



**Families Together, Inc.**



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# Connections

Spring 2014

A quarterly publication from Families Together, Inc., the Parent Training and Information and Health Information Center for the state of Kansas

## Together We Can Learn Conference

Despite the cold and blustery day, there were about 130 participants at the 2014 Together We Can Learn Conference. Jo Mascorro, an independent consultant who provides motivational training throughout the nation, spoke to parents and professionals on what ALL adult brains should know about ALL children's brains. As she opened the conference, Jo discussed how we are all creatures of habit with internal clocks and a natural need to know what's coming next. She said, "Our brains want to hear, see, do and need to know that something is 1) about to happen; 2) is happening; 3) almost over; and 4) over." Her fast-paced presentation had all engaged and responding to specific techniques that are designed to teach one on how to respond to the challenging behaviors. Jo's enthusiastic presentation brought laughter to the morning. One participant commented, "Jo's wonderfully funny; she used a multi-sensory approach to remember. I wish a friend of mine could've heard her! I will immediately use some of the strategies both in parenting and being an OT with children."

The day was packed with speakers sharing a variety of information.

There were four quality break-out sessions that followed the morning keynote session. Mark Ward from the Kansas State Department talked about what the school's obligations are in regard to the provision of a Free Appropriate Public Education (FAPE), and educating children with disabilities in their least restrictive environment or LRE. Sean Smith, associate professor of Special Education at Kansas University, focused on technology based solutions to assist students with disabilities. Tami Schwindt-Allen, Families Together, Inc. provided a crowded room with an overview of Kansas' statute on bullying. Scott Adams, a financial planner and one of the founders of the Special Needs Planning Center, talked about the necessary planning for families and their children throughout all stages of life.

The afternoon session were just as full, Ian Kuenzi, (a self-advocate and member connections representative for Sunflower State Health), shared his personal experiences on navigating through school and employment as a person with a disability. Doug Bowman and parents, Michelle Garris and Tammy Schoepner, shared their journeys

and what they have learned through early intervention services. Darla Nelson-Metzger and Lesli Girard presented and overview of the Emergency Safety Interventions regulations for Kansas. They also presented an overview of functional behavioral assessments, behavior intervention plans and prevention strategies.

The day concluded with a presentation from Linda Wilkerson, the coordinator for the Technical Assistance System Network (TASN) Autism and Tertiary Behavior Support Project. She discussed the need for families and schools to work together to identify and design programs for addressing behaviors.

Participants were impressed by these powerful keynote speakers and had great compliments for both ladies. When asked what the most memorable part of the conference was, so many people said it was hard to choose as they loved both of the keynote speakers. The day was full of good, positive learning and great comments. It was a great day for learning and networking.



# How Does Summer School Differ from Extended School Year Services?

**E**xtended School Year (ESY) services are different than general education summer school and must be decided on an individual basis. Each year the IEP team, shall consider the need for ESY. ESY may or may not be provided in conjunction with the general education summer school and may be needed by a child even though summer school is not offered for general education students. A district shall not have a policy that no ESY services will be provided, that they are only available to a certain group or age of children, or that services are only provided for a set amount of time or a specified number of days. The school is not required to provide ESY services merely because the student will benefit from them. Instead, the IEP Team should determine if regression experienced by the student would significantly affect his/her maintenance of skills and behaviors. The nature and severity of the disability(ies) must be considered individually as well.

Services that are crucial in moving toward self-sufficiency and independence, such as dressing or eating, or continued structure to develop behavioral control, must be factored into the decision by the IEP Team when considering the need for ESY. The Office of Special Education Programs (OSEP) has also clarified that emerging skills can be a reason to include ESY in a child's schedule.



## Underserved

The **"underserved" list** is composed of those individuals who are receiving HCBS services, but at some time in the past, they requested an additional service or additional units to meet their needs. They were then added to BASIS as needing services, which was used to create a waiting list that consists of those who requested an additional service. This process does not include those who are still waiting for access to HCBS-IDD services.

The **waiting list** is composed of those individuals who are not receiving any HCBS services, but they may be receiving targeted case management, which is a State Plan service. Those individuals are considered "unserved" and are waiting for access to HCBS-IDD services.

