itself never actually uses the term "access to the general education curriculum." It's generally recognized that "access" alone is not sufficient, just as access to general education classrooms is a necessary but not sufficient condition to ensure inclusion. Instead, the Act requires that students be involved with and progress in the general education curriculum.

Third, a focus on access to the general education curriculum for students with disabilities fundamentally changes the role of the IEP in the design of a student's educational program. Historically, the IEPs of many students, particularly students with more intensive support needs, described an alternative curriculum focused solely on life skills outcomes and functional



content. The access mandates in IDEA, though, presume that the general education curriculum is the starting point for educational program decision making for all students and require IEP teams to consider curricular modifications (such as universal design for learning features), supplementary aids and services, specially designed instruction, and related services that promote involvement and progress. The IEP is not intended to describe an alternative curriculum; instead, it is intended to identify the supports a student needs to be involved with and progress in the general education curriculum and, only then, what other educational needs are not addressed in the general education classroom that warrant instructional focus.

There are, of course, concerns with the IDEA access mandates, some warranted, others not. Of primary concern has been that the general education curriculum in most states, Kansas included, has been generally understood to mean only a limited number of core content areas—particularly math, reading, science, and, to a lesser degree, social studies—that are the focus of state-level (and often high stakes) testing. The concern is that such a focus narrows the curriculum and in some way results in a reduced focus on the other educational needs of students with disabilities. This concern is warranted, but two caveats should be noted. First, it's clear this was never the intent of the access mandates, and if it is occurring, it is a misinterpretation of the Act's intent. Second, from the perspective of a researcher and educator who has been involved with efforts to promote both access to the general education curriculum and high quality instruction on other educational needs for students with more intensive support needs, I believe that, by-and-large, the educational programs of students with disabilities have continued to be designed in a business-as-usual format. That is, students with more intensive support needs tend to still receive primarily (or only) a functional or life skills curriculum, with minimal focus on issues pertaining to the general education curriculum, and that students with higher incidence disabilities, such as learning disabilities, continue to



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

[...continued from page 2](#)

receive mainly an academic-content focused curriculum and to have little, if any, focus on other educational needs, particularly transition-related needs.

Lest one reads the previous observation as overly cynical, I would note that despite the fact that progress in implementing the access mandates has been slow, there are fundamental changes in how the education of some students with disabilities is proceeding based upon the access mandates. In particular, there is now a research-driven knowledge base emerging with regard to factors that contribute to greater student involvement in the general education curriculum, and there is growth in efforts to examine ways to provide instruction for all students in core content areas. From the use of universally-designed curricular materials to the design of direct instruction to promote reading and math, there is now more attention in teaching critical core content areas to students with intellectual and developmental disabilities than any time I can recall. Further, this research is establishing the fact that students who previously were excluded from instruction in core content areas can, in fact, acquire skills related to reading, math, science, and such. As I frequently note with students in my courses, is there really any skill more functional than reading? I'm optimistic that teachers will have greater access to universally designed curricular materials and to strategies to teach core content areas in the coming years.

Second, the access mandates are leading to what those of us at the Beach Center have referred to as a third generation of inclusive practices. First generation inclusive practices involved physically locating students with disabilities in general education classrooms. Second generation inclusive practices involved the development and application of strategies, such as cooperative learning and differentiated instruction, that enabled students to be taught in the general education classroom. The third generation of inclusive practices incorporates outcomes from both previous generations and adds efforts related to person-centered, student directed planning; promoting self-determination; universal design for learning; school wide applications, such as positive behavior supports; and response to intervention models to focus, instead of primarily where a student is educated, or what the student is learning. Research conducted at the Beach Center shows that students with developmental and other disabilities have greater access to the general education curriculum when they are in the general education classroom, making student inclusion in general education classrooms a necessary, though not sufficient, criteria for achieving the goals of the access mandates.

There is much work to be done to ensure that students with disabilities are involved with and progress in the general education curriculum and have their other educational needs met in a quality manner. Change

happens slowly, and often one student at a time. Still, there are few people who would argue against the observation that far too often, students with disabilities are held to very low expectations. The educational programs of far too many students are dictated by their label or type of disability. The IDEA access mandates have provided, and most likely will continue to provide, a vehicle to reverse those trends, and to raise both expectations for students with disabilities and provide opportunities to be involved with, and hopefully progress in, a challenging curriculum while still learning the functional, life skills that they need to acquire.

