



Families Together, Inc.

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Connections Summer 2017

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

Family Story

Thank you to Julie Mayne for sharing your story.

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 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 need 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 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 with whom we could relate because they had been though 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've met has helped give us courage to be the best advocates for our child no matter how hard it might 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 had 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 the support of Families Together if we need it.



Thanks to a grant awarded from the Sunflower Foundation, Families Together, Inc. will be updating our website. Our goal is to make it easier for families to find the information they need. As always, we have a real person who can speak to your individual needs so give us a call today. (See [page 4](#) for our phone numbers.)



Historia Familiar

Gracias a Julie Mayne por compartir tu historia.

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 esperaríamos.

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 la reuniones 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, si no 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, sabemos que siempre contaremos con el apoyo Familias de Unidas si lo necesitamos.



Kansas Personal Care Directory

The Kansas Personal Care Directory is a web-based service designed to assist Kansans of all ages and their families to hire their own respite and personal care workers.

Individuals who wish to register to work as caregivers may use the directory to find the job that's right for them!

Here's some quick tips: Go to www.rewardingwork.org/Kansas to complete the registration form. If you are a member of KanCare, you are eligible for a free subscription. When you register, click "I wish to register with an Access Code" and enter your MCO code as follows:

**Amerigroup MCO: 133578

**Sunflower MCO: 154429

**United MCO: 654671

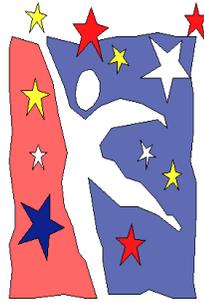
When you are finished with the registration you will be able to post an ad on their FREE Job Board.

If you are a worker, complete the free *Worker Application*. Once completed, potential employers may contact you through the Job Board. Workers never pay a fee to use the Kansas Personal Care Directory.

If you need help using the directory, please email help@rewardingwork.org or call 1-866-212-9675.

For information about respite care or personal care support in Kansas, contact the Kansas Aging and Disability Resource Center at 1-855-200-ADRC (2372) or visit www.kdads.ks.gov.

Education Advocate: Communication is Key



With over 900 students represented by an education advocate, staff of the education advocate program depends on effective communication between appointed advocates, contract staff, and schools. It is our responsibility to ensure that the educational needs of every child served by an education advocate are being met in an appropriate manner. One way we do that is to ask education advocates to complete an annual survey. These were sent out in February and 37% advocates serving a student responded. For those who have ever sent out a survey, this sounds like a great return rate; however, that means that we were not updated on 604 students. The information provided by the survey is extremely important so that we may insure students are being actively and appropriately served. Additionally, data about IEP meeting and other notification requirements, the use of Emergency Safety Interventions, and suspension and expulsion are reported to the Kansas State Department of Education.

If you submitted your survey, we thank you. If you did not, please let us know if the student(s) you serve has moved, been signed out of services, graduated, or had some other change in status. Together, we can make sure kids are being served in the most effective manner!



Come to the Family Fling in Wichita

A few days ago, a young mother called Families Together with a simple question, "Where can I take my children for fun activities without feeling judged?" She stated even the neighborhood children had stopped coming over to play at their house. She wished people understood they are a family first, not just a family with children with autism.

The Family Fling is a unique and free event for families just like hers. Our day in the park provides families with an opportunity to gather, talk, eat, laugh and play. It is a day where acceptance is guaranteed because all our guests are families with a child who has one or more disabilities.

Please join us on September 9th from 10 am until 2 pm at Sedgwick County Park, 6501 W 21st St North for games, crafts, music, lunch and more. We will be in the Plum Building near the Sunrise Boundless Playscape. Please register by September 7th at: www.familyfling2017.eventbrite.com or call Families Together (316) 945-7747. For information in Spanish, please call (800) 499-9443.

From the Director's Desk

Dear Parents and Appointed Education Advocates:

I would like to share with you how the current fiscal situation in Kansas has affected Families Together. The budget issues in Kansas and in the nation have affected the funding Families Together relies upon to provide services to you. Some of the grants from our state partners have been eliminated or cut. Although we will be restructuring some of our services, we will continue to provide three Centers in Kansas to help you navigate the maze of services for families of children and youth with disabilities or special health care needs.

In an effort to continue our services at current levels, it becomes imperative for us to **ask for your help**. Please, consider all the value Families Together services have brought to your family; then consider a donation to ensure you and other families can continue to receive the trainings, referrals and support to access the resources your child/youth need to be successful. You can give a donation by logging onto our website at www.familiestogetherinc.org and click on the **DONATE** button at the top of the page. Or, if you are on Facebook, you may donate using the button on our business page as well.

New to Families Together, Inc., our supporters can become a fundraiser as well. You may log onto our donation site and click on fundraiser and follow the directions. You may ask friends and family to also contribute Families Together by creating an email to let them know about the services you received and how it has helped you and your family. Your participation as a donor or a fundraiser is greatly appreciated.

We also need your help spreading the word about the services Families Together provides. We'd really appreciate it if you would like our Facebook business page and participate in our prize giveaways.

Thank you for your support and for all you do for the people with disabilities that you know and love.

Connie

Families Make the Difference

Families 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.

Calendar of Events

Visit our [Facebook](#) page for more information!

<i>Aug. 1, 2017</i>	<i>Education Advocate Training, Olathe</i>	<i>800-264-6343</i>
<i>Aug. 24, 2017</i>	<i>Education Advocate Training, Salina</i>	<i>800-264-6343</i>
<i>Sept. 9, 2017</i>	<i>Family Fling, Wichita</i>	<i>888-815-6364</i>
<i>Sept 16, 2017</i>	<i>Mothers Matter Too, Great Bend</i>	<i>888-820-6364</i>
<i>Sept. 19, 2017</i>	<i>Education Advocate Training, Topeka</i>	<i>800-264-6343</i>
<i>Sept. 22, 2017</i>	<i>Team Empowerment Conference (TEC), Ft. Riley</i>	<i>800-264-6343</i>
<i>Oct. 13-14, 2017</i>	<i>Spanish Family Enrichment Weekend (FEW), Salina</i>	<i>888-820-6364</i>
<i>Oct. 13, 2017</i>	<i>Parent Leadership Conference, Topeka</i>	<i>800-264-6343</i>
<i>Oct. 19, 2017</i>	<i>Education Advocate Training, Wichita</i>	<i>800-264-6343</i>
<i>Dec. 2, 2017</i>	<i>Health/Education Statewide Conference, Wichita</i>	<i>888-815-6364</i>

[Garden City Center: 1.888.820.6364](#) [Topeka Center: 1.800.264.6343](#) [Wichita Center: 1.888.815.6364](#)

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