Only those on the "underserved" list would have received a letter and form. If an individual who is on the list did not receive a letter or the form was missing from their mailing, a copy of the letter and form are available on the KDADS website at: [http://www.kdads.ks.gov/CSP/IDD/KanCare\\_Imp/2014\\_01\\_31\\_RASL\\_Consumer\\_Letter\\_Form.pdf](http://www.kdads.ks.gov/CSP/IDD/KanCare_Imp/2014_01_31_RASL_Consumer_Letter_Form.pdf).

Additionally, a FAQ for those on the "underserved" list will be posted on the website shortly. The key points include:

1. If someone is on the underserved list and decides that they do not need services now, they can indicate that and wait until services are needed in the future. This is NOT the only opportunity for an individual's needs to be addressed.
2. If needs change in the future, the TCM and Care Coordinator will conduct the assessment process and may update the ISP to include supports and services required to meet assessed needs.

If anyone has any questions about the "underserved" list or would like to contact KDADS about it, they may contact us at 785-296-3473 or [hcbs-ks@kdads.ks.gov](mailto:hcbs-ks@kdads.ks.gov).

# Family Story

By Julie Mayne

Our first contact with Families Together, Inc. came because of some advice from a friend. We were in the middle of transitioning our son from Infant and Toddler Services of Johnson County to services provided by the school district. We were in the middle of getting him officially diagnosed. We were in the middle of dealing with all the feelings that comes with the fact that we were the parents of a special needs kid and this was just dealing with one child, not to mention all the other things you still needed to deal with in life. Needless to say we were exhausted and desperately trying help our child without knowing how.

At our son's two year check-up it was brought to our attention that he did not have as many words as he should at that age. After having him evaluated, we discovered he was a twenty-five month old with the speech of a nine month old. We were shocked and all the feelings, mainly guilt, began to assault us. The next year was spent trying to figure out why he had such a pronounced speech delay. As we watched him grow, we also watched his comprehension grow as well as his frustration to not verbalize his needs. We found we had very few people we could talk to about our son. Since our son is the only special needs kid on either side of the family, we couldn't even talk to our families with any kind of understanding of what we were going through. Friends would either give us advice on what we should do without fully understanding our situation or blow off our concerns telling us he'd be fine, to just wait.

Families Together entered our lives when we were in survival mode just to make it through the day. They introduced us to the Parent-to-Parent Program where now we had someone to talk to who would just listen and tell us they understood. Through the Family Enrichment Weekend, they introduced us to other families who we could relate to because they had been there before or were currently going through the same thing. They helped us work through our barrage of emotions, to know it's ok to feel however it is you're feeling. They supported us during IEP meetings because we felt intimidated. They have helped us file a state complaint when we felt our rights were being violated. Everyone we have met has helped give us courage to be the best advocates for our child no matter how hard it can be.

I am now proud to say that today when we call Families Together it is with joy at the progress we have not only made for our son, but also the progress he has made for himself. He was finally diagnosed with Childhood Apraxia of Speech and we got him in a place where he can succeed. I understand now why they call it a journey. We have our good days, our great days, our not so great days and our really bad days. I'm sure we will always face some kind of challenge, but no matter where we are in our journey, we know we will always have support if we need it.



## From the Director's Desk

Greetings Families and Appointed Education Advocates,

What a brutal winter! All of us at Families Together hope that your family has been healthy and warm. We have sent tips in our [Monday Memo](#) to help with Cabin Fever remedies when kids can't get outside and other tips on staying warm and healthy. If you are not a subscriber to the Monday Memo please go to our website ([www.familiestogetherinc.org](http://www.familiestogetherinc.org)) or call the office nearest to you and we will make sure you are included.

This is the time of the year that many decisions that affect our lives are made in the Kansas Legislature. Your elected representative cannot adequately represent you if they don't know your family and the needs that your child with disabilities might have. Find out who your representative is here: <http://openkansas.org/> Just type in your address and this site will give you the names of the persons who represent you. Call them, write them, attend community events to introduce yourself and your child.

We have some great training coming up this spring: Family Employment Awareness Training in Emporia and Garden City, and a Family Enrichment Weekend in Lawrence. Check the calendar in this newsletter for contact information for each conference. Don't miss out!