## Wonderful Opportunity for Families with Children with Special Needs from Birth-8

The Division for Early Childhood (DEC) is excited to announce an opportunity for families of children with disabilities and other special needs! DEC will offer 25 stipends covering the cost of registration for the 26th Annual International Conference for Young Children with Special Needs and their Families which will be held in Kansas City, Missouri from October 14-17, 2010. The stipend covers full conference registration (a value of more than \$275) as well as optional participation in full-day workshops offered on Thursday October 14 and/or half-day workshops offered Sunday October 17. Go to [www.dec-sped.org](http://www.dec-sped.org) and click the "Conference" link to learn more. The DEADLINE for applications is August 10th. Once approved, Kansas families can apply for an additional scholarship from Families Together, Inc. to cover hotel and parking costs.

This conference provides a unique opportunity to hear from leading experts in early intervention and early childhood special education, become exposed to cutting edge research and ideas, learn about intervention strategies that are being used throughout the world, and see the latest resources. DEC 's annual conference is the conference where professionals come to gain access to the information they need, connect with colleagues, learn new strategies, and become re-energized to continue their work with young children and families. The Executive Board of DEC knows that many family members are also eager for this information and we are committed to providing this opportunity to encourage more parents and family members to participate.

Questions? Call [DeeDee](tel:877-499-5369) in the KC Center for more information. 877-499-5369

# Actualización de Seguros del Autismo

Submitted by Michael L. Wasmer, DVM



El 19 de abril, el Gobernador Parkinson firmo la HB 2160 convirtiendo en ley, convirtiéndose Kansas el estado numero 18 en pasar una legislación imponiendo un seguro medico para pagar el diagnostico y el tratamiento del autismo. Si bien este es un primer paso muy impórtate para la comunidad de autismo de Kansas, los detalles del proyecto de ley se quedan cortos en crear una verdadera reforma de seguro de autismo para todas las familias afectadas.

## ¿Quien esta cubierto por la HB 2160 y que servicios cubre?

Los beneficios de la HB 2160 el Plan de Salud aplica únicamente a los Empleados del Estado de Kansas (las siglas en ingles SEHP) menores de 19 años de edad. Los servicios cubiertos incluyen la evaluación de diagnóstico, análisis aplicado del comportamiento y cualquier tratamiento "recetado u ordenado por un médico autorizado, psicólogo o trabajador social licenciado especialista clínico." tratamientos aprobados deben ser "reconocidos por la literatura revisada por el grupo como proporcionar asistencia médica a los pacientes basándose en el paciente particularmente, trastorno del espectro autista".

## ¿Por qué sólo los empleados del Estado están cubiertos?

Estatuto de Kansas (KSA 40-2249a), exige que cualquier mandato de seguro de salud primero sólo se aplicado a los empleados del estado de Kansas (siglas en ingles SEHP) por lo menos durante un año con el fin de evaluar el costo y el uso de los servicios propuestos. Después de este proyecto piloto inicial ", los legisladores determinan entonces si las disposiciones del mandato sean ampliado a los seguros comerciales.

El proyecto de ley original presentado por el Grupo de Autismo de Kansas, es decir, la Ley de Kate (SB 12 y HB 2367), fue escrito con una excepción a esta ley así lo que las disposiciones del proyecto de ley de inmediato se aplicarían a todas, financiado en su totalidad por las pólizas de seguro. Los argumentos presentados a la legislatura en apoyo de esta a la excepción incluye el hecho de que los datos sobre el costo y el uso de la cobertura propuesta ya existen de los estados que han promulgado una legislación similar. Los datos más convincentes fueron los de Minnesota, donde Blue Cross Blue Shield (Siglas en ingles BCBS) ha sido requerido para cubrir el tratamiento del autismo desde 2001. Datos de Minnesota Blue Cross Blue Shield indican que el costo de proveer tratamiento ilimitado (es decir, sin límites de edad o dólar) para el autismo es sólo 83 centavos por miembro por mes. La legislatura se le facilitó datos similares de Indiana, Carolina del Sur y Texas.

## ¿Qué pasó con la Ley de Kate (SB 12 y HB 2367)?

Una audiencia de ley SB 12 se llevó a cabo en las instituciones financieras del Senado y el Comité de Seguros en enero del 2009. Lamentablemente el progreso se vio obstaculizado hasta finales de marzo del 2010. Sólo después de un tremendo apoyo de la comunidad de autismo de Kansas y una considerable presión política de los que nos apoyan en el Senado, que el senador Teichman acordó introducir "un proyecto de ley de compromiso", es decir, HB 2160.

Defensores volvieron a intentar convencer a los legisladores exonerar el proyecto de ley "proyecto piloto" estatuto. Además de proveer datos de costo y del uso de otros estados, se señaló que el bajo número de individuos con autismo cubiertos por el SEHP de Kansas no puede proporcionar datos estadísticamente significativos. Autoridad de Kansas Póliza de Salud estima que hay 173 niños de 0-22 en el SEHP que tienen un trastorno del espectro autista. Teniendo en cuenta la edad de tope impuesta por la HB 2160, utilizado nueve años de datos de Minnesota, y la actual escasez de proveedores de servicios calificados en Kansas, legisladores se les aconsejó que menos de 15 niños pueden beneficiarse de este proyecto de ley si la cobertura se limita a los miembros SEHP.

Desafortunadamente, nuestros esfuerzos no tuvieron éxito y HB 2160 pasó con el proyecto piloto en su lugar. Para obtener detalles adicionales del proyecto de ley y ver cómo sus legisladores votaron, por favor visite el sitio web de KCAL.

## ¿Cómo va ayudar la HB 2160 a su hijo con autismo?

Si su hijo tiene seguro proveído por el Plan de Salud para los Empleados del Estado de Kansas (SEHP), los servicios descritos a continuación, se cubrirá a partir del 1 de enero del 2011. Por favor, asegúrese de presentar sus reclamaciones inmediatamente. Uso de datos serán evaluados por el legislador para determinar si la cobertura por fin se amplia al plan de seguro comerciales a todo Kansas. Si su hijo no tiene seguro proveído por el

[Continued on page 5...](#)

[...continued from page 4](#)

SEHP pero tiene una póliza completamente financiada, lo mas temprano que la suministración de la HB 2160 se extendería a su hijo es 01 de julio del 2013.

Pólizas de seguro financiado por cuenta propia (por ejemplo, previstas por las grandes empresas como Sprint, Cerner, etc.) no están sujetas a los mandatos estatales y por lo tanto no afecta la aprobación de la HB 2160. Sin embargo, lo que hemos visto en otros estados es que los empleados tienen más éxito en la defensa de la adición de los beneficios del autismo a su plan de seguro una vez que la cobertura similar ha sido mandada por el estado. Información para las familias con plan de seguro-propio se puede encontrar en la página Web del Autism votes (haga clic en "Recursos").

### **¿Cómo me hago en un proveedor de servicio de autismo aprobado por el Plan de Salud de los Empleados del Estado?**

Hay cuatro empresas con la cual contrata el Plan de Salud para los Empleados del Estado de Kansas: BCBS de Kansas, Coventry, Preferred Health y UMR (United Health). Si usted es un proveedor de servicios de autismo, por favor póngase en contacto con cada una de estas empresas tan pronto como sea posible para convertirse en un proveedor aprobado. Por favor, póngase en contacto con Autoridad de Kansas Póliza de Salud al (785) 296-3226 si usted tiene alguna dificultad con este proceso.

### **¡No hemos terminado todavía!**

La aprobación de la HB 2160 fue un primer paso crítico para la comunidad de autismo de Kansas, pero obviamente todavía nos queda mucho trabajo por hacer. La Coalición de Kansas para la legislación del Autismo sigue abogando por la reforma del seguro para todas las familias de Kansas afectadas por el autismo. Nuestros amigos de Autism Speaks y nuestros partidarios en la legislatura de Kansas nos están ayudando a avanzar esta cuestión, pero también necesitamos tu ayuda. Por favor regístrese en el KCAL y Autism Votes en el sitio Web para recibir actualizaciones, póngase en contacto con sus legisladores, para recibir nuestras alertas de acción. Unidos, ¡haremos que esto suceda!

Michael L. Wasmer, DVM

### **Kansas Coalition for Autism Legislation (KCAL)**

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

### **Autism Speaks Kansas Chapter Advocacy Chair**

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

[mike@kscoalitionforautism.org](mailto:mike@kscoalitionforautism.org)

913-626-0668

---

## **Congratulations Connie Zienkewicz on being awarded 2010 Professional of the Year!**

**O**n May 6th in Wichita, Connie Zienkewicz, the executive director of Families Together, was chosen as the 2010 Professional of the Year by The Arc of Sedgwick County.

Several local and statewide leaders in special education expressed their admiration of Connie's contribution and commitment to families whose children receive special education services.

Colleen Riley, Kansas State Director of Special Education Services, commented, "Connie is truly an outstanding community partner. She listens patiently and is always interested in seeing partners come together for the benefit of students with disabilities and their families. It is a pleasure to partner with Connie Zienkewicz!"

Tom Racunas, the assistant director for special education for USD 259, was the presenter. He added, "I have learned more about inclusion from Connie than from anyone else."

Connie said, "This honor could never be accomplished without a dedicated board and staff. Thanks for making me look good!"

Congratulations Connie!



# Autism Insurance Update

Submitted by Michael L. Wasmer, DVM

On April 19, Governor Parkinson signed HB 2160 into law, making Kansas the 18th state to enact legislation requiring health insurance to cover the diagnosis and treatment of autism. While this is a very significant first step for the autism community of Kansas, the details of the bill fall short of what is necessary to create real autism insurance reform for all affected families.



## Who is covered by HB 2160 and what services does it cover?

The benefits of HB 2160 apply only to members of the Kansas State Employees Health Plan (SEHP) who are less than 19 years of age. Covered services include diagnostic evaluation, Applied Behavior Analysis and any treatment “prescribed or ordered by a licensed physician, licensed psychologist or licensed specialist clinical social worker.” Approved treatments must be “recognized by peer reviewed literature as providing medical benefit to the patient based upon the patient’s particular autism spectrum disorder.”

## Why are only state employees covered?

Kansas statute (KSA 40-2249a) requires that any health insurance mandate first apply only to the SEHP for at least one year in order to assess cost and utilization of the proposed services. After this initial “pilot project”, the legislature then determines if provisions of the mandate are extended to commercial insurance.

The original bill introduced by the Kansas Autism Task Force, i.e. Kate’s Law (SB 12 & HB 2367), was written with an exemption to this statute so that provisions of the bill would immediately apply to all fully funded insurance policies. Arguments presented to the legislature in support of this exemption included the fact that data on cost and utilization of proposed coverage already exists from states that have enacted similar legislation. The most compelling of this data is from Minnesota where Blue Cross Blue Shield (BCBS) has been required to cover treatment for autism since 2001. BCBS Minnesota’s data show that the cost of providing *unlimited* treatment (i.e. no age or dollar caps) for autism is only 83 cents per member per month. The legislature was provided similar data from Indiana, South Carolina and Texas.

## What happened to Kate’s Law (SB 12 and HB 2367)?

A hearing for SB 12 was held in the Senate Financial Institutions and Insurance Committee in January 2009. Unfortunately progress was stymied until late March 2010. Only after tremendous advocacy from the Kansas autism community and considerable political pressure from our supporters in the Senate did Senator Teichman agree to introduce a “compromise bill”, i.e. HB 2160.

Advocates again attempted to convince legislators to exempt the bill from the “pilot project” statute. In addition to providing cost and utilization data from other states, it was pointed out that the low number of individuals with autism covered by the Kansas SEHP may not provide statistically significant data. The Kansas Health Policy Authority estimates that there are 173 children aged 0-22 on the SEHP who have an autism spectrum disorder. Considering the age cap imposed by HB 2160, nine years of utilization data from Minnesota, and the existing shortage of qualified service providers in Kansas, legislators were advised that less than 15 children may benefit from this bill if coverage were limited to SEHP members.

Unfortunately, our efforts were unsuccessful and HB 2160 passed with the pilot project in place. For additional details of the bill and to see how your legislator voted, please visit the KCAL website.

## How will HB 2160 help your child with autism?

If your child has insurance provided by the Kansas State Employees Health Plan (SEHP), then the described services will be covered beginning January 1, 2011. Please be sure to file your claims immediately. Utilization data will be evaluated by the legislature to determine if coverage is ultimately extended to commercial insurance plans throughout Kansas. If your child does not have insurance provided by the SEHP but has a fully funded policy, the earliest that the provisions of HB 2160 would be extended to your child is July 1, 2013.

Self-funded insurance policies (e.g. those provided by large companies such as Sprint, Cerner, etc) are not subject to state mandates and are therefore not impacted by passage of HB 2160. However, what we have seen in other states is that employees are more successful in advocating for the addition of autism benefits to their self-insured plans once similar coverage has been mandated by the state. Information for families with self-insured plans can be found on the [Autism Votes](#) website (click on the “Resources” tab).

*[Continued on page 7...](#)*

[...continued from page 6](#)

### How do I become an approved autism service provider for the State Employees Health Plan?

There are four companies with whom the Kansas State Employees Health Plan contracts: BCBS of Kansas, Coventry, Preferred Health and UMR (United Health). If you are an autism service provider, please contact each of these companies as soon as possible to become an approved provider. Please contact the Kansas Health Policy Authority at (785) 296-3226 if you have any difficulty with this process.

### We're not done yet!

Passage of HB 2160 was a critical first step for the autism community of Kansas but obviously we still have much work to do. The Kansas Coalition for Autism Legislation continues to advocate for insurance reform for all Kansas families affected by autism. Our friends at Autism Speaks and our supporters in the Kansas legislature are helping us to move this issue forward but we also need your help. Please register on the KCAL and Autism Votes websites to receive updates and contact your legislators when you receive our action alerts. Together, we will make it happen!

Michael L. Wasmer, DVM

### Kansas Coalition for Autism Legislation (KCAL)

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

### Autism Speaks Kansas Chapter Advocacy Chair

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

[mike@kscoalitionforautism.org](mailto:mike@kscoalitionforautism.org)

913-626-0668



## Bilingual Opening in the Kansas City Center

- ✓ 30 hours per week
- ✓ Some travel and minimal evening/weekend work

The successful candidate should have:

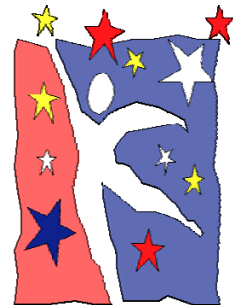
- written & verbal fluency in English & Spanish
- a basic knowledge services for minorities
- an interest in helping others learn about educational rights, and
- strong organizational, presentation and people skills.

\*Parents of children with disabilities encouraged to apply.

Please download the PDF application and fax to DeeDee at the Kansas City Center. Fax **913-287-1972**  
Email: [deedee@familiesaltogetherinc.org](mailto:deedee@familiesaltogetherinc.org)

## Education Advocate Update

Submitted by [Darla Nelson-Metzger](#),  
Topeka Center



Do you still have your survey sitting around? If so, please mail it in! We need to know your willingness to serve and your current contact information. For those of you serving for a student, we need to know about your experiences over the past school year. This data is tabulated and reported to the Kansas State Department of Education. Kari and I rely upon good communication to assist us in keeping track of the nearly 900 kids served by an advocate. Your surveys are an important tool in that process. As always, thank you for your time and dedication to Kansas kids and have a great summer!

## Health Care Reform: Children and Youth with Special Health Care Needs

Now that the intensity of the debate has calmed, and legislation has been passed, you have probably heard that health care is going to be reformed, one way or another. Do you understand what that means for you and your family? Is it true that insurance companies are prohibited from excluding coverage to children based on pre-existing conditions? Yes. Do parents really have the option of keeping adult children on their insurance plans until age 26? Yes. Will it be illegal for insurance companies to drop people from coverage when they get sick? Yes, again!

Although we do know some things about the new law, its impact on this specific population of children is still unclear. As regulations and more clarification are released, Families Together, Inc. will keep you informed. Look for an insert in the next newsletter with the latest information available. We will work to keep you informed as the timelines for implementation proceed. Watch our website (under the Special Health Care Needs links) for more immediate information as we have it.

[www.healthreform.gov](http://www.healthreform.gov)

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

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

# AMBUCS

## *Creating Mobility and Independence For People With Disabilities*

AMBUCS is a national service organization who pride themselves on making a difference in the lives of those with disabilities. Our mission statement is "Creating Mobility and Independence for People with Disabilities". We accomplish this mission by doing community service, giving scholarships to therapists, building ramps, and by giving away therapeutic tricycles called AmTrykes.



Children, regardless of their ability, should experience the simple pleasure of riding a bike. The AmTryke is a therapeutic tricycle that is designed to allow children with a variety of disabilities to do just that. AmTrykes can be pedaled with the hands, feet, or both to make the tricycle move. It allows the child to become mobile, sometimes for the first time in their life. It also helps to build self-esteem, strengthen muscles, improve motor coordination and balance, and increase range of motion while making exercise fun. Most kids are having so much fun riding the AmTryke, they don't actually realize the physical and mental benefits they are receiving. With the AmTryke, there are several customizations that can be done when fitting a child on the tryke, including frame size, frame positioning, seat selection, head rests, lateral support, foot cups, handgrip placement and pedal size. We work very close with physical and occupation therapists to insure that we have the proper fit for each child

### Contact information for Ambucs

Ambucs [www.ambucs.org](http://www.ambucs.org)  
Dodge City [nds620@hotmail.com](mailto:nds620@hotmail.com)  
Salina [www.noonetworkambucs.com](http://www.noonetworkambucs.com)  
Salina [www.breakfastbandids.com](http://www.breakfastbandids.com)  
Hutchinson [www.hutchmbucs.org](http://www.hutchmbucs.org)  
Wichita [aircapiolambucs.com](http://aircapiolambucs.com)  
Enid, OK [www.enidamambucs.org](http://www.enidamambucs.org)

## Camp Confidence:

**For youth (ages 10-14) with Autism Spectrum Disorders**

The activities and exercises at Camp Confidence, in Overland Park, are designed to empower young people on the autism spectrum. It is strategically situated in a school cafeteria, where so many children and adolescents with ASD suffer embarrassment. We will focus on four skills in a sequential, cumulative format: posture, walking, eye contact, and tone of voice. Group activities will introduce targeted skills practiced in a safe, formative environment and for application in real-life situations. Parents will receive daily information on how to practice the skills in the home environment for reinforcement, greater generalization, and increased confidence.



Phone: 913-940-7228/e-mail: [camp.confidence@yahoo.com](mailto:camp.confidence@yahoo.com)

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



Dear Parents and Education Advocates:

We hope that your summer break has started well with more opportunities for you and your child or youth with disabilities to explore other activities. There are some great ideas in this newsletter about other ways to use your time and energy.

Families Together has some new opportunities for parents to work with schools in helping students with disabilities.

1. We will be partnering with the Technical Assistance projects at the Kansas Department of Education to help families partner with schools in the areas of math, reading, least restrictive environment and transition services. Our partnership with the Technical Assistance projects will help them to reach parents with more substantive ways to impact the learning of your children and youth.
2. We will be sending information regionally about a new format for our transition conferences this fall. We have partnered with the Beach Center on Disability and the Kansas Health Policy Authority to create "Family Employment Awareness Training" (FEAT). This curriculum and tour of local sites that employ persons with disabilities is COMING!
3. Another coalition of funders has allowed Families Together, Inc. staff members to be trained on four new curricula that will be available to groups across the state in the next year. These workshops are: Getting and Keeping the First Job; The Journey to Adulthood: What Parents Need to Know (Sexuality); Skills for Effective Parent Advocacy; and, Working for Change: Using the Power of a Personal Story.

These new projects are avenues to help schools find significant ways to include parents in their efforts. Parent Engagement is a revitalized emphasis of the Multi-Tier System of Supports (MTSS) and the efforts by schools to serve all students. We, at Families Together, Inc., hope to work with all parents of children with disabilities and appointed education advocates to make that engagement meaningful and fruitful for the children and youth we care about.

Have a restful and fun summer!

*Connie*





# FAMILY STORY

## Rolling With the Tide

by Kristina McCollum

Lola Rosalie Shea was born a little over 3 years ago, 3 very long minutes after I passed through the hospital doors. Now that I've had some time to get to know her, I can see the true humor in her arrival (and now that enough time has gone by since I nearly gave birth on Ward Parkway in our '96, dog-hauling, teal green Isuzu Rodeo). That very day in December, 3 weeks before her Christmas day due date, Lola's daddy & his Pop-Pop painted her bedroom bright pink. In true Lola style she read this as a clear indication that we were ready; let's go! As a 3 ½ year old this now manifests itself every morning as Lola takes her time to wake up, but once she's awake it's time to get dressed and get a move on. It's a quality in her that I admire, one that I lack—I have no problem spending the day at home in my pajamas.

During our 48 hours in the hospital after Lola's birth, nurses would pop their heads in and remark about how she'd been the "3 minute delivery". As her parents, we proudly showed her off and in those first days often commented on how very quiet she was; she'd passed her hearing test and aside from some initial shock of being born that quickly was very healthy. My husband Ben had been a quiet baby, and like Lola for the first two weeks of life barely made a noise. Our oldest son Jack has more than enough conversation inside himself to fill a house, let alone a room or a few silent moments, so initially we saw Lola's calm, peaceful demeanor as a blessing! Our youngest child, Isaac, has taken Jack's chatty cues and run with them. To this day we thank God that Lola is reserved and quieter, not only is it endearing it also compliments her brothers' inherent desire to make noise at all times. And for those first weeks and months it was nice, but when Lola was turning 2 and had an obviously fewer amount of words than her peers I began to wonder if there was more to it than just her personality. She was trying very hard to communicate with us, with everyone whom she felt comfortable being with, but her words weren't coming through clearly.

I am happy to say that Lola had Families Together on her side when those questions began to stir. My mom, Lesli Girard, has been working with Families Together for over twenty years and now is the director in the Topeka center. Families Together has been part of the majority of my life; I am quite comfortable with 'disabilities'. I was able to tap into my resources right away and Lola was evaluated by Johnson County Infant/Toddler. The agency representatives came to our home and more or less engaged Lola in play and conversation. From the beginning, things have been on Lola's level—at her level of understanding and even on the floor, closer to her eye level. She was found eligible and soon began to receive services, and in order to do so we created an Individualized Family Service Plan (or IFSP). An amazing speech therapist was appointed as Lola's weekly visitor and as a family we learned many different tools and techniques to aid Lola. Our family is grateful for the early intervention, as it has played a major role in Lola's abilities to kick down her communication barriers.

Recently we made the transition from in home visits with Infant/Toddler (Part C) to the school system (Part B). Even with my knowledge of the IEP process and vocabulary, it was an intimidating journey. When I read in type Lola's name and "disability" and "significant delay" I couldn't help but become a little overwhelmed and emotional. My Mom was there that day, to hold my hand and be Lola's Gramma and advocate, and gave me a reassuring nod. I was able to remember that these words described a very small part of who Lola is; while these words felt harsh and seemed scary, they paled in comparison to her spirit and her desire to talk with us! My own fears and doubts had to be pushed aside and I had to be her voice, until together we'd found hers.

Over the past year Lola's annunciation and mouth awareness have matured leaps and bounds. She is becoming fairly easy for others to understand, even out of context. Lola has always had an opinion, but she is just now able to put those feelings and emotions into distinguishable words. She will still have us repeat what she's said every once in awhile, to be sure that she's been heard correctly, but it has been amazing to see her frustration at not being understood begin to subside. With our Infant/Toddler speech pathologist, her current speech pathologist at "Jack's school", her devoted and doting Gramma Lesli, and the rest of the hearts that have been captured by Lola, we feel very confident that her goal of being clearly understood by Kindergarten seems more than feasible. We know that there is sometimes repetitious and tedious work, transitions, and small hurdles ahead but after all she is the "3 minute delivery" and she's ours. Ben, Jack, Isaac, and I tell Lola every day that we love her voice; because the truth is that Lola's voice is even more beautiful than in our dreams, when it hadn't yet been found. We are excited and honored to keep watering it and seeing it grow!



# 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)

3500 SW 10th Room 011E • Topeka, Kansas 66604  
785-783-2975 • e-mail: [jgroff@kpirc.org](mailto:jgroff@kpirc.org)  
website: [www.kpirc.org](http://www.kpirc.org)

## NICHCY

*National Information Center for  
Children and Youth with Disabilities*

**NICHCY Website**  
[www.nichcy.org](http://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](http://www.nichcy.org)

# CHECK OUT THESE WEBSITES!



### Resources for foster youth

The University of Kansas School of Social Welfare and SRS have produced a new website developed to assist older foster youth in Kansas with the transition to independent living.

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

### KC metro websites with great summer resources

- ★ <http://www.kckidsfun.com/2010/03/2010-kansas-city-summer-camps-special-needs/>
- ★ <http://www.kcparent.com/More/Guides/CampGuide.aspx>
- ★ <http://www.horizon-academy.org/SiteResources/Data/Templates/t1.asp?docid=514&DocName=Program%20Info>
- ★ <http://www4.smsd.org/autism/html25741.htm>
- ★ <http://www.kcspectrum.com/SiteResources/Data/Templates/t4.asp?docid=589&DocName=Summer%20Camps%20and%20Summer%20Programs%20>

The **Center on the Social and Emotional Foundations for Early Learning (CSEFEL)** is focused on promoting the social emotional development and school readiness of young children birth to age 5. CSEFEL is a national resource center funded by the Office of Head Start and Child Care Bureau for disseminating research and evidence-based practices to early childhood programs across the country

<http://www.vanderbilt.edu/csefel/>

The **Technical Assistance Center on Social Emotional Intervention for Young Children**, also known as TACSEI, is a five-year grant made possible by the [U.S. Department of Education, Office of Special Education Programs](http://www.ed.gov). TACSEI takes the research that shows which practices improve the social-emotional outcomes for young children with, or at risk for, delays or disabilities and creates **FREE** products and resources to help decision-makers, caregivers, and service providers apply these best practices in the work they do every day.  
[www.challengingbehavior.org](http://www.challengingbehavior.org)

# KS Emergency Services for Children (EMSC)

*Submitted by Phyllis Laramore*

**K**ansas Emergency Services for Children's (EMSC) interest is to invite/recruit families who are being served by our emergency medical responders in collaborative relationships between health care professionals and families, that uses those relationships to assist in providing quality EMS care and promoting overall community health and safety. It acknowledges and uses the family's knowledge of their family member's condition and their skills in communicating with and caring for their family member. It emphasizes the importance of keeping family members informed about their loved one's condition, prognosis, and treatment. Family-centered care encourages family presence during procedures and the inclusion of family representatives on committees and advisory councils designed to guide health care organizations and create public policy. Family centered Pre-hospital Care embraces family-centered care principles during on scene treatment, transport, and transition of care to in-hospital health care providers.

The goal of family-centered care is to achieve the best possible outcome for children, and all other patients, through mutually beneficial collaboration of health care professionals and family members. Families desire to be kept informed, to have their questions answered and to participate in their loved one's care. They generally object to processes that make them feel helpless, uninformed or uninvolved. Patients generally want to feel assured that they are receiving the care and treatment they need and desire to be comforted and supported by their families during care. Meeting the family's needs can help reduce patient and family anxiety. It is a part of good patient care that can make our jobs easier!

We would like to work with families across Kansas but especially those with children with special health care needs... facilitating communication between the family, the healthcare provider and the emergency medical services provider in their own community. EMSC would like to have conversations with the families/caregivers so that we can advocate for their interests and definitely, the child's, so that our local EMS agencies and staff are prepared to care for pediatric patients.

EMSC welcomes the opportunity to discuss family-centered care with families. The behaviors that demonstrate this goal are: attention to human needs (individualized care, informing of expectations and collaborating with care providers); respect, patient accountability, inclusive (honest, open-direct communication); communicating with families (identify EMS provider, team member as liaison to facilitate communication, include member of family in resuscitation and decision making as they desire and capable) to facilitate communication and continuity of care (favorite toy or security object, distraction techniques, verbal/non-verbal cues, simple language/style, sharing what to expect and role of family member; demonstrate cultural competency and awareness of language barriers (obtain interpreter); and demonstration of developmentally appropriate language for age when caring for children. EMSC feels the experience of receiving EMS services for our children is most appreciated when the family feels that we cared about and provided the best care to their child in a vulnerable and intimate situation. How parents feel about the experience is very much a consideration and evaluation measure of EMSC services.

As the Family Representative, I would like to invite families to join us in working together towards these goals of providing not only superior clinical care for our children in an emergency but to do so with a family-centered perspective.

Phyllis Laramore  
816-234-1607

(Editor's note: Families Together encourages families to call Phyllis and provide information and feedback on this critical issue for them and their children with special health care needs.)



# Summer Calendar of Events

Date	Event	Contact
July 30-31, 2010	Parent Networking Conference for Native Americans, <a href="#">Topeka</a>	800-264-6343
Aug 28, 2010	Step By Step Walk, <a href="#">Wichita</a>	888-815-6364
Sept 18, 2010	Step By Step Walk, <a href="#">Kansas City</a>	877-499-5369
Sept 18, 2010	Paradise Poker Run, <a href="#">Wichita</a>	888-815-6364
Sept 25, 2010	Step By Step Walk, <a href="#">Hutchinson</a> *for more details on the walks go to <a href="http://www.families-together-inc.org">www.families-together-inc.org</a>	888-815-6364
October 22-23, 2010	Spanish Family Enrichment Weekend, <a href="#">Garden City</a>	888-820-6364

## 2010 Kaw Valley Special Rodeo

Sponsored by: *The Kaw Valley Rodeo Association (KVRA)*



**Sandy Chandler**  
785-532-3313  
[schandle@ksu.edu](mailto:schandle@ksu.edu)

**Friday, July 23, 2010**  
**7:00 PM**  
**Wells Arena, Cico Park**  
**Riley County Fair**  
**Grounds**  
**Manhattan, Kansas**

The Kaw Valley Special Rodeo is an opportunity for children with special needs to participate in rodeo events with pro rodeo "partners" assisting in fun and noncompetitive activities. All events are designed to be appropriate to the special needs of the children. Safety considerations are foremost at all times. Each child can choose any or all of the events they want.

For detailed information and to enroll your child in the 2010 Special Rodeo, **please by contact by July 19th:** →

Return Service Requested

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

Non-Profit Organization  
U.S. POSTAGE  
PAID  
Permit No. 849  
Topeka, Kansas