Hoping for Spring,

*Connie*

# Historia Familiar

Por Julie Mayne

Nuestro primer contacto con Familias Unidas, Inc. se dio porque un amigo nos lo recomendó. Estábamos en medio de la transición de nuestro hijo de los Servicios para Infantes y Niños del condado de Johnson hacia los servicios proveídos por el distrito escolar. Nosotros estábamos en el proceso de obtener oficialmente su diagnóstico. Nosotros estábamos entre lidiando con todos nuestros sentimientos que vienen con el hecho de que fuéramos los padres de un niño con necesidades especiales y solo teníamos un niño, sin mencionar las otras cosas de la vida con las que también se tienen que enfrentar. No es necesario mencionar pero nosotros ya estábamos exhaustos y desesperados tratando de ayudar a nuestro hijo sin saber cómo hacerlo.

En la cita médica de los dos años de nuestro hijo, nos informaron que él no tenía tantas palabras como las que debería tener un niño de su edad. Después de ser evaluado, descubrimos que siendo un niño de veinticinco meses de edad él hablaba como si fuera de nueve meses. Nos asombramos, tantos sentimientos, principalmente de culpa comenzaron a atormentarnos. El siguiente año lo pasamos tratando de ver por qué él tuvo tanto retraso en el habla. Mientras lo vimos crecer, también vimos como su comprensión creció al igual que su frustración al no poder verbalizar sus necesidades. También encontramos que teníamos pocas personas con la que podíamos hablar acerca de nuestro hijo. Nuestro hijo es el único con necesidades especiales en nuestras familias, no podíamos hablar del tema con ellos esperando que entendieran por lo que estábamos pasando. Nuestros amigos nos daban consejos en que debíamos de hacer sin entender por completo la situación, o desechando nuestras preocupaciones diciéndonos que todo estaría bien, que solo esperáramos.

Familias Unidas entró en nuestras vidas cuando estábamos en modo de supervivencia. Ellos nos presentaron el programa Padre-a-Padre donde ahora teníamos a alguien con quien hablar, quien nos escuchara y nos dijera que nos entendía. A través de la Semana de Enriquecimiento Familiar, nos presentaron a otras familias con quien podíamos tener afinidad porque ellos han pasado o están pasando por la misma situación. Ellos nos ayudaron a enfrentar nuestras emociones, y saber que está bien sentirse como nos sentíamos. Familias Unidas nos apoyó durante las juntas de IEP porque nos sentíamos intimidados. También, nos ayudaron a levantar una queja formal cuando sentíamos que nuestros derechos habían sido violados. Cada persona que hemos conocido nos ha ayudado a ser los mejores defensores de nuestro hijo no importando que tan difícil pueda parecer.

Estoy muy orgullosa en decir ahora que cuando llamamos a Familias Unidas es con gozo debido al progreso que hemos tenido no solo con nuestro hijo, sino también con el progreso que el mismo ha tenido. Él finalmente fue diagnosticado con Apraxia de Lenguaje Infantil, y ya se encuentra en un lugar donde puede tener éxito. Ahora entiendo por qué le llaman un viaje. Hemos tenido nuestros días buenos, mejores, otros no tanto y los peores; estoy segura que siempre enfrentaremos algún tipo de reto, pero no importa en qué parte del viaje nos encontremos, sabremos que siempre contaremos con el apoyo si lo necesitamos.

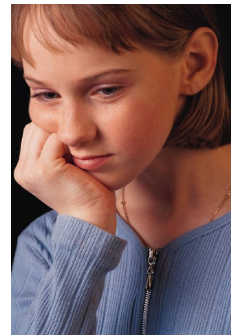


## Shortage of Foster Parents for Children with Special Needs

It's a sad reality, but some Kansas children must live in foster homes for their own health and security.

Many foster children have suffered traumatic abuse and neglect, saddling them with a range of physical, emotional, developmental, and learning disabilities. Some of these "special needs" foster children are technology dependent or have medical conditions that include cerebral palsy, shaken-baby syndrome, or drug-exposure. Unfortunately, there's a chronic shortage of available foster parents to provide the care and attention these children so desperately need. In Sedgwick County alone, 230 children must be placed in foster homes outside the county because there aren't enough closer to home. At least 150 more foster homes are needed in Sedgwick County to provide safe, loving homes to children with behavioral, emotional, or physical conditions.

Saint Francis Community Services, a faith-based child and family services agency serves thousands of children in 75 Kansas counties. They regularly provide free, local training for persons willing to open both their homes and their hearts to children in need. Persons interested in fostering a child with special needs are encouraged to contact Saint Francis Community Services at 866-999-1599.



# Calendar of Events

<b><i>April 25, 2014</i></b>	<b><i>Family Employment Awareness Training Part 2, Garden City</i></b>	<b><i>888-820-6364</i></b>
<b><i>April 25-26, 2014</i></b>	<b><i>Family Enrichment Weekend, Lawrence</i></b>	<b><i>800-264-6343</i></b>
<b><i>May 6, 2014</i></b>	<b><i>Education Advocate Training, Wichita</i></b>	<b><i>800-264-6343</i></b>
<b><i>October 4, 2014</i></b>	<b><i>Family Employment Awareness Training Part 1, Wichita</i></b>	<b><i>888-815-6364</i></b>
<b><i>October 17, 2014</i></b>	<b><i>Family Employment Awareness Training Part 2, Wichita</i></b>	<b><i>888-815-6364</i></b>
<b><i>October 18, 2014</i></b>	<b><i>Family Employment Awareness Training Part 1, Derby</i></b>	<b><i>888-815-6364</i></b>
<b><i>October 24, 2014</i></b>	<b><i>Family Employment Awareness Training Part 2, Derby</i></b>	<b><i>888-815-6364</i></b>

## Helpful Resources:

Kansas Multi-Tier System of Supports (MTSS) [www.kansasmtss.org](http://www.kansasmtss.org)

Kansas' Technical Assistance System Network (TASN) [ksdetasn.org](http://ksdetasn.org)

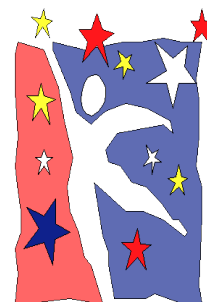
Kansas Parent Information Resource Center (KPIRC) [www.kpirc.org](http://www.kpirc.org)



## Education Advocate Update:

### It's Coming!

Each year, program staff sends out over 1200 surveys to all education advocates. Advocates who are currently serving one or more students have already received their survey and those not currently serving will receive their survey this month. Please take a few minutes to complete the surveys and send them back to us. The information that you provide is very important to us. Not only does it ensure we have your current contact information, but informs us of your willingness to serve. The student section of the surveys provides us with essential information about your role and the school's compliance with state and federal requirements. The data we receive from these surveys is provided to the Kansas State Department of Education. Most importantly, the surveys provide us with information about the status of the students you serve. Adoption finalizations, graduations, and changes in location prompt an action of cancellation or a change in advocate appointments. We must ensure children are receiving appropriate representation in their education and the information you provide assists us in this endeavor. Your time and energies are appreciated... keep up the good work! As always, if you have questions or concerns, please contact Families Together!





# KanCare and Long Term Support Services for HCBS participants

Starting February 1, 2014 KanCare will cover your home and community based (HCBS) services and targeted case management. There are 12 services under the Intellectual and Developmental Disability (IDD) program. You may receive some or all of IDD program services. **These services are:**

Assistive services	Day support
Medical Alert Rental	Financial Management Services
Overnight Respite	Personal Assistant Services
Residential Supports	Specialized Medical Care
Supportive Home Care	Sleep Cycle Support
Supported Employment	Wellness Monitoring

**What remains the same is:** you will still be able to access services through the Community Developmental Disability Organization (CDDO). Your CDDO will continue to do the eligibility assessment for the IDD program every year and you can still keep your targeted case manager (TCM) and service providers of your choice. The plan of care will still be reviewed by your TCM and updated as your needs change.

**What is different is:** how the care coordinator from your Managed Care Organization (MCO) will be interacting with your TCM to create a new plan of care. There will be no changes to your existing plan of care until your MCO and TCM create a new plan of care with you.



**The case coordinator is:** the person from your MCO who will work with your targeted case manager to develop your plan of care and make sure you have the services you need. Changes to your existing plan of care will occur when your MCO and targeted case manager create a new plan of care with you. The care coordinator with your MCO can help you understand your KanCare benefits, arrange medical appointments, find services, and access a specialist for your behavioral or physical healthcare needs.

With these new changes KDAD will be hosting calls with IDD system consumers and stakeholders to address KanCare implementation issues. The Lunch and Learn calls are scheduled for Wednesdays from 12:00 to 1:00; and will continue until there is no longer a need for them. Callers may submit questions to: [kancare.ombudsman@kdads.ks.gov](mailto:kancare.ombudsman@kdads.ks.gov).

Registration for the calls is required and can be completed at the following website:

[http://www.kdads.ks.gov/CSP/IDD/KanCare\\_Imp/IDD\\_Implementation\\_Calendar.html](http://www.kdads.ks.gov/CSP/IDD/KanCare_Imp/IDD_Implementation_Calendar.html)

Call in Number: 1.866.620.7326

Conference Code: 4283583031

# KanCare y los Servicios a Largo Plazo para los participantes de HCBS

**I**niciando el 1ro. de Febrero del 2014, KanCare cubrirá los servicios basados en su casa y comunidad, a parte del manejo de casos específicos. Hay 12 servicios bajo los programas de Discapacidad Intelectual y Retraso del Desarrollo y usted puede recibir todos o una parte de los servicios del programa IDD.

## Los servicios incluyen:

Servicios de asistencia	Soporte durante el día
Renta de alertas medicas	Servicios de administración financiera
Servicios en la Noche	Servicios de asistencia personalizada
Apoyo residencial	Cuidado médico especializado
Cuidado en casa	Soporte en el ciclo del sueño
Apoyo en el Empleo	Monitoreo de bienestar

**Lo que sigue siendo igual es:** usted podrá seguir teniendo acceso a los servicios a través de la Organización para la Comunidad de Desarrollo para Discapacitados (CDDO). El CDDO continuara con las evaluaciones para seguir siendo elegible para el programa de IDD cada año y usted puede permanecer con su coordinador de caso (TCM) y los proveedores de servicios a su elección. El plan de cuidado seguirá siendo revisado por su TCM y actualizado según como cambien sus necesidades.



**La diferencia está en:** cómo el coordinador de la organización de manejo de cuidado (MCO) que usted eligió interactúa con su TCM para crear un nuevo plan de cuidado. No habrá cambios en su plan existente de cuidado hasta que su MCO y TCM creen un nuevo plan de cuidado con usted.

**El coordinador de casos es:** la persona de MCO que trabajará con el manejador de caso específico para desarrollar su plan de cuidado, y se asegurará de que usted tenga los servicios que necesita. Los cambios en su plan actual de cuidado ocurrirán cuando su MCO y su manejador de caso creen un nuevo plan de cuidado. El coordinador de cuidado y su MCO puede ayudarle a entender los beneficios de KanCare, hacer citas médicas, encontrar servicios, y acceder un especialista para sus necesidades de comportamiento o de salud física.

Con estos nuevos cambios, KDAD será el anfitrión de las llamadas semanales con el sistema de consumidores IDD y las partes interesadas para abordar cuestiones o problemas en la implementación del KanCare. Las llamadas "Almuerzo y Aprendizaje" serán agendadas los miércoles de 12:00 - 1pm; y continuaran durante el primer trimestre del 2014. Las personas pueden enviar sus preguntas al [kancare.ombudsman@kdads.ks.gov](mailto:kancare.ombudsman@kdads.ks.gov).

El registro para la llamada es un requisito, solo complete la información a través del siguiente website:

**[http://www.kdads.ks.gov/CSP/IDD/KanCare\\_Imp/IDD\\_Implementation\\_Calendar.html](http://www.kdads.ks.gov/CSP/IDD/KanCare_Imp/IDD_Implementation_Calendar.html)**

Número: 1.866.620.7326

Código de la conferencia: 4283583031

# Families make the difference.

**F**amilies Together, Inc. founded in 1982, serves as the Parent Training and Information Center and Family to Family Health Information Center for Kansas and provides opportunities for families to come together and meet other families who are navigating the special education and disability services maze. Each year, Families Together, Inc. provides, without fees, direct support to thousands of Kansas families. In addition, through workshops, conferences and partnerships with state, local and national organizations, Families Together provides training to nearly 4,000 families and professionals working with children and youth with disabilities and special health care needs.

**Garden City Center 1-888-820-6364**

**gardencity@familiestogetherinc.org**

**Kansas City Center 1-877-499-5369**

**kansascity@familiestogetherinc.org**

**Topeka Center 1-800-264-6343**

**topeka@familiestogetherinc.org**

**Wichita Center 1-888-815-6364**

**wichita@familiestogetherinc.org**

Visit our website at:

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